

## CCE Participants Data Dictionary

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**Section I: Basic study/participant information**

SID_DI	HEIRS participant ID - de-identified	Char \$11.
PREFLANG	Preferred Language 1=English 2=Spanish 3=Mandarin 4=Vietnamese	Num 6.
RACE	Participant Race 1=Hispanic 2=Asian/Pacific Islander 3=African American 4=Caucasian 5=Other: American Indian, Multiple, Unknown	Num 4.
AGE	Calculated Age	Num 4.
GENDER	What is your gender 1=Male 2=Female	Num 4.
GENOTYPE	Genotype 1= C282Y/C282Y 2= C282Y/H63D 3= H63D/H63D 4= C282Y/- 5= H63D/- 6= -/- 7= MISSING	Num 2.
IN_INITIAL_SCREENING	Initial Screening indicator 1=Yes	Num 2.

**Section II: Initial Screening Consent**

CONSTSIGNED_IS	Signed Consent Form 1=Yes 3=Withdrawn	Num 4.
DSIGNED_IS	Date Consent Form signed (Number of days from given date)	Num 4.
BLDSTORE_IS	May we store your blood? 1=Yes 2=No	Num 4.
DWITHDRAWN_IS	Date Withdrew consent (Number of days from given date)	Num 4.

**Section III: Initial Screening**

DISFORM	Initial Screen Form Date (Number of days from given date)	Num 4.
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DOCVISIT	Q5: I came in for a doctor visit or to have my blood drawn, and found out about it 1=Yes	Num 4.
PHCALL	Q5: I received a phone call or letter from the study, inviting me to participate 1=Yes	Num 4.
CAMEINTO	Q5: I came into the clinic or lab with a friend or family member, and found out about it 1=Yes	Num 4.
FMEMBER	Q5: My family member was in this study and told me about it 1=Yes	Num 4.
NEWSTV	Q5: I learned about it in the newspaper, in the community, on the TV, or on the radio 1=Yes	Num 4.
HEAROTH	Q5: Other 1=Yes	Num 4.
FIRSTIME	Q6: Is this the first time you have been asked to participate in this study 1=Yes 2=No	Num 4.
HLTHRES	Q7a: (old form)I want to help by taking part in research 1=Important 2=Not important	Num 4.
DRPART	Q7b: (old form)My doctor thought that I should take part in this study 1=Important 2=Not important	Num 4.
IRONPROB	Q7c: (old form)I want to know if I have problems too high or too low) 1=Important 2=Not important	Num 4.
HAVEHEMO	Q7d: (old form)I have iron overload or hemochromatosis 1=Important 2=Not important	Num 4.
MIGHT	Q7e: (old form)I think I might have iron overload or hemochromatosis 1=Important 2=Not important	Num 4.
MEDCOND	Q7f: (old form)I have another medical condition 1=Important 2=Not important	Num 4.

RELAHEMO	Q7g: (old form) My blood relative has/had iron overload or hemochromatosis 1=Important 2=Not important	Num 4.
ELSEHEMO	Q7h: (old form) Someone else I know has/had iron overload or hemochromatosis 1=Important 2=Not important	Num 4.
OTHREAS	Q7i: (old form) Other reason 1=Important 2=Not important	Num 4.
TOOMUCH	Q7a: Too much iron in your body, iron overload or hemochromatosis 1=Yes 2=No 3=Not Sure	Num 4.
ARTHRITI	Q7b: Arthritis 1=Yes 2=No 3=Not Sure	Num 4.
DIABETES	Q7c: Diabetes 1=Yes 2=No 3=Not Sure	Num 4.
LIVER	Q7d: Liver disease or liver cancer 1=Yes 2=No 3=Not Sure	Num 4.
HRTFAIL	Q7e: Heart failure 1=Yes 2=No 3=Not Sure	Num 4.
IMPOT	Q7f: Fertility problems or impotence 1=Yes 2=No 3=Not Sure	Num 4.
BLDRELA	Q8: Have any of your blood relatives had iron overload or hemochromatosis, or been treated by having their blood drawn on a regular basis? 1=Yes 2=No 3=Not Sure	Num 4.
ANYONE	Q10: (old form)Have you ever known anyone else who had to donate blood for his or her health 1=Yes 2=No 3=Not Sure	Num 4.

PREGNANT	Q9: For women only: Are you pregnant, have you been pregnant within the past 3 months, or are you breast feeding 1=Yes 2=No 3=Not Sure	Num 4.
HEALTH	Q10: In general, would you say your health is 1=Poor 2=Fair 3=Average 4=Good 5=Excellent	Num 4.
SICKEASY	Q11a: I seem to get sick a little easier than other people 1=Definitely true 2=Mostly true 3=Don't know 4=Mostly false 5=Definitely false	Num 4.
HLTHANY	Q11b: I am as healthy as anybody 1=Definitely true 2=Mostly true 3=Don't know 4=Mostly false 5=Definitely false	Num 4.
HLTHWORS	Q11c: I expect my health to get worse 1=Definitely true 2=Mostly true 3=Don't know 4=Mostly false 5=Definitely false	Num 4.
HLTHEXC	Q11d: My health is excellent 1=Definitely true 2=Mostly true 3=Don't know 4=Mostly false 5=Definitely false	Num 4.
NERVOUS	Q12a: Have you been a nervous person 1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little of the time 6=None of the time	Num 4.

DOWNDUMP	<p>Q12b: Have you felt so down in the dumps that nothing could cheer you up</p> <p>1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little of the time 6=None of the time</p>	Num 4.
CALM	<p>Q12c: Have you felt calm and peaceful</p> <p>1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little of the time 6=None of the time</p>	Num 4.
BLUE	<p>Q12d: Have you felt downhearted and blue</p> <p>1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little of the time 6=None of the time</p>	Num 4.
HAPPY	<p>Q12e: Have you been a happy person</p> <p>1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little of the time 6=None of the time</p>	Num 4.
SHOULDISH	<p>Q13: Information about a person's genetic risk should be shared with other family members.</p> <p>1=Strongly Agree 2=Agree 3=Disagree 4=Strongly Disagree</p>	Num 4.
GENETEST	<p>Q14: In general, I think genetic testing to find out about disease risk is a good idea</p> <p>1=Strongly Agree 2=Agree 3=Disagree 4=Strongly Disagree</p>	Num 4.
GOODTRT	<p>Q15a: There might be a good treatment by the time you developed the disease</p> <p>1=Strongly Agree 2=Agree 3=Disagree 4=Strongly Disagree</p>	Num 4.

CHGLIFE	Q15b: You could change to a healthier lifestyle to prevent getting the disease 1=Strongly Agree 2=Agree 3=Disagree 4=Strongly Disagree	Num 4.
PREPFUTU	Q15c: You could prepare better for the future 1=Strongly Agree 2=Agree 3=Disagree 4=Strongly Disagree	Num 4.
SHAREINF	Q15d: You could share this information with family members 1=Strongly Agree 2=Agree 3=Disagree 4=Strongly Disagree	Num 4.
INSURE	Q16a: You might have trouble getting or keeping your insurance 1=Strongly Agree 2=Agree 3=Disagree 4=Strongly Disagree	Num 4.
HELPLESS	Q16b: You might feel helpless because you can't change your genes 1=Strongly Agree 2=Agree 3=Disagree 4=Strongly Disagree	Num 4.
FEELLESS	Q16c: Knowing that you had a gene that put you at risk could make you feel less healthy 1=Strongly Agree 2=Agree 3=Disagree 4=Strongly Disagree	Num 4.
BADNEWS	Q16d: You could be bringing bad news into your family 1=Strongly Agree 2=Agree 3=Disagree 4=Strongly Disagree	Num 4.
HEREDITY	Q17a: Heredity (it runs in your family) 1=Very important 2=Somewhat important 3=Not important 4=Not sure	Num 4.

ENVIRON	Q17b: The environment (ex. Water/air pollution) 1=Very important 2=Somewhat important 3=Not important 4=Not sure	Num 4.
FATE	Q17c: Fate or chance (bad luck) 1=Very important 2=Somewhat important 3=Not important 4=Not sure	Num 4.
PSYCHO	Q17d: Psychological factors (ex. Stress) 1=Very important 2=Somewhat important 3=Not important 4=Not sure	Num 4.
LIFESTYL	Q17e: Lifestyle (ex. smoking, drinking, eating a high fat diet) 1=Very important 2=Somewhat important 3=Not important 4=Not sure	Num 4.
GHSCALE_IS	SF-36 General Health Scale - Initial Screening	Num 8.
MHSCALE_IS	SF-36 Mental Health Scale - Initial Screening	Num 8.
LETTERID	Type of Initial Screening test results letter 1A = C282Y/C282Y, C282Y/+, C282Y/H63D, H63D/H63D, H63D/+ with elevated iron levels 1B = C282Y/C282Y with normal iron levels 1C = +/+ with elevated iron levels 1D = C282Y/C282Y with iron alert levels 2 = +/+ with normal iron levels 2A = +/+ with iron alert levels 3 = C282Y/H63D, H63D/H63D, C282Y/+ with normal iron levels 3A = C282Y/H63D, H63D/H63D, C282Y/+ with iron alert levels 4 = H63D/+ with normal iron levels 4A = H63D/+ with iron alert levels 5 = Incomplete or Missing Lab Results	Char \$2.

**Section IV: Initial Screen Lab Results**

HOURS_IS	Hours since last food	Num 10.2
SERUM	Serum Iron Note 0='<5'	Num 7.2
SF_IS	Serum Ferritin Note 7.5 = '<15'	Num 10.2
TS_IS	Transferrin Saturation Note 1.5 = '<3'	Num 10.2
UIBC	Unsaturated Iron Binding Capacity	Num 8.2



TIBC	Total Iron Binding Capacity	Num 8.2
CASE_CONTROL	Invited CCE Case or Control 1=Case 2=Control	Num 2.
ELEVATED_INDICATOR	Elevated ts and sf at initial screening 1=elevated	Num 2.

**Section V: CCE Consent Form**

CONSTSIGNED_CCE	Signed Consent Form 1=Yes	Num 4.
DSIGNED_CCE	Date Consent Form signed (Number of days from given date)	Num 4.
HIPAAAUTH	Signed Hipaa authorization 1=Yes 2=No	Num 4.
DATEHIPAA	Date Hipaa authorization signed (Number of days from given date)	Num 4.
BLDSTORE_CCE	May we store your blood? 1=Yes 2=No	Num 4.
DWITHDRAWN_CCE	Date Withdrew consent (Number of days from given date)	Num 4.
CCE_ATTEND	CCE attended indicator 1=Yes	Num 2.

**Section VI: Clinical Assessment**

DCAVISIT	Date Clinical Assessment Form was filled out (Number of days from given date)	Num 4.
HEIGHT	Q7: Height in inches	Num 4.
WEIGHT	Q8: Body weight in pounds	Num 6.1
TEMPER	Q9: Body Temperature in Fahrenheit	Num 7.1
BMI	Body Mass Index	Num 6.1
PULSE	Q10: Pulse in beats per minute	Num 4.
SBP	Q11: Systolic Blood Pressure in mmHg	Num 11.
DBP	Q12: Diastolic Blood Pressure in mmHg	Num 11.

HEPATOM	Q13: Liver: Hepatomegaly (liver palpable $\geq$ 2cm below R. costal margin or xiphoid process on deep inspiration) 1-Yes 2-No 3-Not sure	Num 4.
SPLENOM	Q14: Liver: Splenomegaly (spleen palpable below L. costal margin) 1-Yes 2-No 3-Not sure	Num 4.
BRADY	Q15a: Heart Arrythmia: Bradycardia (<40 beats per minute) 1-Yes 2-No 3-Not sure	Num 4.
TACHY	Q15b: Heart Arrythmia: Tachycardia (>100 beats per minute) 1-Yes 2-No 3-Not sure	Num 4.
PREMACON	Q15c: Heart Arrythmia: Frequent premature contractions ( $\geq$ 1 ectopic beat per min.) 1-Yes 2-No 3-Not sure	Num 4.
ABNORMAL	Q15d: Heart Arrythmia: Other abnormal rhythm 1-Yes 2-No 3-Not sure	Num 4.
MURMUR	Q15e: Heart Arrythmia: Murmur (any prolonged sound produced by the heart) 1-Yes 2-No 3-Not sure	Num 4.
EDEMA	Q15f: Heart Arrythmia: Edema (symmetrical edema of dependent areas, usually lower extremities, with or without pitting) 1-Yes 2-No 3-Not sure	Num 4.
PIGMENT	Q16: Skin: Increased pigmentation on sun-exposed or unexposed areas (grayish or brownish shades) 1-Yes 2-No 3-Not sure	Num 4.

BLISTER	Q17: Skin: Blistering, ulcers, scarring of sun-exposed skin 1-Yes 2-No 3-Not sure	Num 4.
HYPERTRI	Q18: Skin: Hypertrichosis (excess hair growth in sun-exposed areas) 1-Yes 2-No 3-Not sure	Num 4.
MPJOINTS	Q19: Bones and Joints: MP joints: Swollen or tender 1-Yes 2-No 3-Not sure	Num 4.

**Section VII: CCE Lab Values**

RETIC	Reticulocyte count (%) Reference Range: 0.4-2.5 %	Num 6.1
TS_CCE	% Iron Saturation iron binding protein (%) Reference Range: 15-50 %	Num 8
SF_CCE	Serum Ferritin Concentration (ng/mL) Reference Range: 20-300 ng/mL (M) 10-120 ng/mL (F15-45y) 10-300 ng/mL (F45-127y) Note: 7.5 = '<15'	Num 8
ALT	Serum Activity Alanine Aminotransferase (U/L) Reference Range: 0-31 U/L (F) 0-40 U/L (M) Note: 3 = '<4'	Num 8
AST	Serum Activity Aspartate Aminotransferase (U/L) Reference Range: 0-31 U/L (F) 0-37 U/L (M)	Num 8
CRP	Serum Concentration C-Reactive Protein (mg/dL) Reference Range: 0-0.5 mg/dL Note: 0.2 = '<0.3'	Num 8
LD	Serum activity lactate dehydrogenase (U/L) Reference Range: 94-250 U/L	Num 8
BILT	Serum concentration total bilirubin (mg/dL) Reference Range: 0.0-1.0 mg/dL	Num 8
DBIL	Serum concentration direct bilirubin (mg/dL) Reference Range: 0.0-0.3 mg/dL	Num 8
IBIL	Serum concentration indirect bilirubin (mg/dL) Reference Range: 0.0-0.7 mg/dL	Num 8

HAPT	Serum haptoglobin concentration (mg/dL) Reference Range: 30-200 mg/dL Note: 19 = '<20'	Num 8
HOURS_CCE	Hours since last ate food	Num 8
HEPATITS	Hepatitis B Surface Antigen or Hepatitis C virus antibody POSITIVE or NEGATIVE	Char \$15
FEBR	Serum iron binding capacity (ug/dL) Reference Range: 228-428 ug/dL	Num 8
FER	Serum iron concentration (ug/dL) Reference Range: 45-160 ug/dL (M) 30-160 ug/dL (F)	Num 8
GGT	Serum activity of gamma glutamyl transferase (U/L) Reference Range: 7-33 U/L (F) 11-51 U/L (M) Note 2 = '<3'	Num 8
GLUC	Serum glucose concentration (mg/dL) Reference Range: 60-115 mg/dL	Num 8
HA1	Hemoglobin A1 (%total hemoglobin) Reference Range: 94.3-98.5 %	Num 8
HA2	Hemoglobin A2 (%total hemoglobin) Reference Range: 1.5-3.7 %	Num 8
HBELP	Abnormal hemoglobin type	Num 8
HCT	Hematocrit (%red blood cells in whole blood) Reference Range: 40-53% (M) 35-47% (F)	Num 8
HF	Hemoglobin F-fetal (%total hemoglobin) Reference Range: 0.0-2.0%	Num 8
HGB	Hemoglobin Concentration (g/dL) Reference Range: 13.3-17.7 g/dL (M) 11.7-15.7 g/dL (F)	Num 8
HGC	Hemoglobin C (%total hemoglobin) Reference Range: 0.0-0.0 %	Num 8
HGE	Hemoglobin E (%total hemoglobin) Reference Range: 0.0-0.0 %	Num 8
HOTHER	Hemoglobin Other (%total hemoglobin) Reference Range: 0.0-0.0 %	Num 8
HS	Hemoglobin S-sickle cell (%total hemoglobin) Reference Range: 0.0-0.0 %	Num 8
INS	Insulin concentration (mIU/L) Reference Range: 0-20 mIU/L	Num 8

MCH	Mean corpuscular hemoglobin/RBC (picograms) Reference Range: 26.5-35.0 pg	Num 8
MCHC	Mean corpuscular hemoglobin conc/RBC (g/dL) Reference Range: 32-36 g/dL	Num 8
MCV	Mean corpuscular volume (femtoliters) Reference Range: 78-100 fL	Num 8
RBC	Red blood cell count (# cells/10 <sup>12</sup> /L) Reference Range: 4.4-5.9 (M) x10 <sup>12</sup> /L 3.8-5.2 (F) x10 <sup>12</sup> /L	Num 8
RDW	Red cell distribution width (%) Reference Range: 10.0-15.0 %	Num 8
WBC	White blood cell count (# cells/10 <sup>9</sup> /L) Reference Range: 4.0-11.0 x10 <sup>9</sup> /L	Num 8
PLT	Platelet (# platelets/10 <sup>9</sup> /L) Reference Range: 150-450 x10 <sup>9</sup> /L	Num 8
WNEUT	Neutrophils (%neutrophils in WBC count) Reference Range: 40-75 %	Num 8
WLYMP	Lymphocytes (%lymphocytes in WBC count) Reference Range: 20-48 %	Num 8
WMONO	Monocytes (%monocytes in WBC count) Reference Range: 0-12 %	Num 8
WEOS	Eosinophils (%eosinophils in WBC count) Reference Range: 0-6 %	Num 8
WBASO	Basophils (%basophils in WBC count) Reference Range: 0-2 %	Num 8
ANEUT	Absolute neutrophils (# cells/10 <sup>9</sup> /L) Reference Range: 1.6-8.3 x10 <sup>9</sup> /L	Num 8
ALYMP	Absolute lymphocytes (# cells/10 <sup>9</sup> /L) Reference Range: 0.8-5.3 x10 <sup>9</sup> /L	Num 8
AMONO	Absolute monocytes (# cells/10 <sup>9</sup> /L) Reference Range: 0-1.3 x10 <sup>9</sup> /L	Num 8
AEOS	Absolute eosinophils (# cells/10 <sup>9</sup> /L) Reference Range: 0-0.7 x10 <sup>9</sup> /L	Num 8
ABASO	Absolute basophils (# cells/10 <sup>9</sup> /L) Reference Range: 0-0.2 x10 <sup>9</sup> /L	Num 8

**Section VIII: Medical History**

DMHVISIT	Date of visit (Number of days from given date)	Num 4.
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ssFeetSw	Q1:	Experienced swelling of feet or ankles 1=Yes 2=No 3=Don't Know	Num 4.
ssSkinCh	Q2:	Experienced change in skin color 1=Yes 2=No 3=Don't Know	Num 4.
ssWeight	Q3:	Experienced unexplained weight loss 1=Yes 2=No 3=Don't Know	Num 4.
ssAdomSw	Q4:	Experienced abdominal swelling or fluid 1=Yes 2=No 3=Don't Know	Num 4.
ssLossDr	Q5:	Experienced trouble having an erection or loss of sexual drive 1=Yes 2=No 3=Don't Know	Num 4.
ssChrFt	Q6:	Repeatedly bothered by chronic fatigue/weakness 1=Yes 2=No 3=Don't Know	Num 4.
ssShrtBr	Q7:	Repeatedly bothered by shortness of breath 1=Yes 2=No 3=Don't Know	Num 4.
ssJntStf	Q8:	Repeatedly bothered by joint stiffness/pain/ache 1=Yes 2=No 3=Don't Know	Num 4.
ssThirst	Q9:	Repeatedly bothered by excessive thirst 1=Yes 2=No 3=Don't Know	Num 4.
ssPlyUr	Q10:	Repeatedly bothered by polyuria (excessive urination) 1=Yes 2=No 3=Don't Know	Num 4.
ssUnxAdm	Q11:	Repeatedly bothered by unexplained abdominal pain or discomfort 1=Yes 2=No 3=Don't Know	Num 4.

ssUnxCon	Q12: Repeatedly bothered by unexplained confusion or memory loss 1=Yes 2=No 3=Don't Know	Num 4.
mhHemo	Q13: Ever told that you have/had iron overload or hemochromatosis 1=Yes 2=No 3=Don't Know	Num 4.
mhAnemia	Q14: Ever told that you have/had anemia (low iron) 1=Yes 2=No 3=Don't Know	Num 4.
mhSC	Q15: Ever told that you have/had sickle cell anemia 1=Yes 2=No 3=Don't Know	Num 4.
mhThal	Q16: Ever told that you have/had thalassemia or other inherited anemia 1=Yes 2=No 3=Don't Know	Num 4.
mhBlood	Q17: Ever told that you have/had unusual blood loss (vomiting or coughing up blood, blood in stool, or blood in urine) 1=Yes 2=No 3=Don't Know	Num 4.
mhDiab	Q18: Ever told that you have/had diabetes 1=Yes 2=No 3=Don't Know	Num 4.
mhDiabMd	Q18a: Are you taking medication for diabetes? 1=Yes 2=No	Num 4.
mhDiabIn	Q18b: Are you taking insulin for diabetes? 1=Yes 2=No	Num 4.
mhDiabPl	Q18c: Are you taking pills for diabetes? 1=Yes 2=No	Num 4.
mhDiabTr	Q18d: At what age was diabetes first treated? 1=Yes 2=No 3=Don't Know	Num 4.

mhLiver	Q19: Ever told that you have/had liver disease? 1=Yes 2=No 3=Don't Know	Num 4.
mhLivFat	Q19a: Ever told that you have/had Fatty liver? 1=Yes 2=No 3=Don't Know	Num 4.
mhLivCir	Q19b: Ever told that you have/had cirrhosis? 1=Yes 2=No 3=Don't Know	Num 4.
mhLivCan	Q19c: Ever told that you have/had liver cancer (cancer that started in the liver)? 1=Yes 2=No 3=Don't Know	Num 4.
mhHep	Q19e: Ever told that you have/had hepatitis A or B or C or other type. 1=Yes 0=No	Num 1.
mhThyr	Q20: Ever told that you have/had thyroid disease (over-active or under-active thyroid)? 1=Yes 2=No 3=Don't Know	Num 4.
mhHrt	Q21: Ever told that you have/had heart failure or weak heart? 1=Yes 2=No 3=Don't Know	Num 4.
mhHrtAb	Q22: Ever told that you have/had abnormal heart rhythm, heart beat, or action/arrhythmia? 1=Yes 2=No 3=Don't Know	Num 4.
mhHrtOth	Q23: Ever told that you have/had other heart disease or heart attack? 1=Yes 2=No 3=Don't Know	Num 4.
mhArth	Q24: Ever told that you have/had arthritis? 1=Yes 2=No 3=Don't Know	Num 4.



mhOsteo	Q25: Ever told that you have/had osteoporosis (weak, think, or brittle bones)? 1=Yes 2=No 3=Don't Know	Num 4.
mhPorph	Q26: Ever told that you have/had porphyria cutanea tarda? 1=Yes 2=No 3=Don't Know	Num 4.
mhChrInf	Q28: Ever told that you have/had chronic inflammation, chronic infection, autoimmune disease or lupus? 1=Yes 2=No 3=Don't Know	Num 4.
mhCancer	Q29: Ever told that you have/had cancers (other than those starting in the liver)? 1=Yes 2=No 3=Don't Know	Num 4.
mhChemo	Q30: Ever had chemotherapy or bone marrow transplant? 1=Yes 2=No 3=Don't Know	Num 4.
rhMenPr	Q31a: Ever seen a doctor for menstrual problems? 1=Yes 2=No 3=Don't Know	Num 4.
rhBleed	Q31b: Ever seen a doctor for in-between bleeding? 1=Yes 2=No 3=Don't Know	Num 4.
rhStop	Q31c: Ever seen a doctor for early stopping of periods? 1=Yes 2=No 3=Don't Know	Num 4.
rhPreg	Q32: Ever been pregnant? 1=Yes 2=No 3=Don't Know	Num 4.
rhPregNm	Q32a: Number of pregnancies	Num 4.
rhBirths	Q32b: Number of live births	Num 4.
rhPregC	Q33: Are you currently pregnant? 1=Yes 2=No 3=Don't Know	Num 4.

rhMen	Q34: Gone through menopause? 1=Yes 2=No 3=Don't Know	Num 4.
rhMenAge	Q34a: Age at menopause?	Num 4.
rhMenar	Q35: Age at menarche?	Num 4.
rhHyst	Q36: Had a hysterectomy? 1=Yes 2=No 3=Don't Know	Num 4.
rhHysAge	Q36a: Age at hysterectomy?	Num 4.
btEver	Q37: Ever had blood transfusions? 1=Yes 2=No 3=Don't Know	Num 4.
btTotal	Q37a: Number of pints/units transfused in a lifetime?	Num 4.
gt10	Q37b Have you had more than 10 pints/units transfused in a lifetime? 1=Yes 2=No	Num 4.
btWhole	Q38: Ever donated whole blood at a blood bank? 1=Yes 2=No 3=Don't Know	Num 4.
btWholeU	Q38a: Number of whole blood units in lifetime?	Num 4.
liBrRest	Q39a: Get short of breath while resting in a chair? 1=Yes 2=No	Num 4.
liBrLevel	Q39b: Get short of breath while walking on level ground? 1=Yes 2=No	Num 4.
liBrQuik	Q39c: Get short of breath when walking quickly or uphill? 1=Yes 2=No 3=Never do this	Num 4.
liAlcoh	Q40: Ever consumed alcoholic beverages? 1=Yes 2=No	Num 4.
liAlcAge	Q41: Age started consuming alcoholic beverages?	Num 4.
liAlcPr	Q42: Presently drink alcoholic beverages? 1=Yes 2=No	Num 4.

liAlcYr	Q42a: Number of years have been drinking alcoholic beverages?	Num 4.
liAlcYrN	Q42b: Number of years did you drink alcoholic beverages?	Num 4.
liAlcNum	Q42c: Usual number of drinks you had per week before stopping?	Num 4.
dmGrade	Q43: Highest grade of school completed 1=Less than HS 2=HS 3=Some univ. 4=Bachelors 5=Post-graduate	Num 6.

**Section IX: Additional Medical History Questions**

Note: Asked if answered 'YES' to question 13 of the medical history form.

DMHAVISIT	Date of visit (Number of days from given date)	Num 4.
PHLEB	Have you ever had phlebotomy as treatment for your iron overload or HH? 1=No 2=Yes	Num 4.
BIOPSY	Have you ever had a liver biopsy? 1=No 2=Yes	Num 4.

**Section X: Food Frequency - Individual Questions**

FOR FOOD ITEMS REGULAR OR DRAFT BEER THROUGH DIET SODAS USE THE FOLLOWING FORMAT:

- Average use during last year
- 1 - Never or hardly ever
- 2 - Once a month
- 3 - 2 - 3 times a month
- 4 - Once a week
- 5 - 2 - 3 times a week
- 6 - 4 - 6 times a week
- 7 - Once a day
- 8 - 2 - 3 times a day
- 9 - 4 or more times a day
- Blank - Not Answered
- \* - Multiple Answers

Q368	Regular or Draft Beer Frequency	Char \$1.
Q369	Light Beer Frequency	Char \$1.
Q370	White or Pink Wine Frequency	Char \$1.
Q371	Red Wine Frequency	Char \$1.
Q372	Hard Liquor Frequency	Char \$1.

FOR FOOD ITEMS REGULAR OR DRAFT BEER THROUGH HARD LIQUOR USE THE FOLLOWING FORMAT:

- Usual Serving Size
  - 1 - 1 can or bottle or less
  - 2 - 2 cans or bottles
  - 3 - 3 cans or bottles
  - 4 - 4 cans or more
  - Blank - Not Answered
  - \* - Multiple Answers

Q375	Regular or Draft Beer Serving Size	Char \$1.
Q376	Light Beer Serving Size	Char \$1.
Q377	White or Pink Wine Serving Size	Char \$1.
Q378	Red Wine Serving Size	Char \$1.
Q379	Hard Liquor Serving Size	Char \$1.

**Section XI: Food Frequency Summary Variables**

AVERAGE DAILY INTAKE FROM FOODS:

iron	Iron (mg)	Num 15.3
alc	Alcohol (g)	Num 15.3

AVERAGE DAILY INTAKE FROM VITAMIN AND MINERAL SUPPLEMENTS:

sIron	Iron from Supplements (mg)	Num 15.3
sIron2	Iron from Supplements where use was >= 2 years (mg)	Num 15.3
DMFPIron	Daily Meat-Fish-Poultry (MFP) Iron (mg)	Num 15.3

**Section XII: Liver Biopsy Pathology Report Summary Form**

PATHSUM	Pathology Report 1=Pathology report entered for participant	Num 8.
PATH_DVISIT	Date of Pathology Report Form (Number of days from given date)	Num 4.
DBIOPSY	Liver biopsy date (Number of days from given date)	Num 4.

DIAGNOSES RELATED TO IRON OVERLOAD INDICATED ON PATHOLOGY REPORT

DIAGNONE	None indicated 1=Yes	Num 8.
DIAGALCOHOL	Alcoholic liver disease 1=Yes	Num 8.

DIAGCIRRHOSIS	Cirrhosis 1=Yes	Num 8.
DIAGHEP	Hepatitis B,C, or Other POSTIVIVE NEGATIVE	Num 8.
DIAGNASH	Non-alcoholic steatohepatitis (NASH) 1=Yes	Num 8.
DIAGFATLIVER	Fatty liver 1=Yes	Num 8.
DIAGFIBROSIS	Fibrosis 1=Yes	Num 8.
DIAGPRIME	Primary hemochromatosis 1=Yes	Num 8.
DIAGSECOND	Secondary hemochromatosis 1=Yes	Num 8.
DIAGNOSPEC	Hemochromatosis no specified 1=Yes	Num 8.
DIAGSECIO	Hemosiderosis (secondary iron overload) 1=Yes	Num 8.
DIAGOTHERIO	Other iron overload 1=Yes	Num 8.
DIAGOTHERLD	Other liver disease 1=Yes	Num 8.
AMOUNT AND DISTRIBUTION OF STAINABLE IRON:		
PATH_BILIARY	Biliary Epithelium: 1=Absent 2=Present 3=Not reported	Num 8.
PATH_MALLORY	Mallory bodies: 1=Absent 2=Present 3=Not reported	NUM 8.
PATH_KUPFFER	Kupffer cells/Macrophages: 1=Absent 2=Present/not increased 3=Increased 4=Not reported	NUM 8.
HEPAPROSE	Hepatocytes: If prose only 1=Absent 2=Present/not increased 3=Increased 4=Not reported	Num 8.

HEPAGRADE4	Hepatocytes: If graded-Four (4) point scale grade	Num 8.
HEPAGRADE6	Hepatocytes: If graded-Six (6) point scale grade	Num 8.
PATH_HEPIRONCONC	Is the hepatic iron concentration available 1=Yes 2=No	Num 8.
DRYWEIGHT1	If HIC is available, indicate dry weight. $\mu\text{mol/g}$	Num 8.
DRYWEIGHT2	If HIC is available, indicate dry weight. $\mu\text{g/g}$	Num 8.
WETWEIGHT1	If HIC is available, indicate wet weight. $\mu\text{mol/g}$	Num 8.
WETWEIGHT2	If HIC is available, indicate wet weight. $\mu\text{g/g}$	Num 8.
PARTAGE	Participants age in years	Num 8.

**Section XIII: Central Reading Liver Biopsy Form**

CRLIVER	Central Reading 1=Central Reading done for participant	Num 8.
CR_DVISIT	Date of Visit (Number of days from given date)	Num 4.
ADEQHIST	Sample adequate for histology 1=Yes 2=No	Num 8.
ADEQIRON	Sample adequate for quantification of iron 1=Yes 2=No	Num 8.
CR_KUPFFER	Stainable iron identified in Kupffer cells/Macrophages (0-4)	Num 8.
CR_BILIARY	Stainable iron identified in Biliary epithelium 1=Absent 2=Present 3=Not Reported	Num 8.
MICROHEPA	Stainable iron identified in Microscopic iron score hepatocytes (0-4)	Num 8.

CR_MALLORY	Stainable iron identified in Mallory bodies 1=Absent 2=Present 3=Not Reported	Num 8.
CR_HEPAIRONCONC	Hepatic Iron Concentration $\mu\text{mol/g}$ dry weight	Num 8.
FIBROSIS	Fibrosis Score (0-4)	Num 8.
FATCHANGE	Fatty Changes 0=None 1=Mild 2=Moderate 3=Severe	Num 8.
INFLAM	Inflammation 0=None 1=Mild 2=Moderate 3=Severe	Num 8.
CELLTYPE	If inflammation is present, cellular type 1=Lymphocytic 2=Mixed 3=Neutrophilic	Num 8.

**Section XIV: Quantitative Phlebotomy**

DEP	SF < 50 achieved 1=Yes 2=No	Num 11.
TOTIRON	Total Iron Removed	Num 8.
QPH_CCE_FLAG	1. cce = phleb < qph 2. cce = phleb = qph 3. qph < cce = phleb 4. qph < cce < phleb 5. qph < phleb < cce 6. cce = qph < phleb 7. cce < qph < phleb 8. cce < qph = phleb 9. cce < phleb < qph 10. cce = phleb, no qph 11. cce < phleb, no qph 12. qph < cce, phleb=no/missing 13. cce < qph, phleb=no/missing 14. cce = qph, phleb=no/missing 15. no qph data, phleb=no/missing	Char \$35.
QPH_PRIOR_CCE	Use for cce iron-related lab data exclusions o = include x = exclude	Char \$2.





CLREASY	I found the information I received to be clear and easy to understand 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
ENOUGH	I received enough information 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
STILQUES	I still have questions about hemochromatosis and iron overload or my test results 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
*****		
GOODIDEA	In general, I think genetic testing to find out about disease risk is a good idea 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
NOGENES	I do not have any known hemochromatosis gene variations 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
BOTHGENE	I have hemochromatosis gene variations in both my hemochromatosis genes 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
ONEGENE	I have hemochromatosis gene variations in one, but not both of my hemochromatosis genes 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
DONOTIO	I do not have iron overload 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
DOIO	I do have iron overload 1=Strongly agree 2=Agree 3=Disagree	Num 4.

4=Strongly disagree

INFAMILY I have hemochromatosis gene variations that may also be present in members of my family Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

\*\*\*\*\*

What were you told to do in response to your test results?

NORECOMM There were no specific recommendation made to me Num 4.  
1=Yes  
2=No  
3=Not sure

TALKMYDR Talk to my personal physician about my test results Num 4.  
1=Yes  
2=No  
3=Not sure

MYDRTEST Have my personal physician test the amount of iron in my blood about once a year. Num 4.  
1=Yes  
2=No  
3=Not sure

BLDDRAWN Have my blood drawn to lower the amount of iron in my blood Num 4.  
1=Yes  
2=No  
3=Not sure

TALKFAM Talk to family members about their possible risk for hemochromatosis or iron overload Num 4.  
1=Yes  
2=No  
3=Not sure

\*\*\*\*\*

REHELP Do you think these recommendations will help your health Num 4.  
1=Probably not  
2=Not sure  
3=Probably yes  
4=Does not apply

FOLLOWRE Do you feel confident that you can follow the recommendations Num 4.  
1=Probably not  
2=Not sure  
3=Probably yes  
4=Does not apply

\*\*\*\*\*

Please indicate whether and how much you have experienced each statement since you have received your test results?

UPSET	Feeling upset, sad or anxious about your test results 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
RELIEVED	Feeling relieved that no known hemochromatosis gene variations exist in your family 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
LOSSCONT	Feeling a loss of control because of you test results 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
PROBJOY	Having problems enjoying your life because of your test results 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
WORSE	Worrying about your risk of developing IO or Hemo. or having your condition get worse 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
MORECONT	Feeling more in control of you future health 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
THINKING	Thinking about your test results has caused problems in you work or family life 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
FRUSTRAT	Feeling frustrated that no known hemochromatosis gene variations have been found that explain the iron overload in your family 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
EASYFOLL	Feeling relieved that the guidelines about how to deal with your particular results are so clear and easy to follow 1=Never	Num 4.

2=Rarely  
3=Sometimes  
4=Often

WORRYING Worrying about the confidentiality of your test results Num 4.  
1=Never  
2=Rarely  
3=Sometimes  
4=Often

ASGOODAS Feeling that people don't think you are as good as they are Num 4.  
1=Never  
2=Rarely  
3=Sometimes  
4=Often

RISKFAM Worrying about the risk to your family Num 4.  
1=Never  
2=Rarely  
3=Sometimes  
4=Often

FEELGLAD Feeling glad that you took part in this research Num 4.  
1=Never  
2=Rarely  
3=Sometimes  
4=Often

\*\*\*\*\*

SHAREINF\_PR Information about a person's genetic risk should be shared with other family members Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

RSKSHARE The person who has the genetic risk should share the info directly with family members Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

DRPERM The doctor of the person at risk should inform family members only if the person at risk gives permission Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

DRINFORM      The doctor of the person at risk should inform family members if the person at risk will not share the information      Num 4.  
                  1=Strongly agree  
                  2=Agree  
                  3=Disagree  
                  4=Strongly disagree

\*\*\*\*\*

With whom would you be most likely to share information about inherited health risk?

SPOUSE      Spouse or partner      Num 4.  
                  1=Would not share  
                  2=Would definitely share  
                  3=Would share with some but not all  
                  4=Does not apply

CHILDREN      Children      Num 4.  
                  1=Would not share  
                  2=Would definitely share  
                  3=Would share with some but not all  
                  4=Does not apply

PARENTS      Parents      Num 4.  
                  1=Would not share  
                  2=Would definitely share  
                  3=Would share with some but not all  
                  4=Does not apply

BROTHERSIS      Brothers and sisters      Num 4.  
                  1=Would not share  
                  2=Would definitely share  
                  3=Would share with some but not all  
                  4=Does not apply

OTHRELA      Other relatives      Num 4.  
                  1=Would not share  
                  2=Would definitely share  
                  3=Would share with some but not all  
                  4=Does not apply

FRIENDS      Close friends      Num 4.  
                  1=Would not share  
                  2=Would definitely share  
                  3=Would share with some but not all  
                  4=Does not apply

DOCTOR      Doctor      Num 4.  
                  1=Would not share  
                  2=Would definitely share  
                  3=Would share with some but not all  
                  4=Does not apply

EMPLOYER      Employer      Num 4.  
                  1=Would not share  
                  2=Would definitely share  
                  3=Would share with some but not all  
                  4=Does not apply

\*\*\*\*\*

How likely are you to...

SPOUTEST	Encourage your spouse/partner to be tested for risk of hemochromatosis or iron overload 1=Very unlikely 2=Unlikely 3=Likely 4=Very likely 5=Does not apply	Num 4.
PRENATAL	Have prenatal testing of your unborn child for risk of hemochromatosis or iron overload 1=Very unlikely 2=Unlikely 3=Likely 4=Very likely 5=Does not apply	Num 4.
NEWBORN	Have your future newborn children tested for risk of hemochromatosis or iron overload 1=Very unlikely 2=Unlikely 3=Likely 4=Very likely 5=Does not apply	Num 4.
KIDS18	Have your children under 18 tested for risk of hemochromatosis or iron overload 1=Very unlikely 2=Unlikely 3=Likely 4=Very likely 5=Does not apply	Num 4.
ADULTKID	Encourage your adult children to get genetic testing for risk of hemochromatosis or IO 1=Very unlikely 2=Unlikely 3=Likely 4=Very likely 5=Does not apply	Num 4.
B4MARRY	Encourage your adult children to get genetic testing before they get married 1=Very unlikely 2=Unlikely 3=Likely 4=Very likely 5=Does not apply	Num 4.
B4CHILD	Encourage your adult children to get genetic testing before they have children 1=Very unlikely 2=Unlikely 3=Likely 4=Very likely 5=Does not apply	Num 4.

\*\*\*\*\*

Please give your opinion on why people get sick.

HEREDITY\_PR Heredity (it runs in the family) Num 4.  
1=Very important  
2=Somewhat important  
3=Not important  
4=Not Sure

ENVIRON\_PR The environment (water or air pollution) Num 4.  
1=Very important  
2=Somewhat important  
3=Not important  
4=Not Sure

FATE\_PR Fate or chance (bad luck) Num 4.  
1=Very important  
2=Somewhat important  
3=Not important  
4=Not Sure

STRESS Psychological factors (such as stress) Num 4.  
1=Very important  
2=Somewhat important  
3=Not important  
4=Not Sure

LIFESTYL\_PR Lifestyle (smoking, drinking, eating a high fat diet) Num 4.  
1=Very important  
2=Somewhat important  
3=Not important  
4=Not Sure

\*\*\*\*\*

HEALTH\_PR In general would you say your health is... Num 4.  
1=Poor  
2=Fair  
3=Average  
4=Good  
5=Excellent

SICKEASY\_PR I seem to get sick a little easier than other people Num 4.  
1=Definitely true  
2=Mostly true  
3=Don't know  
4=Mostly false  
5=Definitely false

ASHEALTH I am as healthy as anybody I know Num 4.  
1=Definitely true  
2=Mostly true  
3=Don't know  
4=Mostly false  
5=Definitely false

GETWORSE	I expect my health to get worse 1=Definitely true 2=Mostly true 3=Don't know 4=Mostly false 5=Definitely false	Num 4.
EXCELLEN	My health is excellent 1=Definitely true 2=Mostly true 3=Don't know 4=Mostly false 5=Definitely false	Num 4.
NERVOUS_PR	Have you been a very nervous person 1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little bit of the time 6=None of the time	Num 4.
DOWNDUMP_PR	Have you felt so down in the dumps that nothing could cheer you up 1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little bit of the time 6=None of the time	Num 4.
CALM_PR	Have you felt calm and peaceful 1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little bit of the time 6=None of the time	Num 4.
FELTBLUE	Have you felt downhearted and blue 1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little bit of the time 6=None of the time	Num 4.
HAPPY_PR	Have you been a happy person 1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little bit of the time 6=None of the time	Num 4.



RANKHEMO Compared to other medical conditions, I would rank hemochromatosis as Num 4.  
1=One of the least serious  
2...3...4...  
5=One of the most serious

\*\*\*\*\*

Which of the following problems are associated with hemochromatosis or iron overload?

ARTHRITI\_PR Arthritis-like pain Num 4.  
1=Yes  
2=No  
3=Don't know

IMPOTENT Impotence Num 4.  
1=Yes  
2=No  
3=Don't know

PAINMENS Painful menstrual periods Num 4.  
1=Yes  
2=No  
3=Don't know

PROSTATE Prostate or ovarian cancer Num 4.  
1=Yes  
2=No  
3=Don't know

HEARTAB Heart abnormalities Num 4.  
1=Yes  
2=No  
3=Don't know

DIABETES\_PR Diabetes Num 4.  
1=Yes  
2=No  
3=Don't know

MS Multiple sclerosis Num 4.  
1=Yes  
2=No  
3=Don't know

FATIGUE Fatigue Num 4.  
1=Yes  
2=No  
3=Don't know

ASTHMA Asthma Num 4.  
1=Yes  
2=No  
3=Don't know

\*\*\*\*\*

IRONBAD	Too much iron in the blood is always bad 1=True 2=False 3=Don't know	Num 4.
IRONBUIL	In hemochromatosis, iron builds up in the body and causes damage 1=True 2=False 3=Don't know	Num 4.
NEVERDIE	People never die because of hemochromatosis 1=True 2=False 3=Don't know	Num 4.
BLDREMOV	The best way to treat hemochromatosis is to have blood removed until iron levels go back to normal 1=True 2=False 3=Don't know	Num 4.
NOTREAT	There is no treatment for hemochromatosis 1=True 2=False 3=Don't know	Num 4.
WATERDAY	People with hemochromatosis can prevent symptoms by drinking 8 glasses of water a day 1=True 2=False 3=Don't know	Num 4.
ORGANDAM	It is not important to treat hemochromatosis until organ damage has occurred 1=True 2=False 3=Don't know	Num 4.
NOTKNOW	A person can have hemochromatosis and not know it 1=True 2=False 3=Don't know	Num 4.
HIGHBP	A person with hemochromatosis has too much blood, resulting in high blood pressure 1=True 2=False 3=Don't know	Num 4.
GENETEST_PR	A gene test can tell you if you already have iron overload 1=True 2=False 3=Don't know	Num 4.

EVERYONE	Everyone who has variations in their hemochromatosis genes will have too much iron in their blood 1=True 2=False 3=Don't know	Num 4.
WHITES	Only White people are at risk for iron overload 1=True 2=False 3=Don't know	Num 4.
ALLVARY	All variations in hemochromatosis genes increase your risk of having too much iron by the same amount 1=True 2=False 3=Don't know	Num 4.
WOMENEAR	Women tend to develop hemochromatosis earlier in life than men do 1=True 2=False 3=Don't know	Num 4.
SIBSRISK	If someone has hemochromatosis, their brothers and sisters are also at risk 1=True 2=False 3=Don't know	Num 4.
FAM2GENE	An individual may have one variation in their hemochromatosis gene but others in the same family may have two hemochromatosis genes with variations 1=True 2=False 3=Don't know	Num 4.
*****		
I think genetic testing IS a good idea because...		
GOODTRT_PR	There might be a treatment by the time you developed the disease 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
REASSURE	You might not have the gene for the disease and would be reassured 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.

WHATEVER	It is always good to know whatever you can about your health 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
CURABLE	You could get frequent medical screening to catch the disease at a curable stage 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
CHANGELS	You could change to a healthier lifestyle 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
GENETHER	There might be gene therapy that could prevent you from getting the disease 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
SHAREFAM	You could share this risk information with family members 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
PREPARE	You could prepare better for the future 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
*****		
I think genetic testing IS NOT a good idea because...		
INSURANC	You might have trouble getting or keeping your health insurance 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
HELPLESS_PR	You might feel helpless because you can't change your genes 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.

FUTUEMP	It could be a problem if an employer or future employer found out about your test results 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
WORRYBAD	You could spend a lot of time worrying about something bad that is still in the future 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
LIFEINS	You might have trouble getting life or disability insurance 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
LESSHLTH	Knowing that you had a gene that put you at risk could make you feel less healthy 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
BADNEWS_PR	You could be bringing bad news into your family 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
*****		
DROFFICE	Is there one particular clinic, health center or doctor's office that you usually go to if you are sick or need health advice 1=Yes 2=No	Num 4.
HOWLONG	How long as it been since you last visited a doctor for a routine check up 1=Less than a year 2=1-2 years 3=3-5 years 4=More than 5 years 5=Not sure	Num 4.
CHOLEST	Do you know your cholesterol level 1=I know the exact number 2=I know if it's too high or low 3=I was told by I've forgotten 4=I don't remember having my cholesterol checked	Num 4.

SEATBELT	Do you use a seatbelt when driving 1=Always 2=Usually 3=Sometimes 4=Rarely 5=Never	Num 4.
SUNSCRN	Do you use a sunscreen product 1=Yes, all year long 2=Yes, but only in the summer 3=Rarely 4=Never	Num 4.
DISABINS	Do you have disability insurance 1=Yes 2=No 3=Don't know	Num 4.
LIFEPOLI	Do you have a life insurance policy 1=Yes 2=No 3=Don't know	Num 4.
HLTHINS	Do you have health insurance (any type) 1=Yes 2=No 3=Don't know	Num 4.
MOSTCOST	If you have health insurance, who pays most of the cost of the insurance 1=Employer 2=Government (state/province) 3=Me or my family 4=Don't know 5=Does not apply	Num 4.
UNEMPLOY	Unemployed 0=No 1=Yes	Num 4.
SELFEMP	Self employed 0=No 1=Yes	Num 4.
FEDGOV	Employed by federal government 0=No 1=Yes	Num 4.
STATEGOV	Employed by state/province 0=No 1=Yes	Num 4.
PRIV50	Private employer (50 or fewer employees) 0=No 1=Yes	Num 4.

PRIV51 Private employer (51 or more employees) Num 4.  
0=No  
1=Yes

SCHOOL What is the highest grade of school you've completed Num 4.  
1=Less than high school  
2=High school degree  
3=Some university, college or vocational training  
4=Bachelor's degree (BA/BS)  
5=Post-graduate training

\*\*\*\*\*

GHSCALE\_PR SF-36 General Health Scale - Post Results Num 4.

MHSCALE\_PR SF-36 Mental Health Scale - Post Results Num 4.

**Section XVI: 1-Year Post Result Follow-up**

ELSI\_1y returned ELSI 1-year followup form Char

DVISIT\_1y Date of Visit Num 4.  
(Number of days from given date)

\*\*\*\*\*

Since you first heard about the HEIRS study, how much have you used each of the following sources to look for information about hemochromatosis or iron overload?

FAAIPH Phone call or written material from the HEIRS study Num 4.  
1=None  
2=Some  
3=A Lot

FAAIFAM Family Members Num 4.  
1=None  
2=Some  
3=A Lot

FAAILIB The Library Num 4.  
1=None  
2=Some  
3=A Lot

FAAIINF The Internet Num 4.  
1=None  
2=Some  
3=A Lot

FAAIDOC You doctor or other health worker Num 4.  
1=None  
2=Some  
3=A Lot

\*\*\*\*\*

What is your opinion of the information you received from the HEIRS study about hemochromatosis and your test results?

FAINFCLR I found the information I received to be clear and easy to understand Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

FAINFEN I received enough information Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

FAINFQST I still have questions about hemochromatosis and iron overload or my test results Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

\*\*\*\*\*

FAGENTST In general, I think genetic testing to find out about disease risk is a good idea Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

FATRNV I do not have any known hemochromatosis gene variations Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

FATRHHB I have hemochromatosis gene variations in both my hemochromatosis genes Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

FATRHHO I have hemochromatosis gene variations in one, but not both of my hemochromatosis genes Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

FATRNO I do not have iron overload Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree



FATRDO I do have iron overload Num 4.  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

FATRVF I have hemochromatosis gene variations that may Num 4.  
also be present in members of my family  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

\*\*\*\*\*

What were you told to do in response to your test results?

FARESNOS There were no specific recommendation made to me Num 4.  
1=Yes  
2=No  
3=Not sure

FARESPP Talk to my personal physician about my test results Num 4.  
1=Yes  
2=No  
3=Not sure

FARESTST Have my personal physician test the amount of Num 4.  
iron in my blood about once a year.  
1=Yes  
2=No  
3=Not sure

FARESBLD Have my blood drawn to lower the amount of Num 4.  
iron in my blood  
1=Yes  
2=No  
3=Not sure

FARESFAM Talk to family members about their possible risk Num 4.  
for hemochromatosis or iron overload  
1=Yes  
2=No  
3=Not sure

\*\*\*\*\*

FAFOLLOW Have you followed the recommendations that were given Num 4.  
to you regarding hemochromatosis or iron overload  
1=Yes  
2=Some, but not all  
3=No  
4=Does not apply

FAREHELP Do you think these recommendations are help your health Num 4.  
1=Probably not  
2=Not sure  
3=Probably yes  
4=Does not apply

\*\*\*\*\*

Please indicate whether and how much you have experienced each statement since you have received your test results?

- |          |  |        |
|----------|--|--------|
| FAEXPSAD | Feeling upset, sad or anxious about your test results  | Num 4. |
|          | 1=Never  |        |
|          | 2=Rarely   |        |
|          | 3=Sometimes  |        |
|          | 4=Often  |        |
| FAEXPREL | Feeling relieved that no known hemochromatosis gene variations exist in your family  | Num 4. |
|          | 1=Never  |        |
|          | 2=Rarely   |        |
|          | 3=Sometimes  |        |
|          | 4=Often  |        |
| FAEXPLOC | Feeling a loss of control because of you test results  | Num 4. |
|          | 1=Never  |        |
|          | 2=Rarely   |        |
|          | 3=Sometimes  |        |
|          | 4=Often  |        |
| FAEXPENJ | Having problems enjoying your life because of your test results  | Num 4. |
|          | 1=Never  |        |
|          | 2=Rarely   |        |
|          | 3=Sometimes  |        |
|          | 4=Often  |        |
| FAEXPRSK | Worrying about your risk of developing IO or Hemo. or having your condition get worse  | Num 4. |
|          | 1=Never  |        |
|          | 2=Rarely   |        |
|          | 3=Sometimes  |        |
|          | 4=Often  |        |
| FAEXPMOC | Feeling more in control of you future health   | Num 4. |
|          | 1=Never  |        |
|          | 2=Rarely   |        |
|          | 3=Sometimes  |        |
|          | 4=Often  |        |
| FAEXPPRB | Thinking about your test results has caused problems in you work or family life  | Num 4. |
|          | 1=Never  |        |
|          | 2=Rarely   |        |
|          | 3=Sometimes  |        |
|          | 4=Often  |        |
| FAEXPFRU | Feeling frustrated that no known hemochromatosis gene variations have been found that explain the iron overload in your family | Num 4. |
|          | 1=Never  |        |
|          | 2=Rarely   |        |
|          | 3=Sometimes  |        |
|          | 4=Often  |        |

FAEXPGDL	Feeling relieved that the guidelines about how to deal with your particular results are so clear and easy to follow 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
FAEXPCNF	Worrying about the confidentiality of your test results 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
FAEXPGD	Feeling that people don't think you are as good as they are 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
FAEXPFAM	Worrying about the risk to your family 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
FAEXPGLD	Feeling glad that you took part in this research 1=Never 2=Rarely 3=Sometimes 4=Often	Num 4.
*****		
FAGRSHR	Information about a person's genetic risk should be shared with other family members 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FAGR FAM	The person who has the genetic risk should share the info directly with family members 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FAGRPER	The doctor of the person at risk should inform family members only if the person at risk gives permission 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.

FAGRDOC      The doctor of the person at risk should inform      Num 4.  
family members if the person at risk will not  
share the information  
1=Strongly agree  
2=Agree  
3=Disagree  
4=Strongly disagree

\*\*\*\*\*

With whom would you be most likely to share information about inherited health risk?

FAISP          Spouse or partner      Num 4.  
1=Would not share  
2=Would definitely share  
3=Would share with some but not all  
4=Does not apply

FAICH          Children      Num 4.  
1=Would not share  
2=Would definitely share  
3=Would share with some but not all  
4=Does not apply

FAIPAR          Parents      Num 4.  
1=Would not share  
2=Would definitely share  
3=Would share with some but not all  
4=Does not apply

FAIBRO          Brothers and sisters      Num 4.  
1=Would not share  
2=Would definitely share  
3=Would share with some but not all  
4=Does not apply

FAIOTH          Other relatives      Num 4.  
1=Would not share  
2=Would definitely share  
3=Would share with some but not all  
4=Does not apply

FAIFRI          Close friends      Num 4.  
1=Would not share  
2=Would definitely share  
3=Would share with some but not all  
4=Does not apply

FAIDOC          Doctor      Num 4.  
1=Would not share  
2=Would definitely share  
3=Would share with some but not all  
4=Does not apply



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For the family members you DID NOT share information with, check the box that best describes why you did not share information about your risk for iron overload.

FANSTOLD      No one told me to share information about my test results      Num 4.  
                 1=Strongly Agree  
                 2=Agree  
                 3=Disagree  
                 4=Strongly Disagree

FANSTALK      There are certain members of my family that I don't talk to Num 4.  
                 1=Strongly Agree  
                 2=Agree  
                 3=Disagree  
                 4=Strongly Disagree

FANSPROB      The people I didn't tell have too many other problems in      Num 4.  
                 their lives right now  
                 1=Strongly Agree  
                 2=Agree  
                 3=Disagree  
                 4=Strongly Disagree

FANSSTR      The people I didn't tell don't handle stress well      Num 4.  
                 1=Strongly Agree  
                 2=Agree  
                 3=Disagree  
                 4=Strongly Disagree

FANSINFO      My family tends not to talk about or share information      Num 4.  
                 about health, illness and medical issues  
                 1=Strongly Agree  
                 2=Agree  
                 3=Disagree  
                 4=Strongly Disagree

FANSOBL      I don't feel that I had an obligation to share this info      Num 4.  
                 1=Strongly Agree  
                 2=Agree  
                 3=Disagree  
                 4=Strongly Disagree

FANSEMB      I would have felt ashamed or embarrassed to let other know      Num 4.  
                 1=Strongly Agree  
                 2=Agree  
                 3=Disagree  
                 4=Strongly Disagree

FANSBURD      I don't burden others with my problems      Num 4.  
                 1=Strongly Agree  
                 2=Agree  
                 3=Disagree  
                 4=Strongly Disagree

FANSRGHT No one else has a right to know about my health Num 4.  
1=Strongly Agree  
2=Agree  
3=Disagree  
4=Strongly Disagree

FANSSER I didn't think this disease was serious enough to bother my family about it Num 4.  
1=Strongly Agree  
2=Agree  
3=Disagree  
4=Strongly Disagree

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In the past year since you received your test results have you:

FAPYENC Encouraged your spouse/partner to be tested for risk of hemochromatosis or iron overload Num 4.  
1=Yes  
2=No  
3=Does not apply

FAPYUNBC Have prenatal testing of your unborn child for risk of hemochromatosis or iron overload Num 4.  
1=Yes  
2=No  
3=Does not apply

FAPYNEWB Have your newborn children tested for risk of hemochromatosis or iron overload Num 4.  
1=Yes  
2=No  
3=Does not apply

FAPYUN18 Have your children under 18 tested for risk of hemochromatosis or iron overload Num 4.  
1=Yes  
2=No  
3=Does not apply

FAPYRISK Encourage your adult children to get genetic testing for risk of hemochromatosis or iron overload Num 4.  
1=Yes  
2=No  
3=Does not apply

FAPYMAR Encourage your adult children to get genetic testing before they get married Num 4.  
1=Yes  
2=No  
3=Does not apply

FAPYADLT Encourage your adult children to get genetic testing before they have children Num 4.  
1=Yes  
2=No  
3=Does not apply

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Please give your opinion on why people get sick.

FAOPHERE      Heredity (it runs in the family)      Num 4.  
                  1=Very important  
                  2=Somewhat important  
                  3=Not important  
                  4=Not Sure

FAOPENV      The environment (water or air pollution)      Num 4.  
                  1=Very important  
                  2=Somewhat important  
                  3=Not important  
                  4=Not Sure

FAOPFATE      Fate or chance (bad luck)      Num 4.  
                  1=Very important  
                  2=Somewhat important  
                  3=Not important  
                  4=Not Sure

FAOPPSY      Psychological factors (such as stress)      Num 4.  
                  1=Very important  
                  2=Somewhat important  
                  3=Not important  
                  4=Not Sure

FAOPLIFE      Lifestyle (smoking, drinking, eating a high fat diet)      Num 4.  
                  1=Very important  
                  2=Somewhat important  
                  3=Not important  
                  4=Not Sure

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FAHEALTH      In general would you say your health is...      Num 4.  
                  1=Poor  
                  2=Fair  
                  3=Average  
                  4=Good  
                  5=Excellent

FATFSICK      I seem to get sick a little easier than other people      Num 4.  
                  1=Definitely true  
                  2=Mostly true  
                  3=Don't know  
                  4=Mostly false  
                  5=Definitely false

FATFHLTH      I am as healthy as anybody I know      Num 4.  
                  1=Definitely true  
                  2=Mostly true  
                  3=Don't know  
                  4=Mostly false  
                  5=Definitely false



FATFWRSE	I expect my health to get worse 1=Definitely true 2=Mostly true 3=Don't know 4=Mostly false 5=Definitely false	Num 4.
FATFEXC	My health is excellent 1=Definitely true 2=Mostly true 3=Don't know 4=Mostly false 5=Definitely false	Num 4.
FAPYNERV	Have you been a very nervous person 1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little bit of the time 6=None of the time	Num 4.
FAPYDOWN	Have you felt so down in the dumps that nothing could cheer you up 1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little bit of the time 6=None of the time	Num 4.
FAPYCALM	Have you felt calm and peaceful 1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little bit of the time 6=None of the time	Num 4.
FAPYBLUE	Have you felt downhearted and blue 1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little bit of the time 6=None of the time	Num 4.
FAPYHAPY	Have you been a happy person 1=All of the time 2=Most of the time 3=A good bit of the time 4=Some of the time 5=A little bit of the time 6=None of the time	Num 4.

FARANKHH Compared to other medical conditions, I would rank hemochromatosis as Num 4.  
 1=One of the least serious  
 2...3...4...  
 5=One of the most serious

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Which of the following problems are associated with hemochromatosis or iron overload?

FAHPARTH Arthritis-like pain Num 4.  
 1=Yes  
 2=No  
 3=Don't know

FAHPIMP Impotence Num 4.  
 1=Yes  
 2=No  
 3=Don't know

FAHPMEN Painful menstrual periods Num 4.  
 1=Yes  
 2=No  
 3=Don't know

FAHPPROS Prostate or ovarian cancer Num 4.  
 1=Yes  
 2=No  
 3=Don't know

FAHPHRT Heart abnormalities Num 4.  
 1=Yes  
 2=No  
 3=Don't know

FAHPDIAB Diabetes Num 4.  
 1=Yes  
 2=No  
 3=Don't know

FAHPMS Multiple sclerosis Num 4.  
 1=Yes  
 2=No  
 3=Don't know

FAHPFAT Fatigue Num 4.  
 1=Yes  
 2=No  
 3=Don't know

FAHPASTH Asthma Num 4.  
 1=Yes  
 2=No  
 3=Don't know

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FATFBAD	Too much iron in the blood is always bad 1=True 2=False 3=Don't know	Num 4.
FATFDAMG	In hemochromatosis, iron builds up in the body and causes damage 1=True 2=False 3=Don't know	Num 4.
FATFDIE	People never die because of hemochromatosis 1=True 2=False 3=Don't know	Num 4.
FATFBLD	The best way to treat hemochromatosis is to have blood removed until iron levels go back to normal 1=True 2=False 3=Don't know	Num 4.
FATFTRT	There is no treatment for hemochromatosis 1=True 2=False 3=Don't know	Num 4.
FATFPREV	People with hemochromatosis can prevent symptoms by drinking 8 glasses of water a day 1=True 2=False 3=Don't know	Num 4.
FATFORG	It is not important to treat hemochromatosis until organ damage has occurred 1=True 2=False 3=Don't know	Num 4.
FATFNOKN	A person can have hemochromatosis and not know it 1=True 2=False 3=Don't know	Num 4.
FATFMUCH	A person with hemochromatosis has too much blood, resulting in high blood pressure 1=True 2=False 3=Don't know	Num 4.
FATFGENE	A gene test can tell you if you already have iron overload 1=True 2=False 3=Don't know	Num 4.

FATFHHGE	Everyone who has variations in their hemochromatosis genes will have too much iron in their blood 1=True 2=False 3=Don't know	Num 4.
FATFWHTE	Only White people are at risk for iron overload 1=True 2=False 3=Don't know	Num 4.
FATFHHIN	All variations in hemochromatosis genes increase your risk of having too much iron by the same amount 1=True 2=False 3=Don't know	Num 4.
FATFWOMN	Women tend to develop hemochromatosis earlier in life than men do 1=True 2=False 3=Don't know	Num 4.
FATFBRSI	If someone has hemochromatosis, their brothers and sisters are also at risk 1=True 2=False 3=Don't know	Num 4.
FATFIND	An individual may have one variation in their hemochromatosis gene but others in the same family may have two hemochromatosis genes with variations 1=True 2=False 3=Don't know	Num 4.

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I think genetic testing IS a good idea because..

FAGITRT	There might be a treatment by the time you developed the disease 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FAGIRASS	You might not have the gene for the disease and would be reassured 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.

FAGIKNOW	It is always good to know whatever you can about your health 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FAGISCRN	You could get frequent medical screening to catch the disease at a curable stage 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FAGICHNG	You could change to a healthier lifestyle 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FAGITRPY	There might be gene therapy that could prevent you from getting the disease 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FAGISHR	You could share this risk information with family members 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FAGIPREP	You could prepare better for the future 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.

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I think genetic testing IS NOT a good idea because...

FANIHINS	You might have trouble getting or keeping your health insurance 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FANIFEEL	You might feel helpless because you can't change your genes 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.

FANIPROB	It could be a problem if an employer or future employer found out about your test results 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FANIWORY	You could spend a lot of time worrying about something bad that is still in the future 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FANILINS	You might have trouble getting life or disability insurance 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FANIHLTY	Knowing that you had a gene that put you at risk could make you feel less healthy 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
FANINEWS	You could be bringing bad news into your family 1=Strongly agree 2=Agree 3=Disagree 4=Strongly disagree	Num 4.
*****		
FAPYJOB	During the past year, have you had a problem finding or keeping a job, or getting a raise or promotion 1=Yes 2=No	Num 4.
FAPYJOBH	If yes, was the problem related to hemochromatosis or IO 1=Yes 2=No 3=Not certain 4=Does not apply	Num 4.
*****		
FAPYDNR	During the past year, have you been turned down as a Volunteer for free blood donation 1=Yes 2=No 3=Does not apply	Num 4.
FAPYDNRH	If yes, was the problem related to hemochromatosis or IO 1=Yes 2=No 3=Not certain 4=Does not apply	Num 4.

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During the past year, have you had an insurance policy canceled, or had trouble getting, keeping, or increasing the amount of your insurance:

FAIHCAN Health insurance policy Num 4.  
1=Yes  
2=No

FAIHCANH If yes, was the problem related to hemochromatosis or IO Num 4.  
1=Yes  
2=No  
3=Not certain

FAIDCAN Disability insurance policy Num 4.  
1=Yes  
2=No

FAIDCANH If yes, was the problem related to hemochromatosis or IO Num 4.  
1=Yes  
2=No  
3=Not certain

FAILCAN Life insurance policy Num 4.  
1=Yes  
2=No

FAILCANH If yes, was the problem related to hemochromatosis or IO Num 4.  
1=Yes  
2=No  
3=Not certain

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GHSCALE\_1Y SF-36 General Health Scale Num 4.

MHSCALE\_1Y SF-36 Mental Health Scale Num 4.

**Section XVII: Adjudication Decision**

FINAL\_DECISION Final adjudication decision Num 8.  
1=None  
2=Primary  
3=Secondary  
4=IO & Anemia  
5=Indeterminate  
6=Multifactorial