Family Data Dictionary

Section I: Basic study/participant information

SID_DI   HEIRS participant ID – de-identified   Char $11.

DVISIT_CCE   Date of CCE   Num 4.
              (Number of days from a given date)

PREFLANG   Preferred Language   Num 6.
                  1=English
                  2=Spanish
                  3=Mandarin
                  4=Vietnamese

RACE   Participant Race   Num 4.
                  1=Hispanic
                  2=Asian/Pacific Islander
                  3=African American
                  4=Caucasian
                  5=Other: American Indian, Multiple, Unknown

AGE   Calculated Age   Num 8.

GENDER   What is your gender   Char $20.

Section II: Family

MGS   Was this sample sent to MGS for additional genotyping?   Num 4.
                  1=Yes

PROBAND   Is this person a proband   Num 4.
                  1=Yes

Section III: Initial Screening

FIRSTIME   Q6:   Is this the first time you have been asked to   Num 4.
                  participate in this study
                      1=Yes
                      2=No

HLTHRES   Q7a: (old form)I want to help by taking part in   Num 4.
                  research
                      1=Important
                      2=Not important

DRPART   Q7b: (old form)My doctor thought that I should   Num 4.
                  take part in this study
                      1=Important
                      2=Not important

IRONPROB   Q7c: (old form)I want to know if I have problems   Num 4.
                  too high or too low)
                      1=Important
                      2=Not important

HAVEHEMO   Q7d: (old form)I have iron overload or hemochromatosis Num 4.
                      1=Important
                      2=Not important

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MIGHT        Q7e:  (old form)I think I might have iron        Num 4.
                   overload or hemochromatosis
                        1=Important
                        2=Not important


MEDCOND      Q7f:  (old form)I have another medical condition   Num 4.
                        1=Important
                        2=Not important


RELAHEMO     Q7g:  (old form) My blood relative has/had iron    Num 4.
                   overload or hemochromatosis
                        1=Important
                        2=Not important


ELSEHEMO     Q7h:  (old form) Someone else I know has/had iron  Num 4.
                   overload or hemochromatosis
                        1=Important
                        2=Not important


OTHREAS      Q7i:  (old form) Other reason                      Num 4.
                        1=Important
                        2=Not important
TOOMUCH      Q7a:  Too much iron in your body, iron overload    Num 4.
                   or hemochromatosis
                        1=Yes
                        2=No
                        3=Not Sure


ARTHRITI     Q7b:  Arthritis                                    Num 4.
                        1=Yes
                        2=No
                        3=Not Sure


DIABETES     Q7c:  Diabetes                                     Num 4.
                        1=Yes
                        2=No
                        3=Not Sure


LIVER        Q7d:  Liver disease or liver cancer                Num 4.
                        1=Yes
                        2=No
                        3=Not Sure


HRTFAIL      Q7e:  Heart failure                                Num 4.
                        1=Yes
                        2=No
                        3=Not Sure


IMPOT        Q7f:  Fertility problems or impotence              Num 4.
                        1=Yes
                        2=No
                        3=Not Sure
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BLDRELA    Q8:    Have any of your blood relatives had iron          Num 4.
                  overload or hemochromatosis, or been treated by
                  having their blood drawn on a regular basis?
                       1=Yes
                       2=No
                       3=Not Sure

ANYONE     Q10:   (old form)Have you ever known anyone else          Num 4.
                  who had to donate blood for his or her health
                       1=Yes
                       2=No
                       3=Not Sure

PREGNANT   Q9:    For women only: Are you pregnant, have you         Num 4.
                  been pregnant within the past 3 months, or
                  are you breast feeding
                       1=Yes
                       2=No
                       3=Not Sure

HEALTH     Q10:   In general, would you say your health is           Num 4.
                       1=Poor
                       2=Fair
                       3=Average
                       4=Good
                       5=Excellent
SICKEASY   Q11a:  I seem to get sick a little easier                 Num 4.
                       than other people
                       1=Definitely true
                       2=Mostly true
                       3=Don't know
                       4=Mostly false
                       5=Definitely false

HLTHANY    Q11b:  I am as healthy as anybody                         Num 4.
                       1=Definitely true
                       2=Mostly true
                       3=Don't know
                       4=Mostly false
                       5=Definitely false

HLTHWORS   Q11c:  I expect my health to get worse                    Num 4.
                       1=Definitely true
                       2=Mostly true
                       3=Don't know
                       4=Mostly false
                       5=Definitely false

HLTHEXC    Q11d:  My health is excellent                             Num 4.
                       1=Definitely true
                       2=Mostly true
                       3=Don't know
                       4=Mostly false
                       5=Definitely false
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NERVOUS      Q12a: Have you been a nervous person                  Num 4.
                    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

DOWNDUMP     Q12b: Have you felt so down in the dumps              Num 4.
                    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 of the time
                    6=None of the time

CALM         Q12c: Have you felt calm and peaceful                 Num 4.
                    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

BLUE         Q12d: Have you felt downhearted and blue              Num 4.
                    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

HAPPY        Q12e: Have you been a happy person                    Num 4.
                    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

SHOULDSH     Q13: Information about a person's genetic risk        Num 4.
                    should be shared with other family members.
                    1=Strongly Agree
                    2=Agree
                    3=Disagree
                    4=Strongly Disagree

GENETEST     Q14: In general, I think genetic testing to          Num 4.
                    find out about disease risk is a good idea
                    1=Strongly Agree
                    2=Agree
                    3=Disagree
                    4=Strongly Disagree
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GOODTRT      Q15a: There might be a good treatment by the          Num 4.
                   time you developed the disease
                        1=Strongly Agree
                        2=Agree
                        3=Disagree
                        4=Strongly Disagree


CHGLIFE      Q15b: You could change to a healthier lifestyle       Num 4.
                   to prevent getting the disease
                        1=Strongly Agree
                        2=Agree
                        3=Disagree
                        4=Strongly Disagree


PREPFUTU     Q15c: You could prepare better for the future         Num 4.
                        1=Strongly Agree
                        2=Agree
                        3=Disagree
                        4=Strongly Disagree


SHAREINF     Q15d: You could share this information               Num 4.
                   with family members
                        1=Strongly Agree
                        2=Agree
                        3=Disagree
                        4=Strongly Disagree
INSURE       Q16a: You might have trouble getting or              Num 4.
                   keeping your insurance
                        1=Strongly Agree
                        2=Agree
                        3=Disagree
                        4=Strongly Disagree


HELPLESS     Q16b: You might feel helpless because you            Num 4.
                   can't change your genes
                        1=Strongly Agree
                        2=Agree
                        3=Disagree
                        4=Strongly Disagree


FEELLESS     Q16c: Knowing that you had a gene that put you       Num 4.
                   at risk could make you feel less healthy
                        1=Strongly Agree
                        2=Agree
                        3=Disagree
                        4=Strongly Disagree


BADNEWS      Q16d: You could be bringing bad news                 Num 4.
                   into your family
                        1=Strongly Agree
                        2=Agree
                        3=Disagree
                        4=Strongly Disagree
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HEREDITY      Q17a: Heredity (it runs in your family)            Num 4.
                    1=Very important
                    2=Somewhat important
                    3=Not important
                    4=Not sure


ENVIRON       Q17b: The environment (ex. Water/air pollution)    Num 4.
                    1=Very important
                    2=Somewhat important
                    3=Not important
                    4=Not sure


FATE          Q17c: Fate or chance (bad luck)                    Num 4.
                    1=Very important
                    2=Somewhat important
                    3=Not important
                    4=Not sure


PSYCHO        Q17d: Psychological factors (ex. Stress)           Num 4.
                    1=Very important
                    2=Somewhat important
                    3=Not important
                    4=Not sure


LIFESTYL      Q17e: Lifestyle (ex. smoking, drinking,            Num 4.
                    eating a high fat diet)
                    1=Very important
                    2=Somewhat important
                    3=Not important
                    4=Not sure


DOCVISIT      Q5:   I came in for a doctor visit or to have      Num 4.
                    my blood drawn, and found out about it
                          1=Yes


PHCALL        Q5:   I received a phone call or letter from the   Num 4.
                    study, inviting me to participate
                          1=Yes


CAMEINTO      Q5:   I came into the clinic or lab with a friend  Num 4.
                    or family member, and found out about it
                          1=Yes


NEWSTV        Q5:   I learned about it in the newspaper, in the  Num 4.
                    community, on the TV, or on the radio
                          1=Yes


HEAROTH       Q5:   Other                                        Num 4.
                          1=Yes
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Section IV: Initial Screen Lab Results

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BLDSTORE      Permission to store blood?                         Num 4.
                    1=Yes
HOURS         Hours since last food                              Num 10.2

SERUM         Serum Iron                                         Num 7.2
                    Note 0='<5'
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SF              Serum Ferritin                                         Num 10.2
                  Note 7.5 = '<15'

TS              Transferrin Saturation                                 Num 7.2
                  Note 1.5 = '<3'

UIBC            Unsaturated Iron Binding Capacity                      Num 8.2

TIBC            Total Iron Binding Capacity                            Num 8.2

LABRESULT       Participant Genotype                                   Char $11.
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Section V: Clinical Assessment

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HEIGHT          Q7:  Height in inches                                  Num 8.

WEIGHT          Q8:  Body weight in pounds                             Num 6.1

TEMPER          Q9:  Body Temperature in Fahrenheit                    Num 7.1

BMI             Body Mass Index                                        Num 8.

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                             Num 4.
                (liver palpable ≥ 2cm below R. costal margin
                or xiphoid process on deep inspiration)
                1-Yes
                2-No
                3-Not sure

SPLENOM         Q14:  Liver:  Splenomegaly                             Num 4.
                (spleen palpable below L. costal margin)
                1-Yes
                2-No
                3-Not sure

BRADY           Q15a: Heart Arrythmia:  Bradycardia                    Num 4.
                (<40 beats per minute)
                1-Yes
                2-No
                3-Not sure

TACHY           Q15b: Heart Arrythmia:  Tachycardia                    Num 4.
                (>100 beats per minute)
                1-Yes
                2-No
                3-Not sure
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PREMACON     Q15c: Heart Arrythmia:  Frequent premature contractions    Num 4.
                   (≥1 ectopic beat per min.)
                   1-Yes
                   2-No
                   3-Not sure


ABNORMAL     Q15d: Heart Arrythmia:  Other abnormal rhythm               Num 4.
                   1-Yes
                   2-No
                   3-Not sure


MURMUR       Q15e: Heart Arrythmia:  Murmur                              Num 4.
                   (any prolonged sound produced by the heart)
                   1-Yes
                   2-No
                   3-Not sure


EDEMA        Q15f: Heart Arrythmia:  Edema                               Num 4.
                   (symmetrical edema of dependent areas, usually
                   lower extremeties, with or without pitting)
                   1-Yes
                   2-No
                   3-Not sure


PIGMENT      Q16:  Skin:  Increased pigmentation on sun-exposed or       Num 4.
                   unexposed areas
                   (grayish or brownish shades)
                   1-Yes
                   2-No
                   3-Not sure


BLISTER      Q17:  Skin:  Blistering, ulcers, scarring of               Num 4.
                   sun-exposed skin
                   1-Yes
                   2-No
                   3-Not sure


HYPERTRI     Q18:  Skin:  Hypertrichosis                                 Num 4.
                   (excess hair growth in sun-exposed areas)
                   1-Yes
                   2-No
                   3-Not sure


MPJOINTS     Q19:  Bones and Joints:  MP joints:                         Num 4.
                   Swollen or tender
                   1-Yes
                   2-No
                   3-Not sure
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Section VI: CCE Lab Values

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RETIC        Reticulocyte count (%)                                      Num 6.1
             Reference Range:  0.4-2.5 %


TS_CCE       % Iron Saturation iron binding protein (%)                  Num 4.
             Reference Range:  15-50 %
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SF_CCE        Serum Ferritin Concentration (ng/mL)                      Num 4.
              Reference Range:  20-300 ng/mL (M)
                               10-120 ng/mL (F15-45y)
                               10-300 ng/mL (F45-127y)
                   Note:  7.5 = '<15'


ALT           Serum Activity Alanine Aminotransferase (U/L)             Num 8
              Reference Range:  0-31 U/L   (F)
                               0-40 U/L   (M)
                   Note:  3 = '<4'


AST           Serum Activity Aspartate Aminotransferase (U/L)           Num 8
              Reference Range:  0-31 U/L   (F)
                               0-37 U/L   (M)


CRP           Serum Concentration C-Reactive Protein (mg/dL)            Num 8
              Reference Range:  0-0.5 mg/dL
                   Note:  0.2 = '<0.3'


LD            Serum activity lactate dehydrogenase (U/L)                Num 8
              Reference Range:  94-250 U/L


BILT          Serum concentration total bilirubin (mg/dL)               Num 8
              Reference Range:  0.0-1.0 mg/dL


DBIL          Serum concentration direct bilirubin (mg/dL)              Num 8
              Reference Range:  0.0-0.3 mg/dL


IBIL          Serum concentration indirect bilirubin (mg/dL)            Num 8
              Reference Range:  0.0-0.7 mg/dL
HAPT          Serum haptoglobin concentration (mg/dL)                   Num 8
              Reference Range:   30-200 mg/dL
                   Note:  19 = '<20'


HEPATITS      Hepatitis B Surface Antigen or Hepatitis C virus antibody  Char $15
              POSITIVE or NEGATIVE


FEBR          Serum iron binding capacity (ug/dL)                       Num 8
              Reference Range:  228-428 ug/dL


FER           Serum iron concentration (ug/dL)                          Num 8
              Reference Range:  45-160 ug/dL (M)
                               30-160 ug/dL (F)
GGT           Serum activity of gamma glutamyl transferase (U/L)        Num 8
              Reference Range:  7-33 U/L   (F)
                               11-51 U/L   (M)
                   Note 2 = '<3'
GLUC          Serum glucose concentration (mg/dL)                       Num 8
              Reference Range:  60-115 mg/dL


HA1           Hemoglobin A1 (%total hemoglobin)                         Num 8
              Reference Range:  94.3-98.5 %


HA2           Hemoglobin A2 (%total hemoglobin)                         Num 8
              Reference Range:  1.5-3.7 %


HBELP         Abnormal hemoglobin type                                  Num 8
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HCT          Hematocrit (%red blood cells in whole blood)          Num 8
             Reference Range:  40-53% (M)
                               35-47% (F)


HF           Hemoglobin F-fetal  (%total hemoglobin)               Num 8
             Reference Range:  0.0-2.0%


HGB          Hemoglobin Concentration (g/dL)                       Num 8
             Reference Range:  13.3-17.7 g/dL  (M)
                               11.7-15.7 g/dL  (F)


HGC          Hemoglobin C (%total hemoglobin)                      Num 8
             Reference Range:  0.0-0.0 %


HGE          Hemoglobin E (%total hemoglobin)                      Num 8
             Reference Range:  0.0-0.0 %


HOTHER       Hemoglobin Other (%total hemoglobin)                  Num 8
             Reference Range:  0.0-0.0 %


HS           Hemoglobin S-sickle cell (%total hemoglobin)          Num 8
             Reference Range:  0.0-0.0 %


INS          Insulin concentration (mIU/L)                         Num 8
             Reference Range:  0-20 mIU/L


MCH          Mean corpuscular hemoglobin/RBC (picograms)           Num 8
             Reference Range:  26.5-35.0 pg


MCHC         Mean corpuscular hemoglobin conc/RBC (g/dL)           Num 8
             Reference Range:  32-36 g/dL


MCV          Mean corpuscular volume (femtoliters)                 Num 8
             Reference Range:  78-100 fL


RBC          Red blood cell count (# cells/10^12/L)                Num 8
             Reference Range:  4.4-5.9 (M) x10^{12}/L
                               3.8-5.2 (F) x10^{12}/L


RDW          Red cell distribution width (%)                       Num 8
             Reference Range:  10.0-15.0 %


WBC          White blood cell count (# cells/10^9/L)               Num 8
             Reference Range:  4.0-11.0 x10^{9}/L


PLT          Platelet (# platelets/10^9/L)                         Num 8
             Reference Range:  150-450 x10^{9}/L


WNEUT        Neutrophils (%neutrophils in WBC count)               Num 8
             Reference Range:  40-75 %


WLYMP        Lymphocytes (%lymphocytes in WBC count)               Num 8
             Reference Range:  20-48 %
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WMONO          Monocytes (%monocytes in WBC count)                     Num 8
               Reference Range:  0-12 %


WEOS           Eosinophils (%eosinophils in WBC count)                 Num 8
               Reference Range:  0-6 %


WBASO          Basophils (%basophils in WBC count)                     Num 8
               Reference Range:  0-2 %


ANEUT          Absolute neutrophils (# cells/10^9/L)                   Num 8
               Reference Range:  1.6-8.3 x$10^9$/L


ALYMP          Absolute lymphocytes (# cells/10^9/L)                   Num 8
               Reference Range:  0.8-5.3 x$10^9$/L


AMONO          Absolute monocytes (# cells/10^9/L)                     Num 8
               Reference Range:  0-1.3 x$10^9$/L


AEOS           Absolute eosinophils (# cells/10^9/L)                   Num 8
               Reference Range:  0-0.7 x$10^9$/L


ABASO          Absolute basophils (# cells/10^9/L)                     Num 8
               Reference Range:  0-0.2 x$10^9$/L
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Section VII: Medical History

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ssFeetSw    Q1:  Experienced swelling of feet or ankles              Num 4.
                 1=Yes
                 2=No
                 3=Don't Know


ssSkinCh    Q2:  Experienced change in skin color                    Num 4.
                 1=Yes
                 2=No
                 3=Don't Know


ssWeight    Q3:  Experienced unexplained weight loss                 Num 4.
                 1=Yes
                 2=No
                 3=Don't Know


ssAdomSw    Q4:  Experienced abdominal swelling or fluid             Num 4.
                 1=Yes
                 2=No
                 3=Don't Know


ssLossDr    Q5:  Experienced trouble having an erection or           Num 4.
                 loss of sexual drive
                 1=Yes
                 2=No
                 3=Don't Know


ssChrFt     Q6:  Repeatedly bothered by chronic fatigue/weakness     Num 4.
                 1=Yes
                 2=No
                 3=Don't Know
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ssShrtBr    Q7:   Repeatedly bothered by shortness of breath        Num 4.
                  1=Yes
                  2=No
                  3=Don't Know


ssJntStf    Q8:   Repeatedly bothered by joint stiffness/pain/ache  Num 4.
                  1=Yes
                  2=No
                  3=Don't Know


ssThirst    Q9:   Repeatedly bothered by excessive thirst           Num 4.
                  1=Yes
                  2=No
                  3=Don't Know


ssPlyUr     Q10:  Repeatedly bothered by polyuria                   Num 4.
                  (excessive urination)
                  1=Yes
                  2=No
                  3=Don't Know


ssUnxAdm    Q11:  Repeatedly bothered by unexplained abdominal      Num 4.
                  pain or discomfort
                  1=Yes
                  2=No
                  3=Don't Know


ssUnxCon    Q12:  Repeatedly bothered by unexplained confusion      Num 4.
                  or memory loss
                  1=Yes
                  2=No
                  3=Don't Know


mhHemo      Q13:  Ever told that you have/had iron overload         Num 4.
                  or hemochromatosis
                  1=Yes
                  2=No
                  3=Don't Know


mhAnemia    Q14:  Ever told that you have/had anemia (low iron)     Num 4.
                  1=Yes
                  2=No
                  3=Don't Know


mhSC        Q15:  Ever told that you have/had sickle cell anemia    Num 4.
                  1=Yes
                  2=No
                  3=Don't Know


mhThal      Q16:  Ever told that you have/had thalassemia           Num 4.
                  or other inherited anemia
                  1=Yes
                  2=No
                  3=Don't Know
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mhBlood      Q17:  Ever told that you have/had unusual blood loss      Num 4.
                   (vomiting or coughing up blood, blood in stool,
                   or blood in urine)
                   1=Yes
                   2=No
                   3=Don't Know

mhDiab       Q18:  Ever told that you have/had diabetes                Num 4.
                   1=Yes
                   2=No
                   3=Don't Know

mhDiabMd     Q18a: Are you taking medication for diabetes?            Num 4.
                   1=Yes
                   2=No

mhDiabIn     Q18b: Are you taking insulin for diabetes?               Num 4.
                   1=Yes
                   2=No

mhDiabPl     Q18c: Are you taking pills for diabetes?                 Num 4.
                   1=Yes
                   2=No

mhDiabTr     Q18d: At what age was diabetes first treated?            Num 4.
                   1=Yes
                   2=No
                   3=Don't Know

mhLiver      Q19:  Ever told that you have/had liver disease?         Num 4.
                   1=Yes
                   2=No
                   3=Don't Know

mhLivFat     Q19a: Ever told that you have/had Fatty liver?           Num 4.
                   1=Yes
                   2=No
                   3=Don't Know

mhLivCir     Q19b: Ever told that you have/had cirrhosis?             Num 4.
                   1=Yes
                   2=No
                   3=Don't Know

mhLivCan     Q19c: Ever told that you have/had liver cancer           Num 4.
                   (cancer that started in the liver)?
                   1=Yes
                   2=No
                   3=Don't Know

mhHep        Q19e:  Ever told that you have/had hepatitis             Num 1.
                   A or B or C or other type.
                   1=Yes
                   0=No
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mhThyr      Q20:  Ever told that you have/had thyroid disease      Num 4.
                  (over-active or under-active thyroid)?
                  1=Yes
                  2=No
                  3=Don't Know

mhHrt       Q21:  Ever told that you have/had heart failure        Num 4.
                  or weak heart?
                  1=Yes
                  2=No
                  3=Don't Know

mhHrtAb     Q22:  Ever told that you have/had abnormal heart rhythm, Num 4.
                  heart beat, or action/arrthymia?
                  1=Yes
                  2=No
                  3=Don't Know

mhHrtOth    Q23:  Ever told that you have/had other heart disease   Num 4.
                  or heart attack?
                  1=Yes
                  2=No
                  3=Don't Know

mhArth      Q24:  Ever told that you have/had arthritis?            Num 4.
                  1=Yes
                  2=No
                  3=Don't Know

mhOsteo     Q25:  Ever told that you have/had osteoporosis          Num 4.
                  (weak, think, or brittle bones)?
                  1=Yes
                  2=No
                  3=Don't Know

mhPorph     Q26:  Ever told that you have/had porphyria cutanea tarda? Num 4.
                  1=Yes
                  2=No
                  3=Don't Know

mhChrInf    Q28:  Ever told that you have/had chronic inflammation, Num 4.
                  chronic infection, autoimmune disease or lupus?
                  1=Yes
                  2=No
                  3=Don't Know

mhCancer    Q29:  Ever told that you have/had cancers              Num 4.
                  (other than those starting in the liver)?
                  1=Yes
                  2=No
                  3=Don't Know

mhChemo     Q30:  Ever had chemotherapy or bone marrow transplant?  Num 4.
                  1=Yes
                  2=No
                  3=Don't Know
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rhMenPr      Q31a: Ever seen a doctor for menstrual problems?        Num 4.
                  1=Yes
                  2=No
                  3=Don't Know

rhBleed      Q31b: Ever seen a doctor for in-between bleeding?       Num 4.
                  1=Yes
                  2=No
                  3=Don't Know

rhStop       Q31c: Ever seen a doctor for early stopping of periods? Num 4.
                  1=Yes
                  2=No
                  3=Don't Know

rhPreg       Q32:  Ever been pregnant?                               Num 4.
                  1=Yes
                  2=No
                  3=Don't Know

rhPregNm     Q32a: Number of pregnancies                            Num 4.

rhBirths     Q32b: Number of live births                            Num 4.

rhPregC      Q33:  Are you currently pregnant?                       Num 4.
                  1=Yes
                  2=No
                  3=Don't Know

rhMen        Q34:  Gone through menopause?                           Num 4.
                  1=Yes
                  2=No
                  3=Don't Know

rhMenAge     Q34a: Age at menopause?                                 Num 4.

rhMenar      Q35:  Age at menarche?                                  Num 4.

rhHyst       Q36:  Had a hysterectomy?                               Num 4.
                  1=Yes
                  2=No
                  3=Don't Know

rhHysAge     Q36a: Age at hysterectomy?                              Num 4.

btEver       Q37:  Ever had blood transfusions?                      Num 4.
                  1=Yes
                  2=No
                  3=Don't Know

btTotal      Q37a: Number of pints/units transfused in a lifetime?  Num 4.

btWhole      Q38:  Ever donated whole blood at a blood bank?         Num 4.
                  1=Yes
                  2=No
                  3=Don't Know
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btWholeU     Q38a: Number of whole blood units in lifetime?         Num 4.

liBrRest     Q39a: Get short of breath while resting in a chair?     Num 4.
                   1=Yes
                   2=No

liBrLvel     Q39b: Get short of breath while walking on level ground?  Num 4.
                   1=Yes
                   2=No

liBrQuik     Q39c: Get short of breath when walking quickly or uphill?  Num 4.
                   1=Yes
                   2=No
                   3=Never do this

liAlcoh      Q40:  Ever consumed alcoholic beverages?                Num 4.
                   1=Yes
                   2=No

liAlcAge     Q41:  Age started consuming alcoholic beverages?        Num 4.

liAlcPr      Q42:  Presently drink alcoholic beverages?              Num 4.
                   1=Yes
                   2=No
liAlcYr      Q42a: Number of years have been drinking               Num 4.
                   alcoholic beverages?

liAlcYrN     Q42b: Number of years did you drink alcoholic beverages?  Num 4.

liAlcNum     Q42c: Usual number of drinks you had per week           Num 4.
                   before stopping?

dmGrade      Q43:  Highest grade of school completed                 Num 6.
                   1=Less than HS
                   2=HS
                   3=Some univ.
                   4=Bachelors
                   5=Post-graduate

Dmgender     What is your gender (family member)                     Num 6.

gt10         Q37b  Have you had more than 10 pints/units transfused  Num 4.
                   in a lifetime?
                   1=Yes
                   2=No
```

Section VIII: Additional Medical History Questions
Note: Asked if answered 'YES' to question 13 of the medical history form.

```
PHLEB        Have you ever had phlebotomy as treatment               Num 4.
             for your iron overload or HH?
                   1=No
                   2=Yes

BIOPSY       Have you ever had a liver biopsy?                       Num 4.
                   1=No
                   2=Yes
```

Section IX: 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 X: Food Frequency Summary Variables
AVERAGE DAILY INTAKE FROM FOODS:

iron	Iron (mg)	Num 15.3
alc	Alcohol (g)	Num 15.3
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 XI: Liver Biopsy Results Variables

```
DBIOPSY             Liver biopsy date                               Num 4.
                    (Number of days from given date)


DIAGNONE            None indicated                                  Num 8.
                        1=Yes


DIAGALCOHOL         Alcoholic liver disease                         Num 8.
                        1=Yes


DIAGCIRRHOSIS       Cirrhosis                                       Num 8.
                        1=Yes


DIAGHEP             Hepatitis B,C, or Other                         Char $15.
                        POSTIVIVE
                        NEGATIVE


DIAGNASH            Non-alcoholic steatohepatitis (NASH)            Num 8.
                        1=Yes


DIAGFATLIVER        Fatty liver                                     Num 8.
                        1=Yes


DIAGFIBROSIS        Fibrosis                                        Num 8.
                        1=Yes


DIAGPRIME           Primary hemochromatosis                         Num 8.
                        1=Yes


DIAGSECOND          Secondary hemochromatosis                       Num 8.
                        1=Yes


DIAGNOSPEC          Hemochromatosis no specified                    Num 8.
                        1=Yes


DIAGSECIO           Hemosiderosis (secondary iron overload)         Num 8.
                        1=Yes


DIAGOTHERIO         Other iron overload                             Num 8.
                        1=Yes


DIAGOTHERLD         Other liver disease                             Num 8.
                        1=Yes


BILIARY             Biliary Epithelium:                             Num 8.
                        1=Absent
                        2=Present
                        3=Not reported
MALLORY             Mallory bodies:                                 NUM 8.
                        1=Absent
                        2=Present
                        3=Not reported
```

```
KUPFFER              Kupffer cells/Macrophages:                      NUM 8.
                          1=Absent
                          2=Present/not increased
                          3=Increased
                          4=Not reported

HEPAPROSE            Hepatocytes:  If prose only                     Num 8.
                          1=Absent
                          2=Present/not increased
                          3=Increased
                          4=Not reported

HEPAGRADE4           Hepatocytes:  If graded-Four (4) point scale grade    Num 8.

HEPAGRADE6           Hepatocytes:  If graded-Six (6) point scale grade     Num 8.

HEPIRONCONC Is the hepatic iron concentration available        Num 8.
                          1=Yes
                          2=No
DRYWEIGHT1           If HIC is available, indicate dry weight. µmol/g    Num 8.

DRYWEIGHT2           If HIC is available, indicate dry weight.  µg/g     Num 8.

WETWEIGHT1           If HIC is available, indicate wet weight.  µmol/g   Num 8.

WETWEIGHT2           If HIC is available, indicate wet weight. µg/g      Num 8.

PARTAGE              Participants age in years                       Num 8.

PHLEBTRT_COUNT   Number of Phlebotomy Treatment Forms submitted     Num 8.
```

Section XII: Post Results

```
Told1st     Q1 Who first told you about the HEIRS study?        Num 4.

Knowhemo    Q1 How much did you know about hemo or IO before…    Num 4.
```

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?

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

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

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

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


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


Hemofam      Q4 Did you know there might be hemo in your family?  Num 4.


Donate       Q5 Did you know of any family members who donate blood regularly
             For health?                                         Num 4.


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


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


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


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


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


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


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

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


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


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


INFAMILY     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?


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         Num 4.
             iron in my blood about once a year.
                  1=Yes
                  2=No
                  3=Not sure


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


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

```
RECHELP      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                Num 4.
             recommendations
                  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        Num 4.
                  1=Never
                  2=Rarely
                  3=Sometimes
                  4=Often


RELIEVED     Feeling relieved that no known hemochromatosis gene          Num 4.
             variations exist in your family
                  1=Never
                  2=Rarely
                  3=Sometimes
                  4=Often


LOSSCONT     Feeling a loss of control because of you test results        Num 4.
                  1=Never
                  2=Rarely
                  3=Sometimes
                  4=Often


PROBJOY      Having problems enjoying your life because of your           Num 4.
             test results
                  1=Never
                  2=Rarely
                  3=Sometimes
                  4=Often


WORSE        Worrying about your risk of developing IO or Hemo.           Num 4.
             or having your condition get worse
                  1=Never
                  2=Rarely
                  3=Sometimes
                  4=Often


MORECONT     Feeling more in control of you future health                 Num 4.
                  1=Never
                  2=Rarely
                  3=Sometimes
                  4=Often
```

```
THINKING     Thinking about your test results has caused problems      Num 4.
             in you work or family life
                  1=Never
                  2=Rarely
                  3=Sometimes
                  4=Often

FRUSTRAT     Feeling frustrated that no known hemochromatosis gene      Num 4.
             variations have been found that explain the iron
             overload in your family
                  1=Never
                  2=Rarely
                  3=Sometimes
                  4=Often

EASYFOLL     Feeling relieved that the guidelines about how to          Num 4.
             deal with your particular results are so clear
             and easy to follow
                  1=Never
                  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                    Num 4.
             as good as they are
                  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

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

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

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

DRINFORM      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?

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

BROTHSIS      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       Num 4.
             risk of hemochromatosis or iron overload
                1=Very unlikely
                2=Unlikely
                3=Likely
                4=Very likely
                5=Does not apply

PRENATAL     Have prenatal testing of your unborn child for       Num 4.
             risk of hemochromatosis or iron overload
                1=Very unlikely
                2=Unlikely
                3=Likely
                4=Very likely
                5=Does not apply

NEWBORN      Have your future newborn children tested for risk of Num 4.
             hemochromatosis or iron overload
                1=Very unlikely
                2=Unlikely
                3=Likely
                4=Very likely
                5=Does not apply

KIDS18       Have your children under 18 tested for risk of       Num 4.
             hemochromatosis or iron overload
                1=Very unlikely
                2=Unlikely
                3=Likely
                4=Very likely
                5=Does not apply
```

```
ADULTKID      Encourage your adult children to get genetic testing      Num 4.
              for risk of hemochromatosis or IO
                   1=Very unlikely
                   2=Unlikely
                   3=Likely
                   4=Very likely
                   5=Does not apply

B4MARRY       Encourage your adult children to get genetic testing      Num 4.
              before they get married
                   1=Very unlikely
                   2=Unlikely
                   3=Likely
                   4=Very likely
                   5=Does not apply

B4CHILD       Encourage your adult children to get genetic testing      Num 4.
              before they have children
                   1=Very unlikely
                   2=Unlikely
                   3=Likely
                   4=Very likely
                   5=Does not apply

Please give your opinion on why people get sick.

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

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

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

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


SICKEASY_PRfam    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                      Num 4.
                1=Definitely true
                2=Mostly true
                3=Don't know
                4=Mostly false
                5=Definitely false


EXCELLEN    My health is excellent                               Num 4.
                1=Definitely true
                2=Mostly true
                3=Don't know
                4=Mostly false
                5=Definitely false


NERVOUS_PRfam    Have you been a very nervous person              Num 4.
                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


DOWNDUMP_PRfam Have you felt so down in the dumps that nothing    Num 4.
            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
```

```
CALM_PRfam   Have you felt calm and peaceful                      Num 4.
                 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

FELTBLUE     Have you felt downhearted and blue                   Num 4.
                 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

HAPPY_PRfam Have you been a happy person                          Num 4.
                 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

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

I think genetic testing IS a good idea because…

GOODTRT_prfam   There might be a treatment by the time you developed   Num 4.
             the disease
                 1=Strongly agree
                 2=Agree
                 3=Disagree
                 4=Strongly disagree

REASSURE     You might not have the gene for the disease and      Num 4.
             would be reassured
                 1=Strongly agree
                 2=Agree
                 3=Disagree
                 4=Strongly disagree

WHATEVER     It is always good to know whatever you can about     Num 4.
             your health
                 1=Strongly agree
                 2=Agree
                 3=Disagree
                 4=Strongly disagree
```

```
CURABLE      You could get frequent medical screening to catch      Num 4.
             the disease at a curable stage
                  1=Strongly agree
                  2=Agree
                  3=Disagree
                  4=Strongly disagree


CHANGELS     You could change to a healthier lifestyle              Num 4.
                  1=Strongly agree
                  2=Agree
                  3=Disagree
                  4=Strongly disagree


GENETHER     There might be gene therapy that could prevent         Num 4.
             you from getting the disease
                  1=Strongly agree
                  2=Agree
                  3=Disagree
                  4=Strongly disagree


SHAREFAM     You could share this risk information with family members  Num 4.
                  1=Strongly agree
                  2=Agree
                  3=Disagree
                  4=Strongly disagree


PREPARE      You could prepare better for the future                Num 4.
                  1=Strongly agree
                  2=Agree
                  3=Disagree
                  4=Strongly disagree


I think genetic testing IS NOT a good idea because…


INSURANC     You might have trouble getting or keeping your         Num 4.
             health insurance
                  1=Strongly agree
                  2=Agree
                  3=Disagree
                  4=Strongly disagree


HELPLESS_PR  You might feel helpless because you can't change       Num 4.
             your genes
                  1=Strongly agree
                  2=Agree
                  3=Disagree
                  4=Strongly disagree


FUTUEMP      It could be a problem if an employer or future         Num 4.
             employer found out about your test results
                  1=Strongly agree
                  2=Agree
                  3=Disagree
                  4=Strongly disagree
```

```
WORRYBAD      You could spend a lot of time worrying about         Num 4.
              something bad that is still in the future
                   1=Strongly agree
                   2=Agree
                   3=Disagree
                   4=Strongly disagree

LIFEINS       You might have trouble getting life or               Num 4.
              disability insurance
                   1=Strongly agree
                   2=Agree
                   3=Disagree
                   4=Strongly disagree

LESSHLTH      Knowing that you had a gene that put you at          Num 4.
              risk could make you feel less healthy
                   1=Strongly agree
                   2=Agree
                   3=Disagree
                   4=Strongly disagree

BADNEWS_PRFAM     You could be bringing bad news into your family      Num 4.
                   1=Strongly agree
                   2=Agree
                   3=Disagree
                   4=Strongly disagree

DROFFICE      Is there one particular clinic, health center or     Num 4.
              doctor's office that you usually go to if you are
              sick or need health advice
                   1=Yes
                   2=No

HOWLONG       How long as it been since you last visited a         Num 4.
              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

CHOLEST       Do you know your cholesterol level                   Num 4.
                   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

SEATBELT      Do you use a seatbelt when driving                   Num 4.
                   1=Always
                   2=Usually
                   3=Sometimes
                   4=Rarely
                   5=Never
```

```
SUNSCRN     Do you use a sunscreen product              Num 4.
                1=Yes, all year long
                2=Yes, but only in the summer
                3=Rarely
                4=Never

DISABINS    Do you have disability insurance             Num 4.
                1=Yes
                2=No
                3=Don't know

LIFEPOLI    Do you have a life insurance policy          Num 4.
                1=Yes
                2=No
                3=Don't know

HLTHINS     Do you have health insurance (any type)      Num 4.
                1=Yes
                2=No
                3=Don't know

MOSTCOST    If you have health insurance, who pays most of  Num 4.
            the cost of the insurance
                1=Employer
                2=Government (state/province)
                3=Me or my family
                4=Don't know
                5=Does not apply

UNEMPLOY    Unemployed                                   Num 4.
                0=No
                1=Yes

SELFEMP     Self employed                                Num 4.
                0=No
                1=Yes

FEDGOV      Employed by federal government               Num 4.
                0=No
                1=Yes

STATEGOV    Employed by state/province                   Num 4.
                0=No
                1=Yes

PRIV50      Private employer (50 or fewer employees)     Num 4.
                0=No
                1=Yes

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

Hrdother    Q3f Other                                    Num 4.

ELSI_Fam    Returned ELSI Post Results form?             Char $1.
```

```
Dvisit_prfam      Date of one year follow-up form                   Num 4.
                  (Number of days from given date)

GHSCALE_PRfam  SF-36 General Health Scale - Post Results            Num 4.

MHSCALE_PRfam  SF-36 Mental Health Scale - Post Results             Num 4.
```