Initial Screening Participants Data Dictionary

Section I: Basic study/participant information

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

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 4.

GENDER   What is your gender   Num 4.
        1=Male
        2=Female

GENOTYPE   Genotype   Num 2.
        1= C282Y/C282Y
        2= C282Y/H63D
        3= H63D/H63D
        4= C282Y/-
        5= H63D/-
        6= -/-
        7= MISSING

Section II: Initial Screening Consent

CONSTSIGNED_IS   Signed Consent Form   Num 4.
        1=Yes
        3=Withdrawn

DSIGNED_IS   Date Consent Form signed   Num 4.
        (Number of days from given date)

BLDSTORE_IS   May we store your blood?   Num 4.
        1=Yes
        2=No

DWITHDRAWN_IS   Date Withdrew consent   Num 4.
        (Number of days from given date)

Section III: Initial Screening

DISFORM   Initial Screen Form Date   Num 4.
        (Number of days from given date)

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

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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


FMEMBER     Q5:   My family member was in this study and told me    Num 4.
                  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


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


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
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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


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
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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

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
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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

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
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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


HEREDITY      Q17a: Heredity (it runs in your family)                 Num 4.
                            1=Very important
                            2=Somewhat important
                            3=Not important
                            4=Not sure
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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


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          Char $2.
                      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
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Section IV: Initial Screen Lab Results

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HOURS_IS      Hours since last food                                  Num 10.2

SERUM         Serum Iron                                             Num 7.2
                  Note 0='<5'

SF_IS         Serum Ferritin                                         Num 10.2
                  Note 7.5 = '<15'

TS_IS         Transferrin Saturation                                 Num 10.2
                  Note 1.5 = '<3'
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UIBC            Unsaturated Iron Binding Capacity                       Num 8.2

TIBC            Total Iron Binding Capacity                             Num 8.2

CASE_CONTROL        Invited CCE Case or Control                         Num 2.
                        1=Case
                        2=Control

ELEVATED_INDICATOR      Elevated ts and sf at initial screening         Num 2.
                        1=elevated
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Section V: CCE Consent Form

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CONSTSIGNED_CCE   Signed Consent Form                                   Num 4.
                  1=Yes

DSIGNED_CCE       Date Consent Form signed                              Num 4.
                  (Number of days from given date)

HIPAAAUTH         Signed Hipaa authorization                            Num 4.
                        1=Yes
                        2=No

DATEHIPAA         Date Hipaa authorization signed                       Num 4.
                  (Number of days from given date)

BLDSTORE_CCE      May we store your blood?                              Num 4.
                  1=Yes
                  2=No

DWITHDRAWN_CCE    Date Withdrew consent                                 Num 4.
                  (Number of days from given date)

CCE_ATTEND        CCE attended indicator                                Num 2.
                  1=Yes
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Section VI: Clinical Assessment

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DCAVISIT    Date Clinical Assessment Form was filled out                Num 4.
            (Number of days from given date)

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.
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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


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
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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 VII: 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 %


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


HOURS_CCE     Hours since last ate food                            Num 8


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


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
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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 %


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 x10^9/L


ALYMP      Absolute lymphocytes (# cells/10^9/L)                 Num 8
           Reference Range:  0.8-5.3 x10^9/L


AMONO      Absolute monocytes (# cells/10^9/L)                   Num 8
           Reference Range:  0-1.3 x10^9/L


AEOS       Absolute eosinophils (# cells/10^9/L)                 Num 8
           Reference Range:  0-0.7 x10^9/L


ABASO      Absolute basophils (# cells/10^9/L)                   Num 8
           Reference Range:  0-0.2 x10^9/L
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Section VIII: Medical History

DMHVISIT   Date of visit   Num 4.
              (Number of days from given date)

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

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

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

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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


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
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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


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.

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

btWhole       Q38:  Ever donated whole blood at a blood bank?           Num 4.
                    1=Yes
                    2=No
                    3=Don't Know

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
```

Section IX: Additional Medical History Questions

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

```
DMHAVISIT   Date of visit                                            Num 4.
            (Number of days from given date)

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 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
```