Duke University
Duke Office of Clinical Research

## **MDS Distress**

## Data Dictionary Codebook

05/18/2018 2:03pm

| # | Variable /<br>Field Name                               | Field Label<br>Field Note                                     | Field Attributes (Field<br>Type, Validation, Choices,<br>Calculations, etc.) |
|---|--|---|--|
|   |  | ographics And Disease Chaccs_and_disease_characteristics_crf) |  |
| 1 | ptid   | Participant ID  | text   |
| 2 | date_abs   | Date CRF Completed  | text (date_mdy)  |
| 3 | abs_name   | CRF Completed By  | dropdown  1  |
| 4 | oth_abs_name Show the field ONLY if: [abs_name]='9 97' | Other Abstractor, Please Specify                              | text   |
| 5 | mrn  | Medical Record Number   | text, Required, Identifier   |
| 6 | first_name   | First Name  | text, Required, Identifier   |
| 7 | last_name  | Last Name   | text, Required, Identifier   |
| 8 | dob  | Date of Birth   | text (date_mdy), Required,<br>Identifier                                     |
| 9 | gender   | Gender  | dropdown, Required  1 Male   |

|    |   |                             | 2 F                | emale   |     |  |  |
|----|---|-----------------------------|--------------------|---|-----|--|--|
| 0  | race  | Race                        | dropdown, Required |   |     |  |  |
|    |   |                             | 1                  | White   |     |  |  |
|    |   |                             | 2                  | Black or African<br>American                    |     |  |  |
|    |   |                             | 3                  | Asian   |     |  |  |
|    |   |                             | 4                  | Native Hawaiian or<br>other Pacific<br>Islander |     |  |  |
|    |   |                             | 5                  | American Indian or<br>Alaska Native             |     |  |  |
|    |   |                             | 997                | Other   |     |  |  |
|    |   |                             | 998                | Not Reported                                    |     |  |  |
|    |   |                             | 999                | Unknown   |     |  |  |
| 1  | race_oth Show the field ONLY if: [race]='997' | Other Race, Please Specify  | text, I            | Required  |     |  |  |
| 12 | ethnicity                                     | Ethnicity                   | dropo              | down  |     |  |  |
|    |   |                             | 1                  | Hispanic or Latino                              |     |  |  |
|    |   |                             | 2                  | Not Hispanic or<br>Latino                       |     |  |  |
|    |   |                             | 999                | Unknown   |     |  |  |
| 3  | mar_status_cd                                 | Marital Status Code         | dropdown           |   |     |  |  |
|    |   |                             | 1                  | Married   |     |  |  |
|    |   |                             | 2                  | Separated/Divorced                              |     |  |  |
|    |   |                             | 3                  | Widowed   |     |  |  |
|    |   |                             | 4                  | Single (never<br>married)                       |     |  |  |
|    |   |                             | 999                | Unknown   |     |  |  |
| 4  | insc_status                                   | Heath Insurance Status Code | dropo              | down  |     |  |  |
|    |   |                             | 1                  | Medicare  |     |  |  |
|    |   |                             | 2                  | Medicaid  |     |  |  |
|    |   |                             | 3                  | Military/Veteran/Champ                          | ous |  |  |
|    | i e e e e e e e e e e e e e e e e e e e       |                             | 4                  | Private payer(e.g. Blue                         |     |  |  |

|    |  |  | 997   | Other                    |                                  |
|----|--|--|-------|--------------------------|----------------------------------|
|    |  |  | 999   | Unknown                  |                                  |
| 15 | oth_insc_statu<br>s<br>Show the field<br>ONLY if:<br>[insc_status]='<br>997' | Other Health Insurance, Please<br>Specify  | text  |                          |                                  |
| 16 | cancer   | Has participant ever had cancer (excluding basal or squamous cell skin cancer)?    | 1 Y   | down<br>'es<br>Io        |                                  |
| 17 | cancer_yes   | If Yes, check all that apply For participants with history of multiple             | check | I                        | <u> </u>                         |
|    |  | cancers, list the most recent cancer. For participants who presented with multiple | 2     | cancer_yes1 cancer_yes 2 | Anal<br>Bladder                  |
|    |  | primary tumors check all that apply.   | 3     | cancer_yes2 cancer_yes3  | Bone and joint                   |
|    |  |  | 4     | cancer_yes4              | Brain or other nervous system    |
|    |  |  | 5     | cancer_yes5              | Breast                           |
|    |  |  | 6     | cancer_yes6              | Cervix uteri                     |
|    |  |  | 7     | cancer_yes7              | Co on                            |
|    |  |  | 8     | cancer_yes8              | Endometrial                      |
|    |  |  | 9     | cancer_yes9              | Esophagus                        |
|    |  |  | 10    | cancer_yes10             | Kidney and renal pelvis          |
|    |  |  | 11    | cancer_yes11             | Larynx                           |
|    |  |  | 12    | cancer_yes12             | Liver and intrahepatic bile duct |
|    |  |  | 13    | cancer_yes13             | Lung and bronchus                |
|    |  |  | 14    | cancer_yes14             | Lymphoma,<br>Hodgkin             |
|    |  |  | 15    | cancer_yes15             | Lymphoma,<br>Non-<br>Hodgkin     |
|    |  |  | 16    | cancer_yes16             | Leukemia,                        |

|    |  |  |      |              |          | ALL                                     |
|----|--|--|------|--------------|----------|---|
|    |  |  | 17   | cancer_yes^  | 17       | Leukemia,<br>AML                        |
|    |  |  | 18   | cancer_yes′  | 18       | Leukemia,<br>CLL                        |
|    |  |  | 19   | cancer_yes^  | 19       | Leukemia,<br>CML                        |
|    |  |  | 20   | cancer_yes2  | 20       | Melanoma<br>of the skin                 |
|    |  |  | 21   | cancer_yes2  | 21       | Myeloma                                 |
|    |  |  | 22   | cancer_yes2  | 22       | Oral cavity<br>and<br>pharynx<br>cancer |
|    |  |  | 23   | cancer_yes2  | 23       | Ovary                                   |
|    |  |  | 24   | cancer_yes2  | 24       | Pancreas                                |
|    |  |  | 25   | cancer_yes2  | 25       | Prostate                                |
|    |  |  | 26   | cancer_yes2  | 26       | Small<br>Intestine                      |
|    |  |  | 27   | cancer_yes2  | 27       | Stomach                                 |
|    |  |  | 28   | cancer_yes2  | 28       | Testis                                  |
|    |  |  | 29   | cancer_yes2  | 29       | Thyroid                                 |
|    |  |  | 30   | cancer_yes3  | 30       | Vulva                                   |
|    |  |  | 997  | cancer_yes9  |          | Other site                              |
|    |  |  | 999  | cancer_yes9  | 999      | Unknown<br>site                         |
|    |  |  |      | cancer_yes   |          |   |
| 18 | anal_yr_dx Show the field ONLY if: [cancer_yes(1)] = '1' | Section Header: <i>Anal</i> Year Anal cancer diagnosed <i>yyyy</i> | text | . Identifier |          |   |
| 19 | anal_tx  | Anal Cancer treatment received                                     | ched | kbox         | <u> </u> |   |
|    | Show the field   |  | 1    | anal_tx1     |          | diation                                 |
|    | ONLY if:<br>[cancer_yes(1)]                              |  | 2    | anal_tx2     | Che      | emotherapy                              |
|    | = '1'  |  | 3    | anal_tx3     | Sur      | rgery                                   |
|    |  |  | 4    | anal_tx4     |          | ne marrow<br>other stem                 |

|          |   |   |         |              | cell       | tra  | nsplant                                     |
|----------|---|---|---------|--------------|------------|------|---|
|          |   |   | 5       | anal_tx5     | Nor        | ne   |   |
|          |   |   | 999     | anal_tx999   | Unk        | no   | wn  |
| 20       | bladder_yr_dx Show the field ONLY if: [cancer_yes(2)] = '1'                   | Section Header: <i>Bladder</i> Year Bladder cancer diagnosed <i>yyyy</i>        | text,   | ldentifier   |            |      |   |
| 21       | bladder_tx  | Bladder Cancer treatment  | check   | kbox         |            |      |   |
|          | Show the field  | received  | 1       | bladder_tx^  | 1          | Rac  | liation                                     |
|          | ONLY if:<br>[cancer_yes(2)]   |   | 2       | bladder_tx2  | 2          | Che  | motherapy                                   |
|          | = '1'   |   | 3       | bladder_tx3  | 3 :        | Sur  | gery  |
|          |   |   | 4       | bladder_tx4  |            | or ( | ne marrow<br>other stem<br>transplant       |
|          |   |   | 5       | bladder_tx   | 5          | No   | ne  |
|          |   |   | 999     | bladder_tx9  | 999        | Unl  | known                                       |
| <u> </u> | bonejoint_yr<br>_dx<br>Show the field<br>ONLY if:<br>[cancer_yes(3)]<br>= '1' | Section Header: <i>Bone and joint</i> Year Bone and joint cancer diagnosed yyyy | iext, l | ldentifier   |            |      |   |
| 23       | bonejoint_tx  | Bone and joint cancer treatment   | check   | kbox         |            | 1    |   |
|          | Show the field  | received  | 1       | bonejoint_tx | 1          |      | Radiation                                   |
|          | ONLY if:<br>[cancer_yes(3)]   |   | 2       | bonejoint_tx | 2          |      | Chemother                                   |
|          | = '1'   |   | 3       | bonejoint_tx | (3         |      | Surgery                                     |
|          |   |   | 4       | bonejoint_tx | <b>(</b> 4 |      | Bone marro<br>or other ste<br>cell transpla |
|          |   |   | 5       | bonejoint_tx | (5         |      | None  |
|          |   |   | 999     | bonejoint_tx | (99        | 99   | Unknown                                     |
| 24       | brain_nervsyst<br>m_yr_dx   | Section Header: <i>Brain or other nervous</i> system                            | text,   | ldentifier   |            |      |   |
|          | Show the field<br>ONLY if:<br>[cancer_yes(4)]<br>= '1'                        | Year Brain or other nervous system cancer diagnosed                             |         |              |            |      |   |

| 25 brain_nerv<br>m_tx   | -  | Brain or other nervous system cancer treatment received                            | 1                     | brain_nervsystm   | _tx   | 1 Ra                              | diation                                  |  |
|---|--|--|-----------------------|-------------------|-------|-----------------------------------|--|--|
| Show the f  | field  |  | 2                     | brain_nervsystm   |       | 2 Ch                              | emotherapy                               |  |
| ONLY if:  | 25(4)]   |  | 3                     | brain_nervsystm   | _tx   | 3 Su                              | rgery                                    |  |
| = '1'   | [cancer_yes(4)]<br>= '1'                               |  | 4                     | brain_nervsystm   | _tx   | or                                | ne marrow<br>other stem<br>Il transplant |  |
|   |  |  | 5                     | brain_nervsystm   | _tx   | 5 No                              | ne                                       |  |
|   |  |  | 999                   | brain_nervsystm   | _tx   | 999 Un                            | known                                    |  |
| Show the f<br>ONLY if:<br>[cancer_ye<br>= '1'                         | field  | Section Header: <i>Breast</i> Year Breast cancer diagnosed  yyyy                   | text, I               | dentifier         |       |                                   |  |  |
| 27 breast_tx  |  | Breast cancer treatment  | check                 | box               |       |                                   |  |  |
| Show the f  | Show the field<br>ONLY if:<br>[cancer_yes(5)]<br>= '1' | received   | 1                     | breast_tx1        | ation |                                   |  |  |
|   |  |  | 2                     | breast_tx2        | Cher  | nothera                           | ру                                       |  |
| -   |  |  | 3                     | breast_tx3        | Surg  | ery                               |  |  |
|   |  |  | 4                     | breast_tx4        | or ot | marrov<br>her sten<br>ransplar    | n  |  |
|   |  |  | 5                     | breast_tx5        | None  | 2                                 |  |  |
|   |  |  | 999                   | breast_tx999      | Unkr  | iown                              |  |  |
| 28 cervixuteri<br>dx<br>Show the f<br>ONLY if:<br>[cancer_ye<br>= '1' | field  | Section Header: <i>Cervix Uteri</i> Year Cervix Uteri cancer diagnosed <i>yyyy</i> | text, I               | dentifier         |       |                                   |  |  |
| 29 cervixuteri  | i_tx   | Cervix Uteri Cancer treatment  | checkbox              |                   |       |                                   |  |  |
| Show the f  | field  | received   | 1                     | cervixuteri_tx^   |       | Radiatio                          |  |  |
| ONLY if:<br>[cancer_ye  | es(6)]   |  | 2                     | cervixuteri_tx2   |       | Chemoth                           | nerapy                                   |  |
| = '1'   |  |  | 3                     | cervixuteri_tx3   |       | urgery                            |  |  |
|   |  |  |                       | 4 cervixuteri_tx4 |       | Bone ma<br>or other<br>cell trans | stem                                     |  |
|   |  |  | 5                     | cervixuteri_tx!   | 5 1   | None                              |  |  |
|   |  |  | 999 cervixuteri_tx999 |                   |       | Unknown                           |  |  |

| 30 | colonrectum_y<br>r_dx<br>Show the field<br>ONLY if:<br>[cancer_yes(7)]<br>= '1' | Section Header: <i>Colon and rectum</i> Year Colon and rectum cancer diagnosed  yyyy | text, l | dentifier         |   |
|----|---|--|---------|-------------------|---|
| 31 | colonrectum_t<br>x  | Colon and rectum Cancer treatment received   | check   |                   |   |
|    | ^<br>Show the field   | d eather received  | 1       | colonrectum_tx1   | Radiation                                       |
|    | ONLY if:  |  | 2       | colonrectum_tx2   | Chemotherapy                                    |
|    | [cancer_yes(7)]   |  | 3       | colonrectum_tx3   | Surgery   |
|    | = '1'   |  | 4       | colonrectum_tx4   | Bone marrow or other stem cell transplant       |
|    |   |  | 5       | colonrectum_tx5   | None  |
|    |   |  | 999     | colonrectum_tx999 | Unknown   |
| 32 | endometrial_y<br>r_dx<br>Show the field<br>ONLY if:<br>[cancer_yes(8)]<br>= '1' | Section Header: <i>Endometrial</i> Year Endometrial cancer diagnosed yyyy            | text, I | dentifier         |   |
| 33 | endometrial_tx  | Endometrial Cancer treatment   | check   | box               |   |
|    | Show the field  | received   | 1       | endometrial_tx1   | Radiation                                       |
|    | ONLY if: [cancer_yes(8)]  |  | 2       | endometrial_tx2   | Chemotherapy                                    |
|    | = '1'   |  | 3       | endometrial_tx3   | Surgery   |
|    |   |  | 4       | endometrial_tx4   | Bone marrow<br>or other stem<br>cell transplant |
|    |   |  | 5       | endometrial_tx5   | None  |
|    |   |  | 999     | endometrial_tx999 | Unknown   |
| 34 | esphagus_yr_d<br>x<br>Show the field<br>ONLY if:<br>[cancer_yes(9)]<br>= '1'    | Section Header: <i>Esphagus</i> Year Esphagus cancer diagnosed <i>yyyy</i>           | text, I | dentifier         |   |
| 35 | esphagus_tx   | Esphagus Cancer treatment  | check   | box               |   |
|    | Show the field ONLY if:   | received   | 1 2     |                   | Radiation<br>Themotherapy                       |

|    | = '1'  |  | 3       | esphagus_tx3   | S     | urgery  |
|----|--|--|---------|----------------|-------|---|
|    |  |  | 4       | esphagus_tx4   | 0     | one marrow<br>r other stem<br>ell transplant    |
|    |  |  | 5       | esphagus_tx5   | N     | lone  |
|    |  |  | 999     | esphagus_tx9   | 99 L  | nknown  |
| 36 | kidneyrenal_yr<br>_dx<br>Show the field<br>ONLY if:<br>[cancer_yes(10<br>)]= '1' | Section Header: Kidney and Renal Pelvis Year Kidney and Renal Pelvis cancer diagnosed yyyy | text, I | dentifier      |       |   |
| 37 | kidneyrenal_tx   | Kidney and Renal Pelvis Cancer   | check   | box            |       |   |
|    | Show the field   | treatment received   | 1       | kidneyrenal_tx | _1    | Radiation                                       |
|    | ONLY if: [cancer_yes(10  |  | 2       | kidneyrenal_tx | _2    | Chemotherap                                     |
|    | )]= '1'  |  | 3       | kidneyrenal_tx | _3    | Surgery   |
|    |  |  | 4       | kidneyrenal_tx | _4    | Bone marrow<br>or other stem<br>cell transplant |
|    |  |  | 5       | kidneyrenal_tx | _5    | None  |
|    |  |  | 999     | kidneyrenal_tx | _999  | Unknown   |
| 38 | larynx_yr_dx Show the field ONLY if: [cancer_yes(11 )]= '1'                      | Section Header: <i>Larynx</i> Year Larynx cancer diagnosed <i>yyyy</i>                     | text, l | dentifier      |       |   |
| 39 | larynx_tx  | Larynx Cancer treatment  | check   | box            |       |   |
|    | Show the field   | received   | 1       | larynx_tx1     | Radi  | ation   |
|    | ONLY if:<br>[cancer_yes(11   |  | 2       | larynx_tx2     | Cher  | notherapy                                       |
|    | )]= '1'  |  | 3       | larynx_tx3     | Surg  | ery   |
|    |  |  | 4       | larynx_tx4     | or ot | marrow<br>ner stem<br>ransplant                 |
|    |  |  | 5       | larynx_tx5     | Non   |   |
|    |  |  | 999     | larynx_tx999   | Unkr  | own   |
| 40 | liverbileduct_y<br>r_dx  | Section Header: <i>Liver and intrahepatic</i> bile duct                                    | text, l | dentifier      |       |   |
|    | Show the field   | Year Liver and intrahepatic bile duct cancer diagnosed                                     |         |                |       |   |

|    | ONLY if:<br>[cancer_yes(12<br>)]= '1'                        | уууу   |                     |                   |           |  |
|----|--|--|---------------------|-------------------|-----------|--|
| 41 | liverbileduct_tx   | Liver and intrahepatic bile duct   | check               | box               |           | 1  |
|    | Show the field   | Cancer treatment received  | 1 liverbileduct_tx1 |                   | Radiation |  |
|    | ONLY if:<br>[cancer_yes(12                                   |  | 2                   | liverbileduct_tx_ | 2         | Chemotherap                                    |
|    | )]= '1'  |  | 3                   | liverbileduct_tx_ | 3         | Surgery  |
|    |  |  | 4                   | liverbileduct_tx_ | 4         | Bone marrow<br>or other stem<br>cell transplan |
|    |  |  | 5                   | liverbileduct_tx_ | 5         | None   |
|    |  |  | 999                 | liverbileduct_tx_ | 999       | Unknown  |
| .2 | lung_yr_dx Show the field ONLY if: [cancer_yes(13 )]= '1'    | Section Header: <i>Lung and Bronchus</i> Year Lung and Bronchus cancer diagnosed <i>yyyy</i> | text, I             | dentifier         |           |  |
|    | lung_tx  | Lung and Bronchus Cancer   |                     | box               |           |  |
|    | Show the field   | treatment received   | 1                   | lung_tx1          | Radia     | tion   |
|    | ONLY if:   | cancer_yes(13  | 2                   | lung_tx2          | Chem      | otherapy                                       |
|    | )]= '1'  |  | 3                   | lung_tx3          | Surge     | ry   |
|    |  |  | 4                   | lung_tx4          | or oth    | marrow<br>er stem<br>ansplant                  |
|    |  |  | 5                   | lung_tx5          | None      |  |
|    |  |  | 999                 | lung_tx999        | Unkn      | own  |
| 4  | hodgkin_yr_dx Show the field ONLY if: [cancer_yes(14 )]= '1' | Section Header: <i>Lymphoma, Hodgkin</i> Year Lymphoma, Hodgkin cancer diagnosed <i>YYYY</i> | text, I             | dentifier         |           |  |
| 45 | hodgkin_tx   | Lymphoma, Hodgkin Cancer   | check               | box               |           | ,  |
|    | Show the field   | treatment received   | 1                   | hodgkin_tx1       | Ra        | liation  |
|    | ONLY if:<br>[cancer_yes(14                                   |  | 2                   | hodgkin_tx2       | Ch        | emotherapy                                     |
|    | )]= '1'  |  | 3                   | hodgkin_tx3       | Su        | gery   |
|    |  |  | 4                   | hodgkin_tx4       | or        | ne marrow<br>other stem<br>transplant          |

|    |   |   | 5            | hodgkin_tx_ | _5_   | No   | ne                              |        |
|----|---|---|--------------|-------------|-------|------|---------------------------------|--------|
|    |   |   | 999          | hodgkin_tx_ | _999  | Un   | known                           |        |
| 46 | nonhodgkin_yr<br>_dx<br>Show the field<br>ONLY if:<br>[cancer_yes(15<br>)]= '1' | Section Header: <i>Lymphoma, Non-Hodgkin</i> Year Lymphoma, Non-Hodgkin cancer diagnosed <i>YYYYY</i> | text, l      | Identifier  |       |      |                                 |        |
| 47 | nonhodgkin_tx   | Lymphoma, Non-Hodgkin   | check        | kbox        |       |      |                                 |        |
|    | Show the field  | Cancer treatment received   | 1            | nonhodgkin_ | _tx1  |      | Radiatio                        | n      |
|    | ONLY if:<br>[cancer_yes(15  |   | 2            | nonhodgkin_ | _tx2  | 2    | Chemot                          | herapy |
|    | )]= '1'   |   | 3            | nonhodgkin_ | _tx3  | 3    | Surgery                         |        |
|    |   |   | 4            | nonhodgkin_ | _tx4  | 1    | Bone m<br>or other<br>cell tran | stem   |
|    |   |   | 5            | nonhodgkin_ | _tx5  | 5    | None                            |        |
|    |   |   | 999          | nonhodgkin_ | _tx9  | 999  | Unknow                          | /n     |
|    | Show the field<br>ONLY if:<br>[cancer_yes(16<br>)]= '1'                         | Year Leukemia, ALL cancer<br>diagnosed<br><i>yyyy</i>   |              |             |       |      |                                 |        |
| 49 | all_tx  | Leukemia, ALL Cancer treatment  | check        |             |       |      |                                 |        |
|    | Show the field  | received  | 1            | all_tx1     | Radia |      |                                 |        |
|    | ONLY if:<br>[cancer_yes(16  |   | 2            | all_tx2     | Chen  | noth | ierapy                          |        |
|    | )]= '1'   |   | 3            | all_tx3     | Surge | ery  |                                 |        |
|    |   |   | 4            | all_tx4     | or ot | her  | rrow<br>stem<br>plant           |        |
|    |   |   | 5            | all_tx5     | None  | 9    |                                 |        |
|    |   |   | 999          | all_tx999   | Unkr  | nowi | n                               |        |
| 50 | aml_yr_dx   | Section Header: Leukemia, AML   | text, l      | dentifier   |       |      | 1                               |        |
|    | Show the field<br>ONLY if:<br>[cancer_yes(17<br>)]= '1'                         | Year Leukemia, AML cancer<br>diagnosed<br><i>yyyy</i>   |              |             |       |      |                                 |        |
|    |   |   | <del> </del> |             |       |      |                                 |        |
| 51 | aml_tx  | Leukemia, AML Cancer  | check        | (DOX        |       |      |                                 |        |

|    | ONLY if:  |  | 2       | aml_tx2   | Chemo                              | therapy |
|----|---|--|---------|-----------|------------------------------------|---------|
|    | [cancer_yes(17<br>)]= '1'                               |  | 3       | aml_tx3   | Surgery                            | ,       |
|    | /-  |  | 4       | aml_tx4   | Bone m                             |         |
|    |   |  |         |           | or othe cell trar                  |         |
|    |   |  | 5       | aml_tx5   | None                               |         |
|    |   |  | 999     | aml_tx999 | Unknov                             | vn      |
| 52 | cll_yr_dx   | Section Header: <i>Leukemia, CLL</i>   | text, l | dentifier |                                    |         |
|    | Show the field<br>ONLY if:<br>[cancer_yes(18<br>)]= '1' | Year Leukemia, CLL cancer<br>diagnosed<br>yyyy   |         |           |                                    |         |
| 53 | cll_tx  | Leukemia, CLL Cancer treatment   | check   | box       |                                    |         |
|    | Show the field  | received   | 1       | cll_tx1   | Radiatior                          | 1       |
|    | ONLY if:<br>[cancer_yes(18                              |  | 2       | cll_tx2   | Chemoth                            | erapy   |
|    | )]= '1'   |  | 3       | cll_tx3   | Surgery                            |         |
|    |   |  | 4       |           | Bone ma<br>or other:<br>cell trans | stem    |
|    |   |  | 5       | cll_tx5   | None                               |         |
|    |   |  | 999     | cll_tx999 | Unknowr                            | ì       |
| 54 | cml_yr_dx   | Section Header: <i>Leukemia, CML</i>   | text, l | dentifier |                                    |         |
|    | Show the field<br>ONLY if:<br>[cancer_yes(19<br>)]= '1' | Year Leukemia, CML cancer<br>diagnosed<br>yyyy   |         |           |                                    |         |
| 55 | cml_tx  | Leukemia, CML Cancer   | check   | box       |                                    |         |
|    | Show the field  | treatment received   | 1       | cml_tx1   | Radiatio                           | n       |
|    | ONLY if:<br>[cancer_yes(19                              |  | 2       | cml_tx2   | Chemot                             | herapy  |
|    | )]= '1'   |  | 3       | cml_tx3   | Surgery                            |         |
|    |   |  | 4       | cml_tx4   | Bone m<br>or othe<br>cell trar     | rstem   |
|    |   |  | 5       | cml_tx5   | None                               |         |
|    |   |  | 999     | cml_tx999 | Unknov                             | /n      |
| 56 | melanoma_yr_<br>dx<br>Show the field                    | Section Header: <i>Melanoma of the skin</i> Year Melanoma of the skin cancer diagnosed | text, l | dentifier |                                    | _       |

|    | ONLY if:<br>[cancer_yes(20<br>)]= '1'  | уууу   |         |                 |    |   |
|----|--|--|---------|-----------------|----|---|
| 57 | melanoma_tx  | Melanoma of the skin Cancer  |         | box             |    |   |
|    | Show the field   | treatment received   | 1       | melanoma_tx1    |    | Radiation                                       |
|    | ONLY if:<br>[cancer_yes(20   |  | 2       | melanoma_tx2    | •  | Chemotherapy                                    |
|    | )]= '1'  |  | 3       | melanoma_tx3    |    | Surgery   |
|    |  |  | 4       | melanoma_tx4    |    | Bone marrow<br>or other stem<br>cell transplant |
|    |  |  | 5       | melanoma_tx5    |    | None  |
|    |  |  | 999     | melanoma_tx999  |    | Jnknown   |
| 8  | myeloma_yr_d<br>x<br>Show the field<br>ONLY if:<br>[cancer_yes(21<br>)]= '1'     | Section Header: <i>Myeloma</i> Year Myeloma cancer diagnosed yyyy  | text, l | dentifier       |    |   |
| 59 | myeloma_tx   | Myeloma Cancer treatment   | check   | box             |    |   |
|    | Show the field   | received   | 1       | myeloma_tx1     | Ra | adiation  |
|    | ONLY if:   | cancer_yes(21  | 2       | myeloma_tx2     | Cl | nemotherapy                                     |
|    | )]= '1'  |  | 3       | myeloma_tx3     | Sι | ırgery  |
|    |  |  | 4       | myeloma_tx4     | 01 | one marrow<br>other stem<br>Ill transplant      |
|    |  |  | 5       | myeloma_tx5     | N  | one   |
|    |  |  | 999     | myeloma_tx999   | U  | nknown  |
| 0  | oralpharynx_yr<br>_dx<br>Show the field<br>ONLY if:<br>[cancer_yes(22<br>)]= '1' | Section Header: Oral cavity and pharynx cancer  Year Oral cavity and pharynx cancer cancer diagnosed  yyyy | text, I | dentifier       |    |   |
| 51 | oralpharynx_tx   |  | check   | box             |    |   |
|    | Show the field   | Cancer treatment received  | 1       | oralpharynx_tx1 |    | Radiation                                       |
|    | ONLY if:<br>[cancer_yes(22   |  | 2       | oralpharynx_tx2 |    | Chemotherapy                                    |
|    | )]= '1'  |  | 3       | oralpharynx_tx3 |    | Surgery   |
|    |  |  | 4       | oralpharynx_tx4 |    | Bone marrow or other stem                       |

|    |   |  |                   |                           |          | cell transpla                                |
|----|---|--|-------------------|---------------------------|----------|--|
|    |   |  | 5                 | oralpharynx_tx_           |          | None   |
|    |   |  | 999               | oralpharynx_tx_           | 999      | Unknown                                      |
| 62 | ovary_yr_dx   | Section Header: <i>Ovary</i>   | text, I           | dentifier                 |          |  |
|    | Show the field<br>ONLY if:<br>[cancer_yes(23<br>)]= '1'       | Year Ovary cancer diagnosed  yyyy                                    |                   |                           |          |  |
| 63 | ovary_tx  | Ovary Cancer treatment received                                      | check             | box                       | 1        |  |
|    | Show the field  |  | 1                 | ovary_tx1                 | Radia    | ation  |
|    | ONLY if: [cancer_yes(23                                       |  | 2                 | ovary_tx2                 | Cher     | notherapy                                    |
|    | )]= '1'   |  | 3                 | ovary_tx3                 | Surg     | ery  |
|    |   |  | 4                 | ovary_tx4                 | or ot    | marrow<br>her stem<br>ransplant              |
|    |   |  | 5                 | ovary_tx5                 | None     | 2  |
|    |   |  | 999               | ovary_tx999               | Unkr     | nown   |
|    | x<br>Show the field<br>ONLY if:<br>[cancer_yes(24<br>)]= '1'  | Year Pancreas cancer diagnosed yyyy                                  |                   |                           |          |  |
| 65 | pancreas_tx   | Pancreas Cancer treatment  | check             | box                       |          |  |
|    | Show the field  | received   | 1 pancreas_tx1 Ra |                           | adiation |  |
|    | ONLY if: [cancer_yes(24                                       |  | 2                 | pancreas_tx2              | 2 C      | hemotherapy                                  |
|    | )]= '1'   |  | 3                 | pancreas_tx3              | 3 S      | urgery                                       |
|    |   |  | 4                 | pancreas_tx4              | 0        | one marrow<br>r other stem<br>ell transplant |
|    |   |  | 5                 | pancreas_tx5              | 5 N      | lone   |
|    |   |  |                   |                           | 000      | Jnknown                                      |
|    |   |  | 999               | pancreas_tx9              | 199 (    | TIKITOWIT                                    |
| 66 | prostate_yr_dx  | Section Header: <i>Prostate</i>                                      |                   | pancreas_tx9<br>dentifier | 999   C  | TKHOWIT                                      |
| 66 | prostate_yr_dx Show the field ONLY if: [cancer_yes(25 )]= '1' | Section Header: <i>Prostate</i> Year Prostate cancer diagnosed  yyyy |                   | •                         | 999   0  | TIKTIOWIT                                    |

|    | Show the field   | received   | 1    | prostate_tx1      | Ra | diation   |
|----|--|--|------|-------------------|----|---|
|    | ONLY if:<br>[cancer_yes(25   |  | 2    | prostate_tx2      | Ch | emotherapy                                      |
|    | )]= '1'  |  | 3    | prostate_tx3      | Su | rgery   |
|    |  |  | 4    | prostate_tx4      | or | ne marrow<br>other stem<br>l transplant         |
|    |  |  | 5    | prostate_tx5      | No | ne  |
|    |  |  | 999  | 9 prostate_tx999  | Un | known   |
| 68 | smintestine_yr<br>_dx<br>Show the field<br>ONLY if:<br>[cancer_yes(26<br>)]= '1' | Section Header: <i>Small Intestine</i> Year Small intestine cancer diagnosed  yyyy | text | , Identifier      |    |   |
| 69 | smintestine_tx   | Small intestine Cancer treatment   | che  | ckbox             |    |   |
|    | Show the field   | received   | 1    | smintestine_tx1   |    | Radiation                                       |
|    | ONLY if:   |  | 2    | smintestine_tx2   |    | Chemotherapy                                    |
|    | [cancer_yes(26<br>)]= '1'  |  | 3    | smintestine_tx3   |    | Surgery   |
|    |  |  | 4    | smintestine_tx4   |    | Bone marrow<br>or other stem<br>cell transplant |
|    |  |  | 5    | smintestine_tx5   |    | None  |
|    |  |  | 999  | 9 smintestine_tx9 | 99 | Unknown   |
| 70 | stomach_yr_dx  | Section Header: Stomach  | text | , Identifier      |    |   |
|    | Show the field<br>ONLY if:<br>[cancer_yes(27<br>)]= '1'                          | Year Stomach cancer diagnosed  yyyy  |      |                   |    |   |
| 71 | stomach_tx   | Stomach Cancer treatment   | che  | ckbox             |    |   |
|    | Show the field   | received   | 1    | stomach_tx1       | Ra | diation   |
|    | ONLY if:<br>[cancer_yes(27   |  | 2    | stomach_tx2       | Ch | emotherapy                                      |
|    | )]= '1'  |  | 3    | stomach_tx3       | Su | rgery   |
|    |  |  | 4    | stomach_tx4       | or | ne marrow<br>other stem<br>l transplant         |
|    |  |  | 5    | stomach_tx5       | No | ne  |
|    |  |  | 999  | 9 stomach_tx999   | Ur | known   |
| 72 | testis_yr_dx   | Section Header: <i>Testis</i>  | text | , Identifier      |    |   |

|    | Show the field<br>ONLY if:<br>[cancer_yes(28<br>)]= '1'      | Year Testis cancer diagnosed yyyy  |         |                 |        |                                     |
|----|--|--|---------|-----------------|--------|-------------------------------------|
| 73 | testis_tx  | Testis Cancer treatment received   | check   | box             |        |                                     |
|    | Show the field   |  | 1       | testis_tx1      | Radia  | tion                                |
|    | ONLY if:<br>[cancer_yes(28                                   |  | 2       | testis_tx2      | Chem   | otherapy                            |
|    | )]= '1'  |  | 3       | testis_tx3      | Surge  | ry                                  |
|    |  |  | 4       | testis_tx4      | or oth | marrow<br>er stem<br>ansplant       |
|    |  |  | 5       | testis_tx5      | None   |                                     |
|    |  |  | 999     | testis_tx999    | Unkn   | own                                 |
| 74 | thyroid_yr_dx Show the field ONLY if: [cancer_yes(29 )]= '1' | Section Header: <i>Thyroid</i> Year Thyroid cancer diagnosed <i>yyyy</i> | text, I | dentifier       |        |                                     |
| 75 | thyroid_tx   | Thyroid Cancer treatment   | check   | box             |        |                                     |
|    | Show the field   | received   | 1       | thyroid_tx1     | Rad    | iation                              |
|    | ONLY if:<br>[cancer_yes(29                                   |  | 2       | 2 thyroid_tx2 C |        | motherapy                           |
|    | )]= '1'  |  | 3       | thyroid_tx3     | Sur    | ery                                 |
|    |  |  | 4       | thyroid_tx4     | or c   | e marrow<br>ther stem<br>transplant |
|    |  |  | 5       | thyroid_tx5     | Nor    | e                                   |
|    |  |  | 999     | thyroid_tx99    | 9 Unk  | nown                                |
| 76 | vulva_yr_dx  | Section Header: <i>Vulva</i>   | text, l | dentifier       |        | 1                                   |
|    | Show the field<br>ONLY if:<br>[cancer_yes(30<br>)]= '1'      | Year Vulva cancer diagnosed  yyyy  |         |                 |        |                                     |
| 77 | vulva_tx   | Vulva Cancer treatment received  | check   | box             | ı      |                                     |
|    | Show the field   |  | 1       | vulva_tx1       | Radia  | tion                                |
|    | ONLY if:<br>[cancer_yes(30                                   |  | 2       | vulva_tx2       |        | otherapy                            |
|    | )]= '1'  |  | 3       | vulva_tx3       | Surge  |                                     |
|    |  |  | 4       | vulva_tx4       | or oth | marrow<br>er stem<br>ansplant       |

|    |  |  | 5        | vulva_tx             | _5   | None                                      |
|----|--|--|----------|----------------------|--|---|
|    |  |  | 999      | vulva_tx             | _999   | Unknown                                   |
| 78 | other_ca Show the field ONLY if: [cancer_yes(99 7)]= '1'     | Section Header: <i>Other site</i> Other site , please specify  | text     |                      |  |   |
| 79 | other_yr_dx  Show the field ONLY if: [cancer_yes(99 7)]= '1' | Section Header: Other site Year Other site cancer diagnosed yyyy   | text, l  | dentifier            |  |   |
| 80 | other_tx   | Other site Cancer treatment  | check    | cbox                 |  |   |
|    | Show the field ONLY if:                                      | received   | 2        | other_tx<br>other_tx |  | Radiation Chemotherap                     |
|    | [cancer_yes(99<br>7)]= '1'                                   |  | 3        | other_tx_            |  | Surgery                                   |
|    |  | 4  | other_tx |                      | Bone marrow<br>or other stem<br>cell transplan |   |
|    |  |  | 5        | other_tx             | _5   | None                                      |
|    |  |  | 999      | other_tx             | _999   | Unknown                                   |
| 81 | unk_yr_dx Show the field ONLY if: [cancer_yes(99 9)]= '1'    | Section Header: <i>Unknown site</i> Year Unknown site cancer diagnosed  yyyy                               | text, l  | ldentifier           |  |   |
| 82 | unk_tx   | Unknown site Cancer treatment  | check    | box                  |  |   |
|    | Show the field   | received   | 1        | unk_tx′              |  | Radiation                                 |
|    | ONLY if:<br>[cancer_yes(99                                   |  | 2        | unk_tx2              | 2  | Chemotherapy                              |
|    | 9)]= '1'   |  | 3        | unk_tx3              | 3  | Surgery                                   |
|    |  |  | 4        | unk_tx4              |  | Bone marrow or other stem cell transplant |
|    |  |  | 5        | unk_tx               | 5_   | None                                      |
|    |  |  | 999      | unk_tx9              | 999  | Unknown                                   |
| 83 | mi   | Section Header: Charlston Comorbidity<br>Index<br>Myocardial Infarction<br>History of medically documented | l⊢⊢      | es<br>Io             |  |   |

|    |                    | myocardial infarction   |  |
|----|--------------------|---|--|
|    |                    |   | Custom alignment: RH                     |
| 84 | cva                | Cerebrovascular disease<br>History of TIA or CVA with no or minor<br>sequellae                            | radio 1 Yes 0 No                         |
|    |                    |   | Custom alignment: RH                     |
| 85 | pvd                | Peripheral vascular disease Such as peripheral arterial disease / PAD, including symptomatic claudication | radio  1 Yes  0 No  Custom alignment: RH |
| 86 | chf                | Congestive heart failure Symptomatic CHF with response to specific treatment                              | radio 1 Yes 0 No Custom alignment: RH    |
| 87 | dem                | Dementia Any type: Alzheimers, vascular dementia, alcohol-related, but not mild cognitive impairment      | radio 1 Yes 0 No Custom alignment: RH    |
| 88 | ulcer              | Ulcer Patients who have required treatment for Peptic Ulcerative Disease                                  | radio 1 Yes 0 No Custom alignment: RH    |
| 89 | hemi               | Hemiplegia  | radio 1 Yes 0 No Custom alignment: RH    |
| 90 | hepatic_mild       | Hepatic disease (mild) Cirrhosis without PHT, chronic hepatitis   | radio 1 Yes 0 No Custom alignment: RH    |
| 91 | hepatic_mods<br>ev | Hepatic disease (moderate or severe)  | radio<br>1 Yes                           |

|     |                      | Chirrosis with PHT +/- variceal bleeding  | 0 No                                     |
|-----|----------------------|---|--|
|     |                      |   | Custom alignment: RH                     |
| 92  | diabetes_mild<br>mod | Diabetes (mild or moderate)  Diabetes with medication   | radio 1 Yes 0 No                         |
|     |                      |   | Custom alignment: RH                     |
| 93  | diabetes_sev         | Diabetes (severe with end organ damage) Diabetes with Retinopathy, Neuropathy, or Nephropathy                   | radio 1 Yes 0 No                         |
|     |                      |   | Custom alignment: RH                     |
| 94  | pulmdz               | Pulmonary disease (moderate or severe) Symptomatic dyspnea due to chronic respiratory conditions                | radio 1 Yes 0 No                         |
|     |                      |   | Custom alignment: RH                     |
| 95  | contissuedz          | Connective tissue disease<br>SLE, polymyositis, mixed CTD,<br>polymyalgia rheumatica, moderate to<br>severe RA  | radio 1 Yes 0 No                         |
|     |                      |   | Custom alignment: RH                     |
| 96  | renaldz              | Renal disease (moderate or severe)  Creatinine >3 mg/dl (265_mol/l), dialysis, transplantation, uremic syndrome | radio 1 Yes 0 No                         |
|     |                      |   | Custom alignment: RH                     |
| 97  | leuk                 | Leukemia<br>Including acute or chronic leukemias  | radio  1 Yes  0 No  Custom alignment: RH |
| 9,2 | lymph                | Lymphoma  | radio                                    |
| 90  | ι γπιρπ              | Еутприотпа  | 1 Yes 0 No                               |
|     |                      |   | Custom alignment: RH                     |
| 99  | maligsolidtum        | Solid Tumor (without  | radio                                    |

|    | _nomets  | metastases) Initially treated in the last 5 years. Exclude non-melanomatous skin cancers and in situ cervical carcinoma   | 1 Yes 0 No Custom alignment: RH  |  |  |  |
|----|--|---|--|--|--|--|
| 10 | Omaligsolidtum<br>_withmets  | Solid Tumor (with metastases)  Metastatic solid tumors  | radio 1 Yes 0 No   |  |  |  |
| 10 | 1aids  | AIDS Defined as the presence of HIV infection, with either a CD4 count below 200 or an AIDS-defining illness such as pneumocystis pneumonia, HIV-related lymphoma, fungal infection with cryptococcus, etc. | radio 1 Yes 0 No Custom alignment: RH  |  |  |  |
| 10 | 2demographics<br>_and_disease_<br>characteristics<br>_crf_complete | Section Header: Form Status Complete?   | dropdown  0 Incomplete  1 Unverified  2 Complete   |  |  |  |
| In | nstrument: Mds   | Diagnosis (mds_diagnosis)   |  |  |  |  |
| 10 | 3mds_dx  | Date of MDS Diagnosis  Pathologic diagnosis date (usually by bone marrow); mm/dd/yyyy   | text, Identifier   |  |  |  |
| 10 | 4mds_subtype   | MDS Subtype   | dropdown   |  |  |  |
|    |  | Check only one. Patients with CMML are not eligible (aka CMMoL); Patients with overlap disorders (myelodsplactic  | 1 Refractory anemia (RA)   |  |  |  |
|    |  | syndromes/myeloproliferative neoplasma [MDS/MPN]) are not eligible.   | 2 Refractory   |  |  |  |
|    |  |   | 2 Refractory cytopenia with unilineage dysplasia (RCUD)  |  |  |  |
|    |  |   | cytopenia with unilineage dysplasia  |  |  |  |
|    |  |   | cytopenia with unilineage dysplasia (RCUD)  3 Refractory cytopenia with multilineage   |  |  |  |
|    |  |   | cytopenia with unilineage dysplasia (RCUD)  3 Refractory cytopenia with multilineage dysplasia (RCMD)  4 Refractory anemia with ring |  |  |  |

|    |   |  | 7           |                         | syndrome<br>associated with<br>del(5q)   |  |
|----|---|--|-------------|-------------------------|--|--|
|    |   |  |             |                         | Myelodysplastic<br>syndrome,<br>unclassifiable   |  |
|    |   |  | 99          | 99                      | Unknown  |  |
| 10 | 5raeb Show the field ONLY if: [mds_subtype] = '5' | RAEB   | 1<br>2<br>3 | 2 RAEB-2 (10-19% blasts |  |  |
| 10 | 6hgb_dx   | Hemoglobin<br>At time of diagnosis   | tex         | άt                      |  |  |
| 10 | 7hct_dx   | Hematocrit At time of diagnosis  | tex         | άt                      |  |  |
| 10 | 8wbc_dx   | White Blood Cell Count At time of diagnosis  | tex         | αt                      |  |  |
| 10 | 9anc_dx   | Absolute Neutrophil Count At time of diagnosis   | tex         | αt                      |  |  |
| 11 | Oplts_dx  | Platelet Count<br>At time of diagnosis   | tex         | αt                      |  |  |
| 11 | 1bmblasts_dx                                      | Bone Marrow Blast % Blast percentages highter then 20 should be suspect for AML. Contact investigators for verification that the patient should be enrolled. | tex         | αt                      |  |  |
| 11 | 2cytocat_dx                                       | Cytogenetic Category   | rac         | oib                     |  |  |
|    |   | (karyotype)  | 1           |                         | Very Good (-Y or<br>del(11q) [can have<br>only 1 of these to fit<br>into this category])   |  |
|    |   |  | 2           |                         | Good (Normal<br>karyotype, del(5q),<br>del(12p), any double<br>that includes del(5q)<br>[can have only 1 of<br>these to fit into this<br>category] |  |
|    |   |  | 3           |                         | Intermediate<br>(del(7q), +8, +19,<br>i(17q) [can have<br>only 1 of these OR,<br>any other single or<br>double independent                         |  |

|    |                             |  |         | clones])   |
|----|-----------------------------|--|---------|--|
|    |                             |  | 4       | Poor (-7, inv3/t3q/deleq) [can have only 1 of these OR, any double that includes -7 or del(7q) OR complex karoytype with exactly 3 unrelated abnormalities |
|    |                             |  | 5       | Very Poor (Complex karyotype with > 3 unrelated abnormalities)   |
|    |                             |  | 999     | Unknown  |
| 11 | 3ipss_ipssr_date            | Date IPSS / IPSS-R   | text, l | dentifier  |
| 11 | 4ipss_ipssr                 | IPSS or IPSS-R Score?  | radio   |  |
|    |                             |  | 1       | IPSS   |
|    |                             |  | 2       | IPSS-R   |
|    |                             |  | 999     | Unknown/Can't Tell   |
| 11 | 5score                      | IPSS / IPSS-R Score  | text    |  |
| 11 | 6cat                        | IPSS / IPSS-R Category<br>This will be something like "high risk" or<br>"Interdediate-2" | text    |  |
| 11 | 7ageadjipssr_sc<br>ore      | Age-adjusted IPSS-R Score Use website to calculate if necessary                          | text    |  |
| 11 | &ageadjipssr_ca<br>t        | Age-adjusted IPSS-R Category Use website to calculate if necessary                       | text    |  |
| 11 | 9wpss_dx                    | WPSS   | radio   |  |
|    |                             |  | 1       | Very low risk  |
|    |                             |  | 2       | Low risk   |
|    |                             |  | 3       | Intermediate risk  |
|    |                             |  | 4       | High risk  |
|    |                             |  | 5       | Very high risk   |
|    |                             |  | 999     | Unknown  |
| 12 | Omds_diagnosis<br>_complete | Section Header: Form Status  Complete?   | 1 U     | down<br>ncomplete<br>Inverified<br>omplete   |

| 21visitdate     | Visit Date   | text | (date_mdy), ldentifier |    |                                      |
|-----------------|--|------|------------------------|----|--------------------------------------|
| 22disthermo     | 22disthermo Distress Thermometer [0-10]  |      | odown                  |    |                                      |
|                 |  | 0    | 0                      |    |                                      |
|                 |  | 1    | 1                      |    |                                      |
|                 |  | 2    | 2                      |    |                                      |
|                 |  | 3    | 3                      |    |                                      |
|                 |  | 4    | 4                      |    |                                      |
|                 |  | 5    | 5                      |    |                                      |
|                 |  | 6    | 6                      |    |                                      |
|                 |  | 7    | 7                      |    |                                      |
|                 |  | 8    | 8                      |    |                                      |
|                 |  | 9    | 9                      |    |                                      |
|                 |  | 10   | 10                     |    |                                      |
|                 |  | 11   | Not Done               |    |                                      |
| 23disthermo_pro | _pro Distress Thermometer Problem List Check problems participant reports at this visit. | che  | kbox                   |    |                                      |
| blist           |  | 1    | disthermo_problist     | 1  | Child Care                           |
|                 |  | 2    | disthermo_problist:    | 2  | Housing                              |
|                 |  | 3    | disthermo_problist:    | 3  | Insurance/Financial                  |
|                 |  | 4    | disthermo_problist     | 4  | Transportation                       |
|                 |  | 5    | disthermo_problist     | 5  | Work/School                          |
|                 |  | 6    | disthermo_problist     | 5  | Treatment decisions                  |
|                 |  | 7    | disthermo_problist     | 7  | Dealing with children                |
|                 |  | 8    | disthermo_problist     | 3  | Dealing with partner                 |
|                 |  | 9    | disthermo_problist     | 9  | Ability to have children             |
|                 |  | 10   | disthermo_problist     | 10 | Family health issues                 |
|                 |  | 11   | disthermo_problist     | 11 | Depression                           |
|                 |  | 12   | disthermo_problist     | 12 | Fears                                |
|                 |  | 13   | disthermo_problist     | 13 | Nervousness                          |
|                 |  | 14   | disthermo_problist     | 14 | Sadness                              |
|                 |  | 15   | disthermo_problist     | 15 | Worry                                |
|                 |  | 16   | disthermo_problist     | 16 | Loss of interest in usual activities |
|                 |  | 17   | disthermo_problist     | 17 | Spiritual/religious                  |

|                           | 10 -  |  | concerns                  |
|---------------------------|---|--|---------------------------|
|                           | 18 c  | disthermo_problist18   | Appearance                |
|                           | <del>                                  </del>                                 | disthermo_problist19   | Bathing/dressing          |
|                           |   | disthermo_problist20   | Breathing                 |
|                           | <del>                                  </del>                                 |  | Changes in urination      |
|                           |   | ·  |                           |
|                           |   | ·  |                           |
|                           | <del>                                  </del>                                 |  |                           |
|                           |   | ·  | Fatigue                   |
|                           | <del>                                  </del>                                 |  |                           |
|                           | 27 d  | disthermo_problist27   | Fevers                    |
|                           | 28 d  | disthermo_problist28   | Getting around            |
|                           | 29 d  | disthermo_problist29   | Indigestion               |
|                           | 30 d  | disthermo_problist30   | Memory/concentration      |
|                           | 31 d  | disthermo_problist31   | Mouth sores               |
|                           | 32 d  | disthermo_problist32   | Nausea                    |
|                           | 33 d  | disthermo_problist33   | Dry nose/congested        |
|                           | 34 d  | disthermo_problist34   | Pain                      |
|                           | 35 d  | disthermo_problist35   | Sexual                    |
|                           | 36 d  | disthermo_problist36   | Skin dry/itching          |
|                           | 37 d  | disthermo_problist37   | Sleep                     |
|                           | 38 d  | disthermo_problist38   | Substance abuse           |
|                           | 39 d  | disthermo_problist39   | Tingling in hands/feet    |
|                           | 40 d  | disthermo_problist40   | No problems reported      |
| Hemoglobin                | text  |  |                           |
| Hematocrit                | text  |  |                           |
| White Blood Cell Count    | text  |  |                           |
| Absolute Neutrophil Count | text  |  |                           |
| Platelet Count            | text  |  |                           |
| On treatment for MDS?     | 11  | Yes No Unknown   |                           |
|                           | Hematocrit  White Blood Cell Count  Absolute Neutrophil Count  Platelet Count | 21   6   22   6   23   6   24   6   25   6   6   6   6   6   7   6   6   6   6 | 21   disthermo_problist21 |

|    |  |                          | Custo | m alignment: I | RH  |  |
|----|--|--------------------------|-------|----------------|---|--|
| 13 | Otxtype  | Indicate treatment       | check | box            |   |  |
|    | Show the field<br>ONLY if:<br>[treat]= '1'           |                          | 1     | txtype1        | Hypomo<br>Agent<br>[decitab<br>(Dacogo<br>azacitid<br>(Vidaza)            | n), 5-<br>ine  |
|    |  |                          | 2     | txtype2        | Oral Ago<br>[lenalido<br>(Revlim  | omide  |
|    |  |                          | 3     | txtype3        | Clinical  | Trial  |
|    |  |                          | 4     | txtype4        | ESAs (Pidarbepo<br>Aranesp<br>Thromb<br>(romiplo<br>plate,                | im,<br>en,<br>poietin /<br>rocrit, or<br>pietin,<br>o),<br>opoietin<br>ostim, N- |
|    |  |                          | 997   | txtype997      | cytarab<br>SQ), hig<br>chemot<br>(i.e. 7+3<br>induction<br>chemo)<br>cell | herapy<br>in   |
| 13 | 1oth_tx  | Other Treatment, specify | text  |                |   |  |
|    | Show the field<br>ONLY if:<br>[txtype(997)]= '<br>1' |                          |       |                |   |  |
| 13 | 2clintrial_tx  | Clinical Trial, specify  | text  |                |   |  |
|    | Show the field<br>ONLY if:<br>[txtype(3)]= '1'       |                          |       |                |   |  |
| 13 | Bironchel  | Iron chelation therapy?  | radio | <del></del>    |   |  |

|  | Review medication list for meds such as deferasirox (DFX, Exjade, Jadenu) , deferoxamine (Desferal), deferiprone | 1 Yes<br>0 No  |
|--|--|--|
|  | (DFP, Ferriprox)   | 999 Unknown  |
|  |  | Custom alignment: RH   |
| 134transfus  | Transfusions since last visit?   | radio  |
|  |  | 1 Yes  |
|  |  | 0 No   |
|  |  | 999 Unknown  |
|  |  | Custom alignment: RH   |
| 135transfus_freq   | Transfusion requirements as of   | radio  |
| Show the field   | this visit?  | 1 None   |
| ONLY if:<br>[transfus]='1'   |  | 2 Regularly (at least one transfusion every 8 weeks over a period of 3 months) |
|  |  | 999 Unknown frequency  |
| 136transfus_prod   | What type of blood products?   | checkbox   |
| Show the field   |  | 1 transfus_prod1 PRBC  |
| ONLY if:   |  | 2 transfus_prod2 Platele   |
| [transfus]='1'   |  | 997 transfus_prod997 Other   |
|  |  | 999 transfus_prod999 Unkno   |
| 137other_transfus  Show the field ONLY if: [transfus_prod (997)]='1' | Other, please specify  | text   |
| 138wpss  | WPSS   | radio  |
| . 50,,,,53   | 55   | 1 Very low risk  |
|  |  | 2 Low risk   |
|  |  | 3 Intermediate risk  |
|  |  | 4 High risk  |
|  |  | 5 Very high risk   |
|  |  | 999 Unknown  |
| 120000   | ECOC Porformance status  |  |
| 139ecog  | ECOG Performance status  | radio  |

|                   |                                   | 0 0                  |
|-------------------|-----------------------------------|----------------------|
|                   |                                   | 1 1                  |
|                   |                                   | 2 2                  |
|                   |                                   | 3 3                  |
|                   |                                   | 4 4                  |
|                   |                                   | 5 5                  |
|                   |                                   | 999 Unknown          |
|                   |                                   |                      |
|                   |                                   | Custom alignment: RH |
| 140kps            | Karnofsky Performance Status      | radio (Matrix)       |
|                   |                                   | 0 0                  |
|                   |                                   | 10 10                |
|                   |                                   | 20 20                |
|                   |                                   | 30 30                |
|                   |                                   | 40 40                |
|                   |                                   | 50 50                |
|                   |                                   | 60 60                |
|                   |                                   | 70 70                |
|                   |                                   | 80 80                |
|                   |                                   | 90 90                |
|                   |                                   | 100 100              |
|                   |                                   | 999 Unknown          |
| 141amlprogress    | Progression to AML                | radio                |
|                   |                                   | 1 Yes                |
|                   |                                   | 0 No                 |
|                   |                                   | 2 Suspicion for      |
|                   |                                   | 999 Unknown          |
|                   |                                   | Custom alignment: RH |
| 142last_visit     | Is this participant's last visit? | radio                |
|                   | , ,                               | 1 Yes                |
|                   |                                   | 0 No                 |
| 143visit_complete | Section Header: Form Status       | dropdown             |
|                   | Complete?                         | 0 Incomplete         |
|                   |                                   | 1 Unverified         |
|                   |                                   |                      |

|   |   |   | 2 Complete           |
|---|---|---|----------------------|
| In  | strument: <b>Heal</b>                       | thcare Utilization And Hea  | lth                  |
| Status (healthcare_utilization_and_health_status) |   |   |                      |
| 144alive  |   | Alive at end of study?  | radio                |
|   |   | End of study is defined as the last date IRB allows us to look in MRN; 09-30-2015 | 1 Yes                |
|   |   | THE UTIONS US to TOOK III IIIIU, OS SO ZOTS                                       | 0 No                 |
|   |   |   | 999 Unknown          |
|   |   |   | Custom alignment: RH |
| 14  | 5dod  | Enter date of death   | text, Identifier     |
|   | Show the field<br>ONLY if:<br>[alive]='0'   | mm/dd/yyyy  |                      |
| 14  | 6palcare                                    | Was the participant ever seen by  | radio                |
|   |   | palliative care? In the clinic, or via a consult in the hospital?                 | 1 Yes                |
|   |   | via a consaic in the hospital.  | 0 No                 |
|   |   |   | 999 Unknown          |
|   |   |   | Custom alignment: RH |
| 14  | 7counsel                                    | Was the participant ever  | radio                |
|   |   | referred for counseling or to see a therapist?                                    | 1 Yes                |
|   |   | ·   | 0 No                 |
|   |   |   | 999 Unknown          |
|   |   |   | Custom alignment: RH |
| 14  | 8hospice                                    | Did the participant enroll in hospice?  | radio                |
|   |   | nospice:  | 1 Yes                |
|   |   |   | 0 No                 |
|   |   |   | 999 Unknown          |
|   |   |   | Custom alignment: RH |
| 14  | 9hospdate                                   | Date enrolled in hospice  | text, Identifier     |
|   | Show the field<br>ONLY if:<br>[hospice]='1' | mm/dd/yyyy  |                      |
| 15  | 0hospit                                     | Any hospitalizations during   | radio                |
|   |   | study period?   | 1 Yes                |
|   |   |   |                      |

|    |   |  | 0 No 999 Unknown  Custom alignment: RH |
|----|---|--|--|
| 15 | 1numhospit  | Enter number of hospitalizations                           | text                                   |
| 15 | 2hospit_date1 Show the field ONLY if: [numhospit] > =1                    | Date 1 of hospitalizations  Date of Admisssion; mm/dd/yyyy | text, Identifier                       |
| 15 | 3hospit_reason<br>1<br>Show the field<br>ONLY if:<br>[numhospit] ><br>=1  | Reason for hospitalization                                 | text                                   |
| 15 | 4hospit_numda<br>ys1<br>Show the field<br>ONLY if:<br>[numhospit] ><br>=1 | Number of days in the hopsital for this admission          | text                                   |
| 15 | 5hospit_date2 Show the field ONLY if: [numhospit] > =2                    | Date 2 of hospitalizations  Date of Admisssion; mm/dd/yyyy | text, Identifier                       |
| 15 | 6hospit_reason 2 Show the field ONLY if: [numhospit] > =2                 | Reason for hospitalization                                 | text                                   |
| 15 | 7hospit_numda<br>ys2<br>Show the field<br>ONLY if:<br>[numhospit] ><br>=2 | Number of days in the hopsital for this admission          | text                                   |
| 15 | 8hospit_date3<br>Show the field<br>ONLY if:                               | Date 3 of hospitalizations  Date of Admisssion; mm/dd/yyyy | text, Identifier                       |

|    | [numhospit] ><br>=3   |  |                  |
|----|---|--|------------------|
| 15 | 9hospit_reason<br>3<br>Show the field<br>ONLY if:<br>[numhospit] ><br>=3  | Reason for hospitalization                                 | text             |
| 16 | Ohospit_numda<br>ys3<br>Show the field<br>ONLY if:<br>[numhospit] ><br>=3 | Number of days in the hopsital for this admission          | text             |
| 16 | 1hospit_date4 Show the field ONLY if: [numhospit] > =4                    | Date 4 of hospitalizations  Date of Admisssion; mm/dd/yyyy | text, Identifier |
| 16 | 2hospit_reason<br>4<br>Show the field<br>ONLY if:<br>[numhospit] ><br>=4  | Reason for hospitalization                                 | text             |
| 16 | Shospit_numda<br>ys4<br>Show the field<br>ONLY if:<br>[numhospit] ><br>=4 | Number of days in the hopsital for this admission          | text             |
| 16 | 4hospit_date5 Show the field ONLY if: [numhospit] > =5                    | Date 5 of hospitalizations  Date of Admisssion; mm/dd/yyyy | text, Identifier |
|    | 5hospit_reason 5 Show the field ONLY if: [numhospit] > =5                 | Reason for hospitalization                                 | text             |
| 16 | 6hospit_numda   | Number of days in the hopsital                             | text             |

|    | ys5   | for this admission   |   |
|----|---|--|---|
|    | Show the field<br>ONLY if:<br>[numhospit] ><br>=5                         |  |   |
| 16 | 7hospit_date6 Show the field ONLY if: [numhospit] > =6                    | Date 6 of hospitalizations  Date of Admisssion; mm/dd/yyyy | text, Identifier                                      |
| 16 | 8hospit_reason<br>6<br>Show the field<br>ONLY if:<br>[numhospit] ><br>=6  | Reason for hospitalization                                 | text  |
| 16 | 9hospit_numda<br>ys6<br>Show the field<br>ONLY if:<br>[numhospit] ><br>=6 | Number of days in the hopsital for this admission          | text  |
| 17 | 0edvisits   | Emergency Department visits during study period?           | radio  1 Yes  0 No  999 Unknown  Custom alignment: RH |
| 17 | 1num_edvisits   | Enter number of emergency department visits                | text  |
| 17 | 2visit_date1  Show the field  ONLY if:  [num_edvisits] >=1                | Date of emergency department visit                         | text, Identifier                                      |
| 17 | 3visit_reason1 Show the field ONLY if: [num_edvisits] >=1                 | Reason for emergency<br>department visit                   | text  |
| 17 | 4visit_date2  | Date of emergency department visit                         | text, Identifier                                      |

| Show the field<br>ONLY if:<br>[num_edvisits]<br>>=2            |  |                  |
|--|--|------------------|
| 175visit_reason2  Show the field  ONLY if:  [num_edvisits] >=2 | Reason for emergency<br>department visit | text             |
| 176visit_date3  Show the field ONLY if: [num_edvisits] >=3     | Date of emergency department visit       | text, Identifier |
| 177visit_reason3  Show the field ONLY if: [num_edvisits] >=3   | Reason for emergency department visit    | text             |
| 178visit_date4  Show the field  ONLY if:  [num_edvisits] >=4   | Date of emergency department visit       | text, Identifier |
| 179visit_reason4  Show the field  ONLY if:  [num_edvisits] >=4 | Reason for emergency<br>department visit | text             |
| 180visit_date5  Show the field ONLY if: [num_edvisits] >=5     | Date of emergency department visit       | text, Identifier |
| 181visit_reason5  Show the field ONLY if: [num_edvisits] >=5   | Reason for emergency<br>department visit | text             |
| 182visit_date6 Show the field ONLY if:                         | Date of emergency department visit       | text, Identifier |

|    | [num_edvisits] >=6   |  |  |
|----|--|--|--|
| 18 | 3visit_reason6 Show the field ONLY if: [num_edvisits] >=6      | Reason for emergency<br>department visit | text   |
| 18 | 4healthcare_util<br>ization_and_he<br>alth_status_co<br>mplete | Section Header: Form Status  Complete?   | dropdown  0 Incomplete  1 Unverified  2 Complete |