

Demographics And Disease Characteristics Crf

Participant ID _____

Date CRF Completed _____

CRF Completed By ☐  ☐ Other

Other Abstractor, Please Specify _____

Medical Record Number _____

First Name _____

Last Name _____

Date of Birth _____

Gender ☐ Male
☐ Female

Race ☐ White
☐ Black or African American
☐ Asian
☐ Native Hawaiian or other Pacific Islander
☐ American Indian or Alaska Native
☐ Other
☐ Not Reported
☐ Unknown

Other Race, Please Specify _____

Ethnicity ☐ Hispanic or Latino
☐ Not Hispanic or Latino
☐ Unknown

Marital Status Code ☐ Married
☐ Separated/Divorced
☐ Widowed
☐ Single (never married)
☐ Unknown

Health Insurance Status Code ☐ Medicare
☐ Medicaid
☐ Military/Veteran/Champus
☐ Private payer(e.g. Blue Cross/Blue Shield/HMO/Aetna)
☐ Other
☐ Unknown

Other Health Insurance, Please Specify _____

Has participant ever had cancer (excluding basal or squamous cell skin cancer)? ☐ Yes
☐ No

If Yes, check all that apply

- ☐ Anal
- ☐ Bladder
- ☐ Bone and joint
- ☐ Brain or other nervous system
- ☐ Breast
- ☐ Cervix uteri
- ☐ Colon
- ☐ Endometrial
- ☐ Esophagus
- ☐ Kidney and renal pelvis
- ☐ Larynx
- ☐ Liver and intrahepatic bile duct
- ☐ Lung and bronchus
- ☐ Lymphoma, Hodgkin
- ☐ Lymphoma, Non-Hodgkin
- ☐ Leukemia, ALL
- ☐ Leukemia, AML
- ☐ Leukemia, CLL
- ☐ Leukemia, CML
- ☐ Melanoma of the skin
- ☐ Myeloma
- ☐ Oral cavity and pharynx cancer
- ☐ Ovary
- ☐ Pancreas
- ☐ Prostate
- ☐ Small Intestine
- ☐ Stomach
- ☐ Testis
- ☐ Thyroid
- ☐ Vulva
- ☐ Other site
- ☐ Unknown site
- ☐

(For participants with history of multiple cancers, list the most recent cancer. For participants who presented with multiple primary tumors check all that apply.)

Anal

Year Anal cancer diagnosed

(yyyy)

Anal Cancer treatment received

- ☐ Radiation
- ☐ Chemotherapy
- ☐ Surgery
- ☐ Bone marrow or other stem cell transplant
- ☐ None
- ☐ Unknown

Bladder

Year Bladder cancer diagnosed

(yyyy)

Bladder Cancer treatment received

- ☐ Radiation
- ☐ Chemotherapy
- ☐ Surgery
- ☐ Bone marrow or other stem cell transplant
- ☐ None
- ☐ Unknown

Bone and joint

Year Bone and joint cancer diagnosed

(yyyy)

Bone and joint cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Brain or other nervous system

Year Brain or other nervous system cancer diagnosed

(yyyy)

Brain or other nervous system cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Breast

Year Breast cancer diagnosed

(yyyy)

Breast cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Cervix Uteri

Year Cervix Uteri cancer diagnosed

(yyyy)

Cervix Uteri Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Colon and rectum

Year Colon and rectum cancer diagnosed

(yyyy)

Colon and rectum Cancer treatment received

- ☐ Radiation
- ☐ Chemotherapy
- ☐ Surgery
- ☐ Bone marrow or other stem cell transplant
- ☐ None
- ☐ Unknown

Endometrial

Year Endometrial cancer diagnosed

(yyyy)

Endometrial Cancer treatment received

- ☐ Radiation
- ☐ Chemotherapy
- ☐ Surgery
- ☐ Bone marrow or other stem cell transplant
- ☐ None
- ☐ Unknown

Esophagus

Year Esophagus cancer diagnosed

(yyyy)

Esophagus Cancer treatment received

- ☐ Radiation
- ☐ Chemotherapy
- ☐ Surgery
- ☐ Bone marrow or other stem cell transplant
- ☐ None
- ☐ Unknown

Kidney and Renal Pelvis

Year Kidney and Renal Pelvis cancer diagnosed

(yyyy)

Kidney and Renal Pelvis Cancer treatment received

- ☐ Radiation
- ☐ Chemotherapy
- ☐ Surgery
- ☐ Bone marrow or other stem cell transplant
- ☐ None
- ☐ Unknown

Larynx

Year Larynx cancer diagnosed

(yyyy)

Larynx Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Liver and intrahepatic bile duct

Year Liver and intrahepatic bile duct cancer diagnosed

(yyyy)

Liver and intrahepatic bile duct Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Lung and Bronchus

Year Lung and Bronchus cancer diagnosed

(yyyy)

Lung and Bronchus Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Lymphoma, Hodgkin

Year Lymphoma, Hodgkin cancer diagnosed

(yyyy)

Lymphoma, Hodgkin Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Lymphoma, Non-Hodgkin

Year Lymphoma, Non-Hodgkin cancer diagnosed

(yyyy)

Lymphoma, Non-Hodgkin Cancer treatment received

- ☐ Radiation
- ☐ Chemotherapy
- ☐ Surgery
- ☐ Bone marrow or other stem cell transplant
- ☐ None
- ☐ Unknown

Leukemia, ALL

Year Leukemia, ALL cancer diagnosed

(yyyy)

Leukemia, ALL Cancer treatment received

- ☐ Radiation
- ☐ Chemotherapy
- ☐ Surgery
- ☐ Bone marrow or other stem cell transplant
- ☐ None
- ☐ Unknown

Leukemia, AML

Year Leukemia, AML cancer diagnosed

(yyyy)

Leukemia, AML Cancer treatment received

- ☐ Radiation
- ☐ Chemotherapy
- ☐ Surgery
- ☐ Bone marrow or other stem cell transplant
- ☐ None
- ☐ Unknown

Leukemia, CLL

Year Leukemia, CLL cancer diagnosed

(yyyy)

Leukemia, CLL Cancer treatment received

- ☐ Radiation
- ☐ Chemotherapy
- ☐ Surgery
- ☐ Bone marrow or other stem cell transplant
- ☐ None
- ☐ Unknown

Leukemia, CML

Year Leukemia, CML cancer diagnosed

(yyyy)

Leukemia, CML Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Melanoma of the skin

Year Melanoma of the skin cancer diagnosed

(yyyy)

Melanoma of the skin Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Myeloma

Year Myeloma cancer diagnosed

(yyyy)

Myeloma Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Oral cavity and pharynx cancer

Year Oral cavity and pharynx cancer cancer diagnosed

(yyyy)

Oral cavity and pharynx cancer Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Ovary

Year Ovary cancer diagnosed

(yyyy)

Ovary Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Pancreas

Year Pancreas cancer diagnosed

(yyyy)

Pancreas Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Prostate

Year Prostate cancer diagnosed

(yyyy)

Prostate Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Small Intestine

Year Small intestine cancer diagnosed

(yyyy)

Small intestine Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Stomach

Year Stomach cancer diagnosed

(yyyy)

Stomach Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Testis

Year Testis cancer diagnosed

(yyyy)

Testis Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Thyroid

Year Thyroid cancer diagnosed

(yyyy)

Thyroid Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Vulva

Year Vulva cancer diagnosed

(yyyy)

Vulva Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Other site

Other site , please specify _____

Other site

Year Other site cancer diagnosed _____

(yyyy)

Other site Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Unknown site

Year Unknown site cancer diagnosed _____

(yyyy)

Unknown site Cancer treatment received

- ☐ Radiation
☐ Chemotherapy
☐ Surgery
☐ Bone marrow or other stem cell transplant
☐ None
☐ Unknown

Charlston Comorbidity Index

Myocardial Infarction

- ☐ Yes ☐ No
(History of medically documented myocardial infarction)

Cerebrovascular disease

- ☐ Yes ☐ No
(History of TIA or CVA with no or minor sequelae)

Peripheral vascular disease

- ☐ Yes ☐ No
(Such as peripheral arterial disease / PAD, including symptomatic claudication)

Congestive heart failure

- ☐ Yes ☐ No
(Symptomatic CHF with response to specific treatment)

Dementia

- ☐ Yes ☐ No
(Any type: Alzheimers, vascular dementia, alcohol-related, but not mild cognitive impairment)

Ulcer

- ☐ Yes ☐ No
(Patients who have required treatment for Peptic Ulcerative Disease)

Hemiplegia

- ☐ Yes ☐ No

Hepatic disease (mild)

- ☐ Yes ☐ No
(Cirrhosis without PHT, chronic hepatitis)

- Hepatic disease (moderate or severe) ☐ Yes ☐ No
(Cirrhosis with PHT +/- variceal bleeding)
- Diabetes (mild or moderate) ☐ Yes ☐ No
(Diabetes with medication)
- Diabetes (severe with end organ damage) ☐ Yes ☐ No
(Diabetes with Retinopathy, Neuropathy, or Nephropathy)
- Pulmonary disease (moderate or severe) ☐ Yes ☐ No
(Symptomatic dyspnea due to chronic respiratory conditions)
- Connective tissue disease ☐ Yes ☐ No
(SLE, polymyositis, mixed CTD, polymyalgia rheumatica, moderate to severe RA)
- Renal disease (moderate or severe) ☐ Yes ☐ No
(Creatinine >3 mg/dl (265 µmol/l), dialysis, transplantation, uremic syndrome)
- Leukemia ☐ Yes ☐ No
(Including acute or chronic leukemias)
- Lymphoma ☐ Yes ☐ No
- Solid Tumor (without metastases) ☐ Yes ☐ No
(Initially treated in the last 5 years. Exclude non-melanomatous skin cancers and in situ cervical carcinoma)
- Solid Tumor (with metastases) ☐ Yes ☐ No
(Metastatic solid tumors)
- AIDS ☐ Yes ☐ No
(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.)

Mds Diagnosis

Date of MDS Diagnosis

(Pathologic diagnosis date (usually by bone marrow); mm/dd/yyyy)

MDS Subtype

- ☐ Refractory anemia (RA)
☐ Refractory cytopenia with unilineage dysplasia (RCUD)
☐ Refractory cytopenia with multilineage dysplasia (RCMD)
☐ Refractory anemia with ring sideroblasts (RARS)
☐ Refractory anemia with excess blasts (RAEB)
☐ Myelodysplastic syndrome associated with del(5q)
☐ Myelodysplastic syndrome, unclassifiable
☐ Unknown
 (Check only one. Patients with CMML are not eligible (aka CMMoL); Patients with overlap disorders (myelodysplastic syndromes/myeloproliferative neoplasia [MDS/MPN]) are not eligible.)

RAEB

- ☐ RAEB-1 (5-9% blasts)
☐ RAEB-2 (10-19% blasts)
☐ RAEB, unspecified

Hemoglobin

(At time of diagnosis)

Hematocrit

(At time of diagnosis)

White Blood Cell Count

(At time of diagnosis)

Absolute Neutrophil Count

(At time of diagnosis)

Platelet Count

(At time of diagnosis)

Bone Marrow Blast %

(Blast percentages higher than 20 should be suspect for AML. Contact investigators for verification that the patient should be enrolled.)

Cytogenetic Category (karyotype)

- ☐ Very Good (-Y or del(11q) [can have only 1 of these to fit into this category])
☐ Good (Normal karyotype, del(5q), del(12p), any double that includes del(5q) [can have only 1 of these to fit into this category])
☐ Intermediate (del(7q), +8, +19, i(17q) [can have only 1 of these OR, any other single or double independent clones])
☐ Poor (-7, inv3/t3q/deleq) [can have only 1 of these OR, any double that includes -7 or del(7q) OR complex karyotype with exactly 3 unrelated abnormalities]
☐ Very Poor (Complex karyotype with > 3 unrelated abnormalities)
☐ Unknown

Date IPSS / IPSS-R

IPSS or IPSS-R Score?

- ☐ IPSS
- ☐ IPSS-R
- ☐ Unknown/Can't Tell

IPSS / IPSS-R Score

IPSS / IPSS-R Category

(This will be something like "high risk" or "Intermediate-2")

Age-adjusted IPSS-R Score

(Use website to calculate if necessary)

Age-adjusted IPSS-R Category

(Use website to calculate if necessary)

WPSS

- ☐ Very low risk
- ☐ Low risk
- ☐ Intermediate risk
- ☐ High risk
- ☐ Very high risk
- ☐ Unknown

Visit

Visit Date _____

Distress Thermometer [0-10]

- ☐ 0
☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10
☐ Not Done

Distress Thermometer Problem List

- ☐ Child Care
☐ Housing
☐ Insurance/Financial
☐ Transportation
☐ Work/School
☐ Treatment decisions
☐ Dealing with children
☐ Dealing with partner
☐ Ability to have children
☐ Family health issues
☐ Depression
☐ Fears
☐ Nervousness
☐ Sadness
☐ Worry
☐ Loss of interest in usual activities
☐ Spiritual/religious concerns
☐ Appearance
☐ Bathing/dressing
☐ Breathing
☐ Changes in urination
☐ Constipation
☐ Diarrhea
☐ Eating
☐ Fatigue
☐ Feeling swollen
☐ Fevers
☐ Getting around
☐ Indigestion
☐ Memory/concentration
☐ Mouth sores
☐ Nausea
☐ Dry nose/congested
☐ Pain
☐ Sexual
☐ Skin dry/itching
☐ Sleep
☐ Substance abuse
☐ Tingling in hands/feet
☐ No problems reported
(Check problems participant reports at this visit.)

Hemoglobin _____

Hematocrit _____

White Blood Cell Count _____

Absolute Neutrophil Count

Platelet Count

On treatment for MDS?

☐ Yes ☐ No ☐ Unknown

Indicate treatment

- ☐ Hypomethylating Agent [decitabine (Dacogen), 5-azacitidine (Vidaza)]
- ☐ Oral Agent [lenalidomide (Revlimid)]
- ☐ Clinical Trial
- ☐ Growth Factor Shots [G-CSF (filgrastim, Neupogen, Granix), Erythropoietin / ESAs (Procrit, or darbepoietin, Aranesp), Thrombopoietin (romiplostim, N-plate, eltrombopag, or Promacta)]
- ☐ Other [low-dose cytarabine (IV or SQ), high-dose chemotherapy (i.e. 7+3 induction chemo), stem cell transplantation]

Other Treatment, specify

Clinical Trial, specify

Iron chelation therapy?

☐ Yes ☐ No ☐ Unknown

(Review medication list for meds such as deferasirox (DFX, Exjade, Jadenu) , deferoxamine (Desferal), deferiprone (DFP, Ferriprox))

Transfusions since last visit?

☐ Yes ☐ No ☐ Unknown

Transfusion requirements as of this visit?

- ☐ None
- ☐ Regularly (at least one transfusion every 8 weeks over a period of 3 months)
- ☐ Unknown frequency

What type of blood products?

- ☐ PRBC
- ☐ Platelets
- ☐ Other
- ☐ Unknown

Other, please specify

WPSS

- ☐ Very low risk
- ☐ Low risk
- ☐ Intermediate risk
- ☐ High risk
- ☐ Very high risk
- ☐ Unknown

ECOG Performance status

- ☐ 0 ☐ 1 ☐ 2 ☐ 3
- ☐ 4 ☐ 5 ☐ Unknown

	0	10	20	30	40	50	60	70	80	90	100	Unkn own
Karnofsky Performance Status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Progression to AML

☐ Yes ☐ No ☐ Suspicion for

☐ Unknown

Is this participant's last visit?

☐ Yes

☐ No

Healthcare Utilization And Health Status

Alive at end of study?

☐ Yes ☐ No ☐ Unknown
(End of study is defined as the last date IRB allows us to look in MRN; 09-30-2015)

Enter date of death

(mm/dd/yyyy)

Was the participant ever seen by palliative care? In the clinic, or via a consult in the hospital?

☐ Yes ☐ No ☐ Unknown

Was the participant ever referred for counseling or to see a therapist?

☐ Yes ☐ No ☐ Unknown

Did the participant enroll in hospice?

☐ Yes ☐ No ☐ Unknown

Date enrolled in hospice

(mm/dd/yyyy)

Any hospitalizations during study period?

☐ Yes ☐ No ☐ Unknown

Enter number of hospitalizations

Date 1 of hospitalizations

(Date of Admission; mm/dd/yyyy)

Reason for hospitalization

Number of days in the hospital for this admission

Date 2 of hospitalizations

(Date of Admission; mm/dd/yyyy)

Reason for hospitalization

Number of days in the hospital for this admission

Date 3 of hospitalizations

(Date of Admission; mm/dd/yyyy)

Reason for hospitalization

Number of days in the hospital for this admission

Date 4 of hospitalizations

(Date of Admission; mm/dd/yyyy)

Reason for hospitalization

Number of days in the hospital for this admission

Date 5 of hospitalizations

(Date of Admission; mm/dd/yyyy)

Reason for hospitalization

Number of days in the hospital for this admission

Date 6 of hospitalizations

(Date of Admission; mm/dd/yyyy)

Reason for hospitalization

Number of days in the hospital for this admission

Emergency Department visits during study period?

☐ Yes ☐ No ☐ Unknown

Enter number of emergency department visits

Date of emergency department visit

Reason for emergency department visit

Date of emergency department visit

Reason for emergency department visit

Date of emergency department visit

Reason for emergency department visit

Date of emergency department visit

Reason for emergency department visit

Date of emergency department visit

Reason for emergency department visit

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Reason for emergency department visit
