Disease Assessment at Diagnosis

1. What was the date of diagnosis of myelodysplastic / myeloproliferative disorder?

2. What was the MDS / MPS subtype at diagnosis?
   - refractory anemia (RA)
   - refractory anemia with ringed sideroblasts (RARS)
   - refractory anemia with excess blasts (RAEB-1)
   - refractory anemia with excess blasts in transformation (RAEB-2)
   - refractory cytopenia with multilineage dysplasia (RCMD)
   - refractory anemia with ringed sideroblasts with dysplasia (RCMD-RS)
   - 5q– syndrome
   - MDS unclassifiable, not otherwise specified
   - chronic myelomonocytic leukemia (CMMoL)
   - chronic MPS disorder, not otherwise specified
   - chronic neutrophilic leukemia
   - chronic eosinophilic leukemia and hypereosinophilic syndrome
   - polycythemia vera (PCV)
   - chronic idiopathic myelofibrosis (with extramedullary hematopoiesis), myelofibrosis with myeloid metaplasia, acute myelofibrosis or myelosclerosis
   - essential or primary thrombocythemia

Questions followed by the symbol  indicate additional information necessary to complete the question is referenced in the forms instruction manual.

If this is a report of a second or subsequent transplant, check here and continue with question 181.

Disease Assessment at Diagnosis

1. What was the date of diagnosis of myelodysplastic / myeloproliferative disorder?

   Month Day Year

2. What was the MDS / MPS subtype at diagnosis?
   - refractory anemia (RA)
   - refractory anemia with ringed sideroblasts (RARS)
   - refractory anemia with excess blasts (RAEB-1)
   - refractory anemia with excess blasts in transformation (RAEB-2)
   - refractory cytopenia with multilineage dysplasia (RCMD)
   - refractory anemia with ringed sideroblasts with dysplasia (RCMD-RS)
   - 5q– syndrome
   - MDS unclassifiable, not otherwise specified
   - chronic myelomonocytic leukemia (CMMoL)
   - chronic MPS disorder, not otherwise specified
   - chronic neutrophilic leukemia
   - chronic eosinophilic leukemia and hypereosinophilic syndrome
   - polycythemia vera (PCV)
   - chronic idiopathic myelofibrosis (with extramedullary hematopoiesis), myelofibrosis with myeloid metaplasia, acute myelofibrosis or myelosclerosis
   - essential or primary thrombocythemia
This group is recognized as AML in this proposed classification; see question 25.

**Karyotype:**
- Good = normal, –Y, del(5q), del(20q)
- Intermediate = other abnormalities
- Poor = complex (≥ 3 abnormalities) or chromosome 7 abnormalities; see questions 33–96

***Cytopenias = Hb < 10 g/dL; platelets < 100 x 10⁹/L; neutrophils < 1500/µL; see questions 19–23

---

3. Was this a secondary (therapy-linked) disorder?
   - 1. yes
   - 2. no
   - 3. unknown

4. Specify prior disease (malignant or nonmalignant):
   - 1. breast cancer
   - 2. Hodgkin lymphoma
   - 3. non-Hodgkin lymphoma
   - 4. other disease
   - 5. unknown

5. Specify prior disease:

6. Date of diagnosis of prior disease:

   - Month
   - Day
   - Year

Treatment of prior disease included:
- 7. 1. yes
- 2. no
- 3. unknown

    - Chemotherapy

8. 1. yes
- 2. no
- 3. unknown

    - Radiation

9. 1. yes
- 2. no
- 3. unknown

    - Other treatment

11. Did the recipient have other predisposing conditions prior to diagnosis of the hematologic disorder?
   - 1. yes
   - 2. no
   - 3. unknown

12. Specify predisposing condition:
   - 1. aplastic anemia
   - 2. Bloom syndrome
   - 3. Down syndrome
   - 4. Fanconi anemia
   - 5. other condition

Also complete Form 2029 — FAN

13. Specify condition:

---

Questions 14–16 refer to MPS subtypes only (see question 2, options 9–15); if the diagnosis other than MPS, continue with question 17.

14. Did the recipient have systemic symptoms (e.g., fever, sweats, weight loss > 10%) at diagnosis?
   - 1. yes
   - 2. no
   - 3. unknown

15. Did the recipient have splenomegaly at diagnosis?
   - 1. yes
   - 2. no
   - 3. unknown

16. Did the recipient have hepatomegaly at diagnosis?
   - 1. yes
   - 2. no
   - 3. unknown

---

Question 17 refers to MDS only (see question 2, options 1–8); if the diagnosis other than MDS, continue with question 18.

17. What was the disease prognosis score at diagnosis? (see table below)

<table>
<thead>
<tr>
<th>International Prognostic Scoring System (IPSS) for MDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SCORE</strong></td>
</tr>
<tr>
<td>Prognostic variable:</td>
</tr>
<tr>
<td>Percent blasts:</td>
</tr>
<tr>
<td>Karyotype: **</td>
</tr>
<tr>
<td>Cytopenias: ***</td>
</tr>
</tbody>
</table>

* This group is recognized as AML in this proposed classification; see question 25
** Karyotype:
   - Good = normal, –Y, del(5q), del(20q)
   - Intermediate = other abnormalities
   - Poor = complex (≥ 3 abnormalities) or chromosome 7 abnormalities; see questions 33–96
*** Cytopenias = Hb < 10 g/dL; platelets < 100 x 10⁹/L; neutrophils < 1500/µL; see questions 19–23

Fax this form to your designated campus (Milwaukee 414-805-0714 or Minneapolis 612-627-5895).
Laboratory Studies at Diagnosis (Prior to the First Treatment for MDS / MPS)

18. WBC:
   1. ☐ known
   2. ☐ not known

19. Hemoglobin:
   1. ☐ known
   2. ☐ not known

21. Platelets:
   1. ☐ known
   2. ☐ not known

23. Neutrophils:
   1. ☐ known
   2. ☐ not known

24. Monocytes:
   1. ☐ known
   2. ☐ not known

25. Blasts in blood:
   1. ☐ known
   2. ☐ not known

26. Was a bone marrow examination performed at first diagnosis of hematologic disorder (reported at questions 1–2)?
   1. ☐ yes
   2. ☐ no

27. Cellularity:
   1. ☐ decreased
   2. ☐ normal
   3. ☐ increased
   4. ☐ unknown

28. Fibrosis:
   1. ☐ absent
   2. ☐ mild
   3. ☐ moderate
   4. ☐ severe
   5. ☐ unknown

29. Blasts in marrow:
   1. ☐ known
   2. ☐ not known

Specify units:
1. ☐ x 10⁹/L (x 10³/mm³)
2. ☐ x 10⁶/L

1. ☐ g/dL
2. ☐ g/L
3. ☐ mmol/L

20. Was RBC transfused < 30 days before date of test?
   1. ☐ yes
   2. ☐ no

22. Were platelets transfused < 7 days before date of test?
   1. ☐ yes
   2. ☐ no
30. Were cytogenetics tested (conventional or FISH)?

<table>
<thead>
<tr>
<th>Option</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>yes</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>no</td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>unknown</td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

31. Results of test at diagnosis:

- [ ] 1 yes abnormalities identified
- [ ] 2 no evaluable metaphases
- [ ] 3 no abnormalities

Continue with question 32

32. Results of tests after diagnosis and prior to the preparative regimen:

- [ ] 1 yes abnormalities identified
- [ ] 2 no evaluable metaphases on any tests
- [ ] 3 no abnormalities on any tests after diagnosis and before the preparative regimen

Complete questions 65–96 in the table below

Specify abnormalities identified:

<table>
<thead>
<tr>
<th>Cytogenetic abnormality</th>
<th>At diagnosis</th>
<th>Any test result between diagnosis and preparative regimen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monosomy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>–5</td>
<td>33. 1 yes 2 no</td>
<td>65. 1 yes 2 no</td>
</tr>
<tr>
<td>–7</td>
<td>34. 1 yes 2 no</td>
<td>66. 1 yes 2 no</td>
</tr>
<tr>
<td>–17</td>
<td>35. 1 yes 2 no</td>
<td>67. 1 yes 2 no</td>
</tr>
<tr>
<td>–18</td>
<td>36. 1 yes 2 no</td>
<td>68. 1 yes 2 no</td>
</tr>
<tr>
<td>–20</td>
<td>37. 1 yes 2 no</td>
<td>69. 1 yes 2 no</td>
</tr>
<tr>
<td>–X</td>
<td>38. 1 yes 2 no</td>
<td>70. 1 yes 2 no</td>
</tr>
<tr>
<td>–Y</td>
<td>39. 1 yes 2 no</td>
<td>71. 1 yes 2 no</td>
</tr>
<tr>
<td>Trisomy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>+4</td>
<td>40. 1 yes 2 no</td>
<td>72. 1 yes 2 no</td>
</tr>
<tr>
<td>+8</td>
<td>41. 1 yes 2 no</td>
<td>73. 1 yes 2 no</td>
</tr>
<tr>
<td>+11</td>
<td>42. 1 yes 2 no</td>
<td>74. 1 yes 2 no</td>
</tr>
<tr>
<td>+13</td>
<td>43. 1 yes 2 no</td>
<td>75. 1 yes 2 no</td>
</tr>
<tr>
<td>+14</td>
<td>44. 1 yes 2 no</td>
<td>76. 1 yes 2 no</td>
</tr>
<tr>
<td>+21</td>
<td>45. 1 yes 2 no</td>
<td>77. 1 yes 2 no</td>
</tr>
<tr>
<td>+22</td>
<td>46. 1 yes 2 no</td>
<td>78. 1 yes 2 no</td>
</tr>
<tr>
<td>Translocation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>t(3;3)</td>
<td>47. 1 yes 2 no</td>
<td>79. 1 yes 2 no</td>
</tr>
<tr>
<td>t(6;9)</td>
<td>48. 1 yes 2 no</td>
<td>80. 1 yes 2 no</td>
</tr>
<tr>
<td>t(8;21)</td>
<td>49. 1 yes 2 no</td>
<td>81. 1 yes 2 no</td>
</tr>
<tr>
<td>t(15;17) and variants</td>
<td>50. 1 yes 2 no</td>
<td>82. 1 yes 2 no</td>
</tr>
<tr>
<td>t(16;16)</td>
<td>51. 1 yes 2 no</td>
<td>83. 1 yes 2 no</td>
</tr>
<tr>
<td>Deletion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>del(5q) / 5q–</td>
<td>52. 1 yes 2 no</td>
<td>84. 1 yes 2 no</td>
</tr>
<tr>
<td>del(7q) / 7q–</td>
<td>53. 1 yes 2 no</td>
<td>85. 1 yes 2 no</td>
</tr>
<tr>
<td>del(9q) / 9q–</td>
<td>54. 1 yes 2 no</td>
<td>86. 1 yes 2 no</td>
</tr>
<tr>
<td>del(11q) / 11q–</td>
<td>55. 1 yes 2 no</td>
<td>87. 1 yes 2 no</td>
</tr>
<tr>
<td>del(17q) / 17q–</td>
<td>56. 1 yes 2 no</td>
<td>88. 1 yes 2 no</td>
</tr>
<tr>
<td>del(20q) / 20q–</td>
<td>57. 1 yes 2 no</td>
<td>89. 1 yes 2 no</td>
</tr>
<tr>
<td>Inversion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>inv(3)</td>
<td>58. 1 yes 2 no</td>
<td>90. 1 yes 2 no</td>
</tr>
<tr>
<td>inv(16)</td>
<td>59. 1 yes 2 no</td>
<td>91. 1 yes 2 no</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(11q23) balanced abnormality</td>
<td>60. 1 yes 2 no</td>
<td>92. 1 yes 2 no</td>
</tr>
<tr>
<td>12p any abnormality</td>
<td>61. 1 yes 2 no</td>
<td>93. 1 yes 2 no</td>
</tr>
<tr>
<td>complex (≥ 3 distinct abnormalities)</td>
<td>62. 1 yes 2 no</td>
<td>94. 1 yes 2 no</td>
</tr>
<tr>
<td>other abnormality</td>
<td>63. 1 yes 2 no</td>
<td>95. 1 yes 2 no</td>
</tr>
<tr>
<td>specify other abnormality</td>
<td>64. 1 yes 2 no</td>
<td>96. 1 yes 2 no</td>
</tr>
</tbody>
</table>

97. Is a copy of the cytogenetic or FISH report attached?

<table>
<thead>
<tr>
<th>Option</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>yes</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>
## ERROR CORRECTION FORM

### CIBMTR Recipient ID: 

### Initials: 

### CIBMTR Center Number: 

### CIBMTR Recipient ID: 

### CIBMTR Center Number: 

---

**Pre-HSCT Treatment for MDS / MPS**

98. Was therapy given between diagnosis and the start of the preparative regimen?

<table>
<thead>
<tr>
<th>Line of Therapy</th>
<th>1st Line of Therapy</th>
<th>2nd Line of Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systemic Therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date therapy started:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date therapy stopped:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indication for therapy:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date therapy started:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indication for therapy:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If code 4 “other,” specify:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Cytokines:**
  - erythropoietin (EPO) (any formulation)
  - G-CSF (any formulation)
  - GM-CSF
  - interleukin-3 (IL-3)
  - stem cell factor (SCF)
  - other cytokine
  - specify other cytokine

- **Other Therapy:**
  - decitabine (Dacogen)
  - deferiprone (Ferrithiol)
  - dermafagyl (Exjade)
  - deferoxamine (Desferal)
  - hydroxyurea (Droxia, Hydrea)
  - lenalidomide (Revlimid)
  - thalidomide (Thalomid)
  - lopatecan (Hycean)
  - other systemic therapy
  - specify other therapy

- **Best Response to Line of Therapy:**
  - CR
  - HI
  - NR / SD
  - HI-E
  - HI-N
  - AML

---

**Copy this page to report more than 2 lines of therapy; check here if additional pages are attached."**

Fax this form to your designated campus (Milwaukee 414-805-0714 or Minneapolis 612-627-5895).
Transformation

181. Did the recipient transform to a different MDS / MPS subtype prior to the preparative regimen?

1. yes
2. yes, with subsequent complete remission
3. no

182. Specify the MDS subtype at the time of HSCT; or if in complete remission, the most recent subtype:

1. refractory anemia (RA)
2. refractory anemia with ringed sideroblasts (RARS)
3. refractory anemia with excess blasts (RAEB-1)
4. refractory anemia with excess blasts in transformation (RAEB-2)
5. refractory cytopenia with multilineage dysplasia (RCMD)
6. refractory anemia with ringed sideroblasts with dysplasia (RCMD-RS)
7. 5q– syndrome
8. MDS unclassifiable, not otherwise specified
9. chronic myelomonocytic leukemia (CMMoL)
10. chronic MPS disorder, not otherwise specified
11. chronic neutrophilic leukemia
12. chronic eosinophilic leukemia and hypereosinophilic syndrome
13. polycythemia vera (PCV)
14. chronic idiopathic myelofibrosis (with extramedullary hematopoiesis), myelofibrosis with myeloid metaplasia, acute myelofibrosis or myelosclerosis
15. essential or primary thrombocythemia
16. transformed to AML

Specify the AML subtype on the CIBMTR form 2000 – Recipient Baseline Data at question 9.

Answer q. 183 and skip to the signature lines at q. 200.

183. Specify the date of the most recent transformation: 

Month Day Year

Most Recent Disease Assessment Prior to the Start of the Preparative Regimen

Questions 184–186 refer to MPS subtypes only (see question 2, options 9–15); if the diagnosis other than MPS, continue with question 187.

184. Did the recipient have systemic symptoms (e.g., fever, sweats, weight loss > 10%) just prior to the preparative regimen?

1. yes
2. no
3. unknown

185. Did the recipient have splenomegaly just prior to preparative regimen?

1. yes
2. no
3. splenectomy
4. unknown

186. Did the recipient have hepatomegaly just prior to preparative regimen?

1. yes
2. no
3. unknown

Laboratory Studies Prior to the Start of the Preparative Regimen

187. Monocytes in blood:

1. known %
2. not known

188. Blasts in blood:

1. known %
2. not known
189. Was a bone marrow examination performed prior to the start of the preparative regimen?

1. yes
2. no

190. Date of most recent bone marrow examination: [Month] [Day] [Year]

191. Cellularity:

1. decreased
2. normal
3. increased
4. unknown

192. Fibrosis:

1. absent
2. mild
3. moderate
4. severe
5. unknown

193. Blasts in marrow:

1. known
2. not known

Disease Status at the Last Assessment Prior to the Preparative Regimen

194. What was the disease status at the last evaluation prior to the preparative regimen? (see definitions on page 8)

1. never treated
2. complete remission
3. hematologic improvement
4. no response / stable disease
5. progression from hematologic improvement
6. relapse from complete remission
7. not assessed

195. Specify the cell line examined to determine HI status:

1. HI-E
2. HI-P
3. HI-N

196. Date of progression: [Month] [Day] [Year]

197. Date of relapse: [Month] [Day] [Year]

198. Specify reason: __________________________

199. Date of most recent assessment for disease status prior to the preparative regimen: [Month] [Day] [Year]

200. Signed: __________________________

Person completing form

Please print name: __________________________

Phone: (__________) __________________________

Fax: (__________) __________________________

E-mail address: __________________________
### Codes for Indication for Therapy

1. bone marrow failure (anemia, thrombocytopenia, neutropenia)
2. early evidence of progression to leukemia (increasing percentage of blasts)
3. induce complete remission (prior to bone marrow failure or evolution)
4. other indication; specify at line below reporting box

### Codes for Best Response to Line of Therapy

1. **complete remission (CR)** — requires all of the following, maintained for \( \geq 4 \) weeks:
   - bone marrow evaluation: \( < 5\% \) myeloblasts with normal maturation of all cell lines
   - peripheral blood evaluation: hemoglobin \( \geq 11 \) g/dL untransfused and without erythropoietin support; ANC \( \geq 1000 / mm^3 \) without myeloid growth factor support; platelets \( \geq 100 \times 10^9/L \) without thrombopoietic support; 0% blasts

2. **hematologic improvement (HI)** — requires one measurement of the following, maintained for \( \geq 8 \) weeks without ongoing cytotoxic therapy; specify which cell line was measured to determine HI response:
   - HI-E — hemoglobin increase of \( \geq 1.5 \) g/dL untransfused; for RBC transfusions performed for Hgb \( \leq 9.0 \), reduction in RBC units transfused in 8 weeks by \( \geq 4 \) units compared to the pre-treatment transfusion number in the previous 8 weeks
   - HI-P — for pre-treatment platelet count of \( > 20 \times 10^9/L \), platelet absolute increase of \( \geq 30 \times 10^9/L \); for pre-treatment platelet count of \( < 20 \times 10^9/L \), platelet absolute increase of \( \geq 20 \times 10^9/L \) and \( \geq 100\% \) from pre-treatment level
   - HI-N — neutrophil count increase of \( \geq 100\% \) from pre-treatment level and an absolute increase of \( \geq 500 / mm^3 \)

3. **no response / stable disease (NR / SD)** — does not meet the criteria for at least HI, but no evidence of disease progression

4. **progression from hematologic improvement (Prog from HI)** — requires at least one of the following, in the absence of another explanation (e.g., infection, bleeding, ongoing chemotherapy, etc.):
   - \( \geq 50\% \) reduction from maximum response levels in granulocytes or platelets
   - reduction in hemoglobin by \( \geq 1.5 \) g/dL
   - transfusion dependence

5. **relapse from complete remission (Rel from CR)** — requires at least one of the following:
   - return to pre-treatment bone marrow blast percentage
   - decrease of \( \geq 50\% \) from maximum response levels in granulocytes or platelets
   - transfusion dependence, or hemoglobin level \( \geq 1.5 \) g/dL lower than prior to therapy

6. **progression to AML (AML)** — \( \geq 20\% \) blasts in the bone marrow