CIBMTR®
CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH

2014: Myelodysplasia/Myeloproliferative Neoplasms (MDS/MPN) Pre-HCT Data

Registry Use Only
Sequence Number:

Date Received:

Key Fields	

CIBMTR Center Number: ___ ___ ___ ___ ___

CIBMTR Recipient ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___

Date of HCT for which this form is being completed: __ __ __ __ / __ __ / __ __
YYYY MM DD

HCT type (check all that apply) ☐ Autologous ☐ Allogeneic, unrelated ☐ Allogeneic, related

Product type (check all that apply) ☐ Bone marrow
☐ PBSC
☐ Single cord blood unit
☐ Multiple cord blood units
☐ Other product. Specify: _____

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CIBMTR Center Number: ___ ___ ___ ___ ___ CIBMTR Recipient ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___

Subsequent Transplant	

If this is a report of a second or subsequent transplant for the same disease subtype and this baseline disease insert has not been completed for the previous transplant (e.g. patient was on TED track for the prior HCT, prior HCT was autologous with no consent), begin the form at question one.
If this is a report of a second or subsequent transplant for a different disease, begin the form at question one.

Is this the report of a second or subsequent transplant for the same disease?

☐ yes - ***Go to question 123***

☐ no - ***Go to question 1***

Disease Assessment at Diagnosis	Questions: 1-18

1. What was the date of diagnosis? __ __ __ __ / __ __ / __ __
   YYYY MM DD

2. What was the MDS/MPN subtype?

   ☐ Refractory cytopenia with unilineage dysplasia (RCUD) (includes refractory anemia (RA)) (51)
   ☐ Refractory anemia with ringed sideroblasts (RARS) (55)
   ☐ Refractory anemia with excess blasts-1 (RAEB-1) (61)
   ☐ Refractory anemia with excess blasts-2 (RAEB-2) (62)
   ☐ Refractory cytopenia with multilineage dysplasia (RCMD) (64)
   ☐ Childhood myelodysplastic syndrome (Refractory cytopenia of childhood (RCC)) (68)
   ☐ Myelodysplastic syndrome with isolated del(5q) (5q– syndrome) (66)
   ☐ Myelodysplastic syndrome (MDS), unclassifiable (50)
   ☐ Chronic neutrophilic leukemia (165)
   ☐ Chronic eosinophilic leukemia, NOS (166)
   ☐ Essential thrombocythemia (includes primary thrombocytosis, idiopathic thrombocytosis, hemorrhagic thrombocythemia) (58)
   ☐ Polycythemia vera (PCV) (57)
   ☐ Primary myelofibrosis (includes chronic idiopathic myelofibrosis (CIMF), angiogenic myeloid metaplasia (AMM), myelofibrosis/sclerosis with myeloid metaplasia (MMM), idiopathic myelofibrosis) (167)
   ☐ Myeloproliferative neoplasm (MPN), unclassifiable (60)
   ☐ Chronic myelomonocytic leukemia (CMMoL) (54)
   ☐ Myelodysplastic/myeloproliferative neoplasm, unclassifiable (69)

3. Was the disease (MDS/MPN) therapy related?

   ☐ yes →
   ☐ no
   ☐ Unknown

   4. Specify prior disease
      ☐ Breast cancer
      ☐ Hodgkin lymphoma
      ☐ Non-Hodgkin lymphoma
      ☐ Other disease (malignant or nonmalignant) → 5. Specify other prior disease:

      _____

   6. Date of diagnosis of prior disease
      ☐ Known → 7. Date of diagnosis of prior disease: __ __ __ __ / __ __ / __ __
      ☐ Unknown YYYY MM DD

   Specify therapy for prior disease:

   8. Systemic therapy (chemotherapy) ☐ yes ☐ no ☐ Unknown
   9. Radiation ☐ yes ☐ no ☐ Unknown

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10. Other therapy
☐ yes → 11. Specify other therapy: _____
☐ no
☐ Unknown

12. Did the recipient have a predisposing condition?
☐ yes →
☐ no
☐ Unknown

13. Specifiy condition:
☐ Aplastic Anemia **- Also complete CIBMTR form 2028- APL**
☐ Bloom syndrome
☐ Down syndrome
☐ Fanconi anemia **- Also complete CIBMTR Form 2029 - FAN**
☐ Other condition → 14. Specify other condition: _____

15. Did the recipient receive any RBC transfusions at the time of diagnosis and/or during the first year post diagnosis?
☐ yes ☐ no ☐ Unknown

Questions 16-18 refer to MPN subtypes only; if the diagnosis was other than MPN, continue with question 19.

16. Were systemic symptoms (B symptoms) present? (unexplained fever > 38° C; or night sweats; unexplained weight loss > 10% body weight in six months before diagnosis)
☐ yes ☐ no ☐ Unknown

17. Did the recipient have splenomegaly (spleen palpable > 3 cm below left costal margin)?
☐ yes ☐ no ☐ Unknown

18. Did the recipient have hepatomegaly (liver edge palpable > 3 cm below right costal margin)?
☐ yes ☐ no ☐ Unknown

Laboratory Studies at Diagnosis

Questions: 19-39

19. Monocytes
☐ known →
☐ Unknown

20. ___ ___ %

21. Date sample collected: __ __ __ __ / __ __ / __ __
YYYY MM DD

22. Blasts in blood:
☐ known →
☐ Unknown

23. ___ ___ ___ %

24. Date sample collected: __ __ __ __ / __ __ / __ __
YYYY MM DD

25. Was a bone marrow examination performed?
☐ yes →
☐ no
☐ Unknown

26. Date sample collected: __ __ __ __ / __ __ / __ __
YYYY MM DD

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27. Cellularity
- ☐ Decreased (hypocellular)
- ☐ Normal (normocellular)
- ☐ Increased (hypercellular)
- ☐ Unknown

28. Fibrosis
- ☐ Present ☐ Absent ☐ Unknown

29. Were tests for molecular markers performed (e.g. PCR)?
- ☐ yes →
- ☐ no
- ☐ Unknown

30. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

31.	ASXL1	☐ Positive	☐ Negative	☐ Not Done
32.	JAK2 **(For MPN only)**	☐ Positive	☐ Negative	☐ Not Done
33.	ETV6	☐ Positive	☐ Negative	☐ Not Done
34.	EZH2	☐ Positive	☐ Negative	☐ Not Done
35.	P53	☐ Positive	☐ Negative	☐ Not Done
36.	RUNX1	☐ Positive	☐ Negative	☐ Not Done

37. Other molecular marker
- ☐ Positive →
- ☐ Negative →
- ☐ Not Done

38. Specify other molecular marker: _____

Copy questions 37 - 38 if needed for Other Molecular Marker

39. Was documentation submitted to the CIBMTR? ☐ yes ☐ no

Pre-HCT Therapy

Questions: 40-122

40. Was therapy given?
- ☐ yes →
- ☐ no

Specify laboratory findings immediately prior to this line of therapy:

41. WBC
- ☐ Known → 42. ___ ___ ___ ___ ___ ___ • ___ ☐ x 10^9/L (x 10^3/mm^3) ☐ x 10^6/L
- ☐ Unknown

43. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

44. Hemoglobin
- ☐ Known → 45. ___ ___ ___ ___ • ___ ___ ☐ g/dL ☐ g/L ☐ mmol/L
- ☐ Unknown

46. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

47. Was RBC transfused < 30 days before date of test? ☐ yes ☐ no

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48. Platelets

☐ Known → 49. ___ ___ ___ ___ ___ ___ ___ ☐ x 10^9/L (x 10^3/mm^3) ☐ x 10^6/L

☐ Unknown

50. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

51. Were platelets transfused < 7 days before date of test? ☐ yes ☐ no

52. Neutrophils →

☐ Known 53. ___ ___ %

☐ Unknown

54. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

55. Blasts in bone marrow

☐ Known → 56. ___ ___ ___ %

☐ Unknown

57. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

58. Were cytogenetics tested (conventional or FISH)?

☐ yes → 59. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

☐ no

☐ unknown

60. Results of tests

☐ Abnormalities identified →

☐ No evaluable metaphases

☐ No abnormalities

Specify abnormalities identified prior to this line of therapy:

61. Specify number of distinct cytogenetic abnormalities:

☐ One (1)

☐ Two (2)

☐ Three (3)

☐ Four or more (4 or more)

Monosomy

62.	–5	☐ Yes	☐ No
63.	–7	☐ Yes	☐ No
64.	–13	☐ Yes	☐ No
65.	–20	☐ Yes	☐ No
66.	–Y	☐ Yes	☐ No

Trisomy

67.	+8	☐ Yes	☐ No
68.	+19	☐ Yes	☐ No

Translocation

69.	t(1;3)	☐ Yes	☐ No
70.	t(2;11)	☐ Yes	☐ No
71.	t(3;3)	☐ Yes	☐ No
72.	t(3;21)	☐ Yes	☐ No

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73. t(6;9) ☐ Yes ☐ No
74. t(11;16) ☐ Yes ☐ No

Deletion

75. del(3q)/3q– ☐ Yes ☐ No
76. del(5q)/5q– ☐ Yes ☐ No
77. del(7q)/7q– ☐ Yes ☐ No
78. del(9q)/9q– ☐ Yes ☐ No
79. del(11q)/11q– ☐ Yes ☐ No
80. del(12p)/12p– ☐ Yes ☐ No
81. del(13q)/13q- ☐ Yes ☐ No
82. del(20q)/20q– ☐ Yes ☐ No

Inversion

83. inv(3) ☐ Yes ☐ No

Other

84. i17q ☐ Yes ☐ No
85. Other abnormality
    ☐ Yes → 86. Specify other abnormality: _____
    ☐ No

Line of Therapy:

87. Systemic therapy
    ☐ yes → 88. Date therapy started
        ☐ Known → 89. Date started: __ __ __ __ / __ __ / __ __ (YYYY MM DD)
        ☐ Unknown
    ☐ no

90. Date therapy stopped
    ☐ Known → 91. Date stopped: __ __ __ __ / __ __ / __ __ (YYYY MM DD)
    ☐ Unknown

92. Androgen ☐ yes ☐ no
93. Antithymocyte globulin (ATG) ☐ yes ☐ no
94. Azacytidine (Vidaza) ☐ yes ☐ no
95. Bendamustine ☐ yes ☐ no
96. Corticosteroids ☐ yes ☐ no
97. Cytarabine (Ara-C) ☐ yes ☐ no
98. Decitabine (Dacogen) ☐ yes ☐ no
99. Deferiprone (Ferriprox) ☐ yes ☐ no
100. Deferasirox (Exjade) ☐ yes ☐ no
101. Deferoxamine (Desferal) ☐ yes ☐ no
102. Erythropoietin (EPO) (any formulation) ☐ yes ☐ no
103. G-CSF (any formulation) ☐ yes ☐ no
104. GM-CSF ☐ yes ☐ no
105. Hydroxyurea (Droxia, Hydrea) ☐ yes ☐ no
106. Idarubicin (Idamycin) ☐ yes ☐ no

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107. Lenalidomide (Revlimid) ☐ yes ☐ no
108. Ruxolitinib (Jakafi) ☐ yes ☐ no
109. Thalidomide (Thalomid) ☐ yes ☐ no
110. Tyrosine kinase inhibitor (e.g. imatinib mesylate) ☐ yes ☐ no
111. Other systemic therapy
☐ yes → 112. Specify other systemic therapy: _____
☐ no

113. Other therapy
☐ yes → 114. Splenic radiation ☐ yes ☐ no
☐ no 115. Splenectomy ☐ yes ☐ no
116. Other therapy
☐ yes → 117. Specify other therapy: _____
☐ no

118. Best response to line of therapy

☐ Complete remission (CR) **- requires all of the following, maintained for ≥ 4 weeks: * bone marrow evaluation: < 5% myeloblasts with normal maturation of all cell lines * peripheral blood evaluation: hemoglobin ≥ 11 g/dL untrans fused and without erythropoietin support; ANC ≥ 1000/mm^3 without myeloid growth factor support; platelets ≥ 100 x 10^9/L without thrombopoietic support; 0% blasts *- Go to question 120***

☐ Hematologic improvement (HI) **- requires one measurement of the following, maintained for ≥ 8 weeks without ongoing cytotoxic therapy; specify which cell line was measured to determine HI response: * HI-E- hemoglobin increase of ≥ 1.5 g/dL untransfused; for RBC transfusions performed for Hgb ≤ 9.0, reduction in RBC units transfused in 8 weeks by ≥ 4 units compared to the pre-treatment transfusion number in the previous 8 weeks * HI-P- for pre-treatment platelet count of > 20 x 10^9/L, platelet absolute increase of ≥ 30 x 10^9/L; for pre-treatment platelet count of < 20 x 10^9/L, platelet absolute increase of ≥ 20 x 10^9/L and ≥100% from pre-treatment level * HI-N- neutrophil count increase of ≥ 100% from pre-treatment level and an absolute increase of ≥ 500/mm^3 *- Go to question 119***

☐ No response (NR)/stable disease (SD) **- does not meet the criteria for at least HI, but no evidence of disease progression *- Go to question 120***

☐ 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.): * ≥ 50% reduction from maximum response levels in granulocytes or platelets * reduction in hemoglobin by ≥ 1.5 g/dL * transfusion dependence *- Go to question 120***

☐ Relapse from complete remission (Rel from CR) **- requires at least one of the following: * return to pre-treatment bone marrow blast percentage * decrease of ≥ 50% from maximum response levels in granulocytes or platelets * transfusion dependence, or hemoglobin level ≥ 1.5 g/dL lower than prior to therapy *- Go to question 120***

☐ Progression to AML (AML) **- ≥ 20% blasts in the bone marrow *- Go to question 120***

☐ Unknown ***- Go to question 123***

☐ Not assessed ***- Go to question 123***

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

☐ HI-E **- hemoglobin increase of ≥ 1.5 g/dL untransfused; for RBC transfusions performed for Hgb ≤ 9.0, reduction in RBC units transfused in 8 weeks by ≥ 4 units compared to the pre-treatment transfusion number in 8 weeks.**

☐ HI-P **- for pre-treatment platelet count of > 20x 10^9/L, platelet absolute increase of ≥ 30 x 10^9/L; for pre-treatment platelet count of < 20 x 10^9/L,**

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platelet absolute increase of ≥ 20 x 10^9/L and ≥ 100% from pre-treatment level

☐ HI-N **- neutrophil count increase of ≥ 100% from pre-treatment level and an absolute increase of ≥ 500/mm^3**

120. Date assessed: __ __ __ __ / __ __ / __ __
YYYY MM DD

121. Did disease relapse/progress following this line of therapy?

☐ yes → 122. Date of relapse/progression: __ __ __ __ / __ __ / __ __
YYYY MM DD

☐ no

Copy questions 41 - 122 if needed for Line of Therapy

Transformation

Questions: 123-126

123. Did the recipient progress or transform to a different MDS/MPN subtype between diagnosis and the start of the preparative regimen?

☐ yes →

☐ no

124. Was a subsequent complete remission achieved? ☐ yes ☐ no

125. Specify the date of the most recent transformation: __ __ __ __ / __ __ / __ __
YYYY MM DD

126. Specify the MDS/MPN subtype after transformation

☐ Refractory cytopenia with unilineage dysplasia (RCUD) (includes refractory anemia (RA)) (51)

☐ Refractory anemia with ringed sideroblasts (RARS (55)

☐ Refractory anemia with excess blasts-1 (RAEB-1) (61)

☐ Refractory anemia with excess blasts-2 (RAEB-2) (62)

☐ Refractory cytopenia with multilineage dysplasia (RCMD) (64)

☐ Childhood myelodysplastic syndrome (Refractory cytopenia of childhood (RCC)) (68)

☐ Myelodysplastic syndrome with isolated del(5q) (5q– syndrome) (66)

☐ Myelodysplastic syndrome (MDS), unclassifiable (50)

☐ Chronic neutrophilic leukemia (165)

☐ Chronic eosinophilic leukemia, NOS (166)

☐ Essential thrombocythemia (includes primary thrombocytosis, idiopathic thrombocytosis, hemorrhagic thrombocythemia) (58)

☐ Polycythemia vera (PCV) (57)

☐ Primary myelofibrosis (includes chronic idiopathic myelofibrosis (CIMF), angiogenic myeloid metaplasia (AMM), myelofibrosis/sclerosis with myeloid metaplasia (MMM), idiopathic myelofibrosis) (167)

☐ Myeloproliferative neoplasm (MPN), unclassifiable (60)

☐ Chronic myelomonocytic leukemia (CMMoL) (54)

☐ Myelodysplastic/myeloproliferative neoplasm, unclassifiable (69)

☐ Transformed to AML (70) **- Also complete CIBMTR form 2010 *- Go to First Name***

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CIBMTR Center Number: ___ ___ ___ ___ ___ CIBMTR Recipient ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___

Laboratory Studies at Last Evaluation Prior to the Start of the Preparative Regimen (Conditioning)	Questions: 127-153

127. Monocytes

☐ known → 128. ___ ___ %

129. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

☐ Unknown

130. Blasts in blood:

☐ known → 131. ___ ___ ___ %

132. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

☐ Unknown

133. Was a bone marrow examination performed?

☐ yes →

134. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

135. Cellularity

- ☐ Decreased (hypocellular)
- ☐ Normal (normocellular)
- ☐ Increased (hypercellular)
- ☐ Unknown

136. Fibrosis

☐ Present ☐ Absent ☐ Unknown

☐ no

☐ Unknown

137. Were tests for molecular markers performed (e.g. PCR)?

☐ yes →

138. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

139. ASXL1	☐ Positive	☐ Negative	☐ Not Done
140. JAK2 **(For MPN only)**	☐ Positive	☐ Negative	☐ Not Done
141. ETV6	☐ Positive	☐ Negative	☐ Not Done
142. EZH2	☐ Positive	☐ Negative	☐ Not Done
143. P53	☐ Positive	☐ Negative	☐ Not Done
144. RUNX1	☐ Positive	☐ Negative	☐ Not Done

145. Other molecular marker

- ☐ Positive →
- ☐ Negative →
- ☐ Not Done

146. Specify other molecular marker: _____

Copy questions 145 - 146 if needed for Other Molecular Marker

☐ no

☐ Unknown

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147. Was flow cytometry performed?

☐ yes → **Specify tissue and results:**

☐ no

☐ Unknown

148. Blood

☐ yes → 149. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY MM DD)

☐ no

150. Was disease detected? ☐ yes ☐ no

151. Bone marrow

☐ yes → 152. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY MM DD)

☐ no

153. Was disease detected? ☐ yes ☐ no

Disease Assessment at the Last Evaluation Prior to the Preparative Regimen (Conditioning) — Questions: 154-161

Questions 154-156 refer to MPN subtypes only; if the diagnosis is other than MPN, continue with question 157

154. Were systemic symptoms (B symptoms) present? (unexplained fever > 38° C; or night sweats; unexplained weight loss > 10% body weight in six months before last evaluation prior to the start of the preparative regimen)

☐ yes ☐ no ☐ Unknown

155. Did the recipient have splenomegaly (spleen palpable > 3 cm below left costal margin)? ☐ yes ☐ no ☐ Unknown

156 Did the recipient have hepatomegaly (liver edge palpable > 3 cm below right costal margin)? ☐ yes ☐ no ☐ Unknown

157. What was the disease status?

☐ Complete remission (CR) **- requires all of the following, maintained for ≥ 4 weeks: * bone marrow evaluation: < 5% myeloblasts with normal maturation of all cell lines * peripheral blood evaluation: hemoglobin ≥ 11 g/dL untransfused and without erythropoietin support; ANC ≥ 1000/mm^3 without myeloid growth factor support; platelets ≥ 100 x 10^9/L without thrombopoietic support; 0% blasts - *Go to question 161***

☐ Hematologic improvement (HI) **- requires one measurement of the following, maintained for ≥ 8 weeks without ongoing cytotoxic therapy; specify which cell line was measured to determine HI response: * HI-E- hemoglobin increase of ≥ 1.5 g/dL untransfused; for RBC transfusions performed for Hgb ≤ 9.0, reduction in RBC units transfused in 8 weeks by ≥ 4 units compared to the pre-treatment transfusion number in the previous 8 weeks * HI-P- for pre-treatment platelet count of > 20 x 10^9/L, platelet absolute increase of ≥ 30 x 10^9/L; for pre-treatment platelet count of < 20 x 10^9/L, platelet absolute increase of ≥ 20 x 10^9/L and ≥ 100% from pre-treatment level * HI-N- neutrophil count increase of ≥ 100% from pre-treatment level and an absolute increase of ≥ 500/mm^3 - *Go to question 158***

☐ No response (NR)/stable disease (SD) **- does not meet the criteria for at least HI, but no evidence of disease progression - *Go to question 161***

☐ 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.): * ≥ 50% reduction from maximum response levels in granulocytes or platelets * reduction in hemoglobin by ≥ 1.5 g/dL * transfusion dependence - *Go to question 159***

☐ Relapse from complete remission (Rel from CR) **- requires at least one of the following: * return to pre-treatment bone marrow blast percentage * decrease of ≥ 50% from maximum response levels in granulocytes or platelets * transfusion dependence, or hemoglobin level ≥ 1.5 g/dL lower than prior to therapy - *Go to question 160***

☐ Not assessed

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

☐ HI-E **- hemoglobin increase of ≥ 1.5 g/dL untransfused; for RBC transfusions performed for Hgb ≤ 9.0, reduction in RBC units transfused in 8 weeks by ≥ 4 units compared to the pre-treatment transfusion number in 8 weeks - *Go to question 161***

☐ HI-P **- for pre-treatment platelet count of > 20 x 10^9/L, platelet absolute increase of ≥ 30 x 10^9/L; for pre-treatment platelet count of < 20 x 10^9/L, platelet absolute increase of ≥ 20x 10^9/L and ≥**

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100% from pre-treatment level ***- Go to question 161***

☐ HI-N **- neutrophil count increase of ≥ 100% from pre-treatment level and an absolute increase of ≥ 500/mm^3** ***- Go to question 161***

159 Date of progression: __ __ __ __ / __ __ / __ __ ***- Go to question 161***
YYYY MM DD

160. Date of relapse: __ __ __ __ / __ __ / __ __
YYYY MM DD

161. Date assessed: __ __ __ __ / __ __ / __ __
YYYY MM DD

First Name: _____

Last Name: _____

E-mail address: _____

Date: __ __ __ __ / __ __ / __ __
YYYY MM DD

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