



EBMT Centre Identification Code (CIC): \_\_\_\_\_  
 Hospital Unique Patient Number (UPN): \_\_\_\_\_  
 Patient Number in EBMT Registry: \_\_\_\_\_

Treatment Type  IST  
 Treatment Date \_\_\_\_/\_\_\_\_/\_\_\_\_ (YYYY/MM/DD)

## IMMUNOSUPPRESSIVE TREATMENT (IST) --- Day 100 Follow-Up ---

### SURVIVAL STATUS

**Date of follow-up:** \_\_\_\_/\_\_\_\_/\_\_\_\_ (YYYY/MM/DD)  
 (if patient died: date of death. If patient is lost to follow up: date last seen)

**Survival status:**

- Alive
- Dead
- Lost to follow-up

**Date of the last IST for this patient:** \_\_\_\_/\_\_\_\_/\_\_\_\_ (YYYY/MM/DD)

**Main cause of death:**  
 (check only one main cause)

<input type="checkbox"/> Relapse or progression/persistent disease	
<input type="checkbox"/> Secondary malignancy	
<input type="checkbox"/> IST-related	<b>Select treatment related cause:</b> <i>(select all that apply)</i> <input type="checkbox"/> Graft versus Host Disease <input type="checkbox"/> Non-infectious complication <input type="checkbox"/> Infectious complication <i>(select all that apply)</i> <input type="checkbox"/> Bacterial infection <input type="checkbox"/> Viral infection <input type="checkbox"/> Fungal infection <input type="checkbox"/> Parasitic infection <input type="checkbox"/> Infection with unknown pathogen
<input type="checkbox"/> HCT-related	
<input type="checkbox"/> Other; specify: _____	
<input type="checkbox"/> Unknown	

**Was an autopsy performed?**

- No
- Yes
- Unknown



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### BEST RESPONSE

**Best response after this IST:**

- Complete remission (CR)
- Partial remission (PR)
- Haematological improvement (HI); *NIH partial response*
- Stable disease (no change, no response/loss of response)
- Relapse / Progression
- Not evaluated
- Unknown

**Date best response first observed:** \_\_\_\_/\_\_\_\_/\_\_\_\_ (YYYY/MM/DD)  Unknown

### TRANSFUSIONS

**RBC transfusions given since last IST episode:**  No  Yes  Unknown

RBC:

- < 20 units
- 20 - 50 units
- > 50 units
- Unknown

RBC irradiated:

- No
- Yes
- Unknown

**Platelet transfusions given since last IST episode:**  No  Yes  Unknown

Platelets:

- < 20 units
- 20 - 50 units
- > 50 units
- Unknown

Platelets irradiated:

- No
- Yes
- Unknown

*Extended dataset*

### Haematological tests

**Date tests performed:** \_\_\_\_/\_\_\_\_/\_\_\_\_ (YYYY/MM/DD)  Unknown

Haemoglobin (g/dL) \_\_\_\_\_  Not evaluated  Unknown

Was haemoglobin transfused within 4 weeks before assessment?  No  Yes  Unknown

Platelets (10<sup>9</sup> cells/L) \_\_\_\_\_  Not evaluated  Unknown

Were platelets transfused within 7 days before assessment?  No  Yes  Unknown

Neutrophils (10<sup>9</sup> cells/L) \_\_\_\_\_  Not evaluated  Unknown

Reticulocytes (10<sup>9</sup> cells/L) \_\_\_\_\_  Not evaluated  Unknown

Ferritin (ng/mL) \_\_\_\_\_  Not evaluated  Unknown

## SECONDARY MALIGNANCIES AND AUTOIMMUNE DISORDERS

### Did a secondary malignancy or autoimmune disorder occur?

- No
- Yes; **Was this disease an indication for a subsequent HCT/CT/GT/IST?**
- No (complete the non-indication diagnosis form)
  - Yes (complete the relevant indication diagnosis form)
- Unknown

## PNH TESTS AT THIS FOLLOW-UP

### PNH test done:

- No
- Yes: **Date of PNH test:** \_\_\_\_/\_\_\_\_/\_\_\_\_ (YYYY/MM/DD)  Unknown
- Unknown

### PNH diagnostics by flow cytometry:

- Clone absent
- Clone present; **Size of PNH clone in percentage (%):** \_\_\_\_\_
- Unknown

### Flow cytometry assessment done on:

- Granulocytes
- RBC
- Both
- Other; specify: \_\_\_\_\_

### Clinical manifestation of PNH:

- No
- Yes: **Date of clinical manifestation of PNH:** \_\_\_\_/\_\_\_\_/\_\_\_\_ (YYYY/MM/DD)  Unknown

### Anti-complement treatment given?

- No
- Yes (complete the table on the next page)



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**PNH TESTS AT THIS FOLLOW-UP**

Drug	Start date (YYYY/MM/DD)	Treatment stopped/date (YYYY/MM/DD)
<input type="checkbox"/> Eculizumab	____/____/____ <input type="checkbox"/> Unknown	<input type="checkbox"/> No <input type="checkbox"/> Yes: ____/____/____ <input type="checkbox"/> Unknown <input type="checkbox"/> Unknown
<input type="checkbox"/> Ravalizumab	____/____/____ <input type="checkbox"/> Unknown	<input type="checkbox"/> No <input type="checkbox"/> Yes: ____/____/____ <input type="checkbox"/> Unknown <input type="checkbox"/> Unknown
<input type="checkbox"/> Pegcetacoplan	____/____/____ <input type="checkbox"/> Unknown	<input type="checkbox"/> No <input type="checkbox"/> Yes: ____/____/____ <input type="checkbox"/> Unknown <input type="checkbox"/> Unknown
<input type="checkbox"/> Other; specify*: _____	____/____/____ <input type="checkbox"/> Unknown	<input type="checkbox"/> No <input type="checkbox"/> Yes: ____/____/____ <input type="checkbox"/> Unknown <input type="checkbox"/> Unknown

\*Please consult the **LIST OF CHEMOTHERAPY DRUGS/AGENTS AND REGIMENS** on the EBMT website for drugs/regimens names

*If there were more drugs given during one line of treatment add more copies of this page.*