

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	Select treatment related cause: <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

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

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)



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

Treatment Type IST
 Treatment Date ____/____/____ (YYYY/MM/DD)

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.