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)

☐ Relapse or progression/persistent disease	
☐ Secondary malignancy	

☐ IST-related	**Select treatment related cause:** *(select all that apply)*
	☐ Graft versus Host Disease *(Not applicable for IST-related)*
	☐ Non-infectious complication
	☐ Infectious complication
	(select all that apply)
	   ☐ Bacterial infection
	   ☐ Viral infection
	   ☐ Fungal infection
	   ☐ Parasitic infection
	   ☐ Infection with unknown pathogen
	☐ Other treatment related cause of death; specify: _____

☐ HCT-related	
☐ Other cause of death; specify: _____	
☐ Unknown	

EBMT Centre Identification Code (CIC): _ _ _ _
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Patient Number in EBMT Registry: _ _ _ _ _ _ _ _ _

Treatment Type ☐ IST

Treatment Date _ _ _ _/ _ _/ _ _ (YYYY/MM/DD)

BEST RESPONSE

Best response after this IST:

☐ Complete remission (CR):

Is the date that the PR was achieved/first observed known?

☐ No

☐ Yes: **Date PR was achieved/first observed: _ _ _ _ / _ _ / _ _ (YYYY/MM/DD)**

☐ 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
If yes:

RBC: ☐ < 20 units   **RBC irradiated:**   ☐ No
☐ 20 - 50 units   ☐ Yes
☐ > 50 units   ☐ Unknown
☐ Unknown

Platelet transfusions given since last IST episode: ☐ No   ☐ Yes   ☐ Unknown
If yes:

Platelets: ☐ < 20 units   **Platelets irradiated:** ☐ No
☐ 20 - 50 units   ☐ Yes
☐ > 50 units   ☐ Unknown
☐ Unknown

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

Treatment Type ☐ IST

Treatment Date _ _ _ _/ _ _/ _ _ (YYYY/MM/DD)

SECONDARY MALIGNANCIES AND AUTOIMMUNE DISORDERS

Did a secondary malignancy or autoimmune disorder occur?

☐ No

☐ Yes; **Was it a secondary malignancy or autoimmune disorder?**

    ☐ Secondary malignancy

    ☐ Autoimmune disorder

    Date of diagnosis: _ _ _ _/ _ _/ _ _ (YYYY/MM/DD)

    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)
☐ Eculizumab	_ _ _ _ / _ _ / _ _ ☐ Unknown	☐ No ☐ Yes: _ _ _ _ / _ _ / _ _ ☐ Unknown ☐ Unknown
☐ Ravalizumab	_ _ _ _ / _ _ / _ _ ☐ Unknown	☐ No ☐ Yes: _ _ _ _ / _ _ / _ _ ☐ Unknown ☐ Unknown
☐ Pegcetacoplan	_ _ _ _ / _ _ / _ _ ☐ Unknown	☐ No ☐ Yes: _ _ _ _ / _ _ / _ _ ☐ Unknown ☐ Unknown
☐ Other; specify*: _____	_ _ _ _ / _ _ / _ _ ☐ Unknown	☐ No ☐ Yes: _ _ _ _ / _ _ / _ _ ☐ Unknown ☐ 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.