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

☐ HCT-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: _____

☐ Other cause of death; specify: _____

☐ Unknown

Extended dataset

Was an autopsy performed?

☐ No
☐ Yes
☐ Unknown

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
☐ 20 - 50 units
☐ > 50 units
☐ Unknown

RBC irradiated:
☐ No
☐ Yes
☐ Unknown

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

If yes:

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 (10^9 cells/L)	_____	☐ Not evaluated	☐ Unknown
Were platelets transfused within 7 days before assessment?	☐ No	☐ Yes	☐ Unknown
Neutrophils (10^9 cells/L)	_____	☐ Not evaluated	☐ Unknown
Reticulocytes (10^9 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 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 below)

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.