CIC: ..... Hospital UPN: ..... Patient UIC ..... HSCT Date: .....
yyyy - mm - dd

HSCT - Minimum Essential Data - A FOLLOW UP REPORT - ANNUAL

Disease

PRIMARY DISEASE DIAGNOSIS……

Centre Identification

EBMT Code (CIC): ..... Contact person: .....

Hospital: ..... Unit: ..... Email: .....

Patient Data

Date of this report: .....
yyyy - mm - dd

Patient following national / international study / trial: ☐ No ☐ Yes ☐ Unknown

Name of study / trial .....

Hospital Unique Patient Number/ Code: .....

(Compulsory, registrations will not be accepted without this item)

Initials: ..... _ ..... (first name(s) _family name(s))

Date of birth .....
yyyy - mm - dd

Sex ☐ Male ☐ Female
(at birth)

Date of the most recent transplant before this follow up: .....
yyyy - mm - dd

Date of Last Contact

Date of last follow up or death: .....
yyyy - mm - dd

Best response after HSCT (CLL & Myeloma only)

Best disease status (response) after transplant

(prior to any treatment modification in response to a post HSCT disease assessment)

☐ Continued complete remission (CCR)

☐ CR achieved: Date achieved : .....
yyyy - mm - dd

☐ Never in CR: Date assessed: .....
yyyy - mm - dd

☐ Previously reported

Complications after Transplant (Allografts)

If patient has had a previous allograft, fill in the following sections:

Acute Graft Versus Host Disease (Allografts only)

Maximum Grade:

☐ 0 (none) ☐ I ☐ II ☐ III ☐ IV ☐ Present but grade unknown ☐ Not evaluated

Date of onset _____
yyyy - mm - dd

Stage:

Skin	☐ 0 (none)	☐ 1	☐ 2	☐ 3	☐ 4
Liver	☐ 0 (none)	☐ 1	☐ 2	☐ 3	☐ 4
Lower GI tract	☐ 0 (none)	☐ 1	☐ 2	☐ 3	☐ 4
Upper GI tract	☐ 0 (none)	☐ 1			
Other site affected	☐ No	☐ Yes			

Chronic Graft Versus Host Disease present during this period

☐ No *(never)*

Yes: ☐ First episode since last HSCT

Date of diagnosis of cGvHD: _____
yyyy - mm - dd

☐ Recurrence

Date first evidence of cGVHD during this period: _____
yyyy - mm - dd

☐ Continuous since last reported episode

Maximum extent during this period

☐ Limited ☐ Extensive ☐ Unknown

Maximum NIH score during this period

☐ Mild ☐ Moderate ☐ Severe ☐ Not evaluated

☐ Resolved since last report *(currently absent)*

Late graft failure ☐ No ☐ Yes:

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Secondary Malignancy

Did a secondary malignancy, lymphoproliferative or myeloproliferative disorder occur?

☐ No ☐ Yes:

Date of diagnosis: .....
yyyy - mm - dd

Diagnosis: .....

IF THE PATIENT HAS RECEIVED AN ALLOGRAFT PRIOR TO THE DIAGNOSIS OF ACUTE LEUKAEMIA, ANSWER THE FOLLOWING QUESTION

Is this secondary malignancy a donor cell leukaemia? ☐ No ☐ Yes ☐ Not Applicable

Additional Disease Treatment including Cell Therapy

Was additional treatment given for the disease indication for transplant?

☐ No

☐ Yes: Start date of the additional treatment since last report .....
yyyy - mm - dd

-Cell therapy

Did the disease treatment include additional cell infusions ***(excluding a new HSCT)***

☐ No

☐ Yes: Is this cell infusion an allogeneic boost? ☐ No ☐ Yes:

An allo boost is an infusion of cells from the same donor without conditioning, with no evidence of graft rejection.

Is this cell infusion an autologous boost? ☐ No ☐ Yes:

⇨ **If cell infusion is not a boost, please attach the Cell Infusion (CI) sheet on the last page, completing as many sections as episodes of cell infusion that took place during this interval, then continue below**

-Chemo / radiotherapy

Additional disease treatment given excluding cell infusion?

☐ No

☐ Yes: ☐ Prophylaxis / preemptive/ preventive *(planned before the transplant took place)*

☐ For relapse / progression or persistent disease *(not planned)*

Date started .....
yyyy - mm - dd

Chemo/drug

☐ No Tick here if continuous from last follow up report

☐ Yes:

☐	Imatinib mesylate (Gleevec, Glivec)	☐
☐	Dasatinib (Sprycel)	☐
☐	Nilotinib (Tasigna)	☐
☐	Bortezomib (Velcade)	☐
☐	Lenalidomide (Revlimid)	☐
☐	Rituximab (Rituxan, mabthera)	☐
☐	Velafermin (FGF)	☐
☐	Kepivance (KGF, palifermin)	☐
☐	Thalidomide	☐
☐	Eculizumab (Soliris)	☐
☐	Other drug/chemotherapy, specify	☐
	Intrathecal: ☐ No ☐ Yes	

Radiotherapy ☐ No ☐ Yes ☐ Unknown

Relapse or Progression after HSCT

First Relapse or Progression after HSCT *(detected by any method)*

☐ No:

☐ Yes: Date first seen .....
yyyy - mm - dd

☐ Continuous progression since HSCT

Relapse of Leukaemias

*If Yes or Continuous **and** diagnosis is acute or chronic leukaemia, fill in the section below:*

Method of detection of the first relapse or progression after HSCT

Fill in only for acute and chronic **leukaemias**

Relapse/progression detected by **clinical/haematological** method:

☐ No: Date assessed .....

☐ Yes: Date first seen .....
yyyy - mm - dd

☐ Not evaluated

Relapse/progression detected by **cytogenetic** method:

☐ No: Date assessed .....

☐ Yes: Date first seen .....
yyyy - mm - dd

☐ Not evaluated

Relapse/progression detected by **molecular** method:

☐ No: Date assessed .....

☐ Yes: Date first seen .....
yyyy - mm - dd

☐ Not evaluated

Last disease status – All diseases

Disease status when the patient was last assessed? (or date of death)

(record the most recent status and date for each method, depending on the disease)

Was disease detected by clinical/haematological method when the patient was last assessed or date of death?

☐ No ☐ Yes

Last date assessed .....
yyyy - mm - dd

☐ Not evaluated since HSCT was done

Last disease assessment - Leukaemias

Was disease detected by cytogenetic/FISH method when the patient was last assessed or date of death?
Fill in only for acute and chronic **leukaemias**

☐ No ☐ Yes: Was the presence of the disease considered relapse/progression since HSCT? ☐ No ☐ Yes

Last date assessed .....
yyyy - mm - dd

☐ Not evaluated during this period

Was disease detected by molecular method when the patient was last assessed or date of death?
Fill in only for acute and chronic **leukaemias**

☐ No ☐ Yes: Was the presence of the disease considered relapse/progression since HSCT? ☐ No ☐ Yes

Last date assessed .....
yyyy - mm - dd

☐ Not evaluated during this period

Pregnancy after HSCT

Has patient or partner become pregnant after this transplant?

- ☐ No
- ☐ Yes: Did the pregnancy result in a live birth? ☐ No ☐ Yes: ☐ Unknown
- ☐ Unknown

Survival Status

☐ Alive ☐ Dead

Check here if patient lost to follow up ☐

Main Cause of Death *(check only one main cause):*

- ☐ Relapse or Progression/Persistent disease
- ☐ Secondary malignancy
- ☐ HSCT Related Cause
- ☐ Unknown
- ☐ Other_____

Contributory Cause of Death *(check as many as appropriate):*

- ☐ GVHD
- ☐ Interstitial pneumonitis
- ☐ Pulmonary toxicity
- ☐ Infection:
  - ☐ bacterial
  - ☐ viral
  - ☐ Fungal
  - ☐ parasitic
  - ☐ Unknown
- ☐ Rejection/Poor graft function
- ☐ History of severe Veno occlusive disorder (VOD)
- ☐ Haemorrhage
- ☐ Cardiac toxicity
- ☐ Central nervous system (CNS) toxicity
- ☐ Gastrointestinal (GI) toxicity
- ☐ Skin toxicity
- ☐ Renal failure
- ☐ Multiple organ failure
- ☐ Other: _____

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CELL INFUSION (CI) SHEET

CELL INFUSION

Date of first infusion: _____
yyyy - mm - dd

Disease status before this CI ☐ CR ☐ Not in CR ☐ Not evaluated

Cell infusion (CI) regimen *(not HSCT or autologous stem cell re-infusion)*

Source of cell(s): ☐ Allo ☐ Auto
(check all that apply)

Type of cell(s): *(check all that apply)*

☐ Lymphocyte *(DLI)* ☐ Mesenchymal ☐ Fibroblasts ☐ Dendritic cells
☐ NK cells ☐ Regulatory T-cells ☐ Gamma/delta cells ☐ Other, specify _____

Chronological number of CI for this patient _____

Indication: *(check all that apply)*

☐ Planned/protocol ☐ Prophylactic ☐ Mixed chimaerism
☐ Loss/decreased chimaerism ☐ Treatment of aGvHD ☐ Treatment of cGvHD
☐ Treatment for disease ☐ Treatment PTLD, EBV lymphoma
☐ Treatment viral infection ☐ Other, specify: _____

Number of infusions within 10 weeks ..... *(count only infusions that are part of same regimen and given for the same indication)*

Acute Graft Versus Host Disease *(after this infusion but before any further infusion / transplant):*

Maximum Grade: ☐ 0 (none) ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ Present but grade unknown

CELL INFUSION

Date of first infusion: _____
yyyy - mm - dd

Disease status before this CI ☐ CR ☐ Not in CR ☐ Not evaluated

Cell infusion (CI) regimen *(not HSCT or autologous stem cell re-infusion)*

Source of cell(s): ☐ Allo ☐ Auto
(check all that apply)

Type of cell(s): *(check all that apply)*

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☐ Planned ☐ Prophylactic ☐ Mixed chimaerism
☐ Loss/decreased chimaerism ☐ Treatment of aGvHD ☐ Treatment of cGvHD
☐ Treatment for disease ☐ Treatment PTLD, EBV lymphoma
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