

<h1>DAY 0</h1>	<h1>MED-B</h1> <h1>GENERAL INFORMATION</h1>
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TEAM

EBMT Centre Identification Code (CIC)

Hospital Unit

Contact person:

e-mail

Date of this report
 yyyy mm dd

STUDY/TRIAL

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

Name of study / trial

PATIENT

Unique Identification Code (UIC) (to be entered only if patient previously reported)

Hospital Unique Patient Number or Code (UPN):

Compulsory, registrations will not be accepted without this item.

All transplants performed in the same patient must be registered with the same patient identification number or code as this belongs to the patient and not to the transplant.

Initials (first name(s) – surname(s))

Date of birth Sex: Male Female
 yyyy mm dd (at birth)

ABO Group Rh factor: Absent Present Not evaluated

DISEASE

Date of diagnosis :
 yyyy mm dd

PRIMARY DISEASE DIAGNOSIS (CHECK THE DISEASE FOR WHICH THIS TRANSPLANT WAS PERFORMED)

- | | | |
|--|--|--|
| <input type="checkbox"/> Primary Acute Leukaemia
<input type="checkbox"/> Acute Myelogenous Leukaemia (AML) & related Precursor Neoplasms
<input type="checkbox"/> Precursor Lymphoid Neoplasms (old ALL)
<input type="checkbox"/> Therapy related myeloid neoplasms (old Secondary Acute Leukaemia)
<input type="checkbox"/> Chronic Leukaemia
<input type="checkbox"/> Chronic Myeloid Leukaemia (CML)
<input type="checkbox"/> Chronic Lymphocytic Leukaemia (CLL)
<input type="checkbox"/> Lymphoma
<input type="checkbox"/> Non Hodgkin
<input type="checkbox"/> Hodgkin's Disease | <input type="checkbox"/> Myeloma /Plasma cell disorder
<input type="checkbox"/> Solid Tumour
<input type="checkbox"/> Myelodysplastic syndromes / Myeloproliferative neoplasm
<input type="checkbox"/> MDS
<input type="checkbox"/> MDS/MPN
<input type="checkbox"/> Myeloproliferative neoplasm
<input type="checkbox"/> Bone marrow failure including Aplastic anaemia
<input type="checkbox"/> Inherited disorders
<input type="checkbox"/> Primary immune deficiencies
<input type="checkbox"/> Metabolic disorders | <input type="checkbox"/> Histiocytic disorders
<input type="checkbox"/> Autoimmune disease
<input type="checkbox"/> Juvenile Idiopathic Arthritis (JIA)
<input type="checkbox"/> Multiple Sclerosis
<input type="checkbox"/> Systemic Lupus
<input type="checkbox"/> Systemic Sclerosis
<input type="checkbox"/> Haemoglobinopathy |
|--|--|--|

Other diagnosis, specify:

<h1>DAY 0</h1>	<h1>MED-B</h1> <h2>SYSTEMIC LUPUS ERITHEMATOSUS (SLE)</h2>
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Name of Referring Physician _____

Address _____

Fax _____ Email _____

INITIAL DIAGNOSIS

Has the information requested in this section been submitted with a previous transplant registration?

Yes: proceed to "Status of Disease at mobilisation" on page 4

No: proceed with this section

DIAGNOSTIC CRITERIA FOR SYSTEMIC LUPUS ERYTHEMATOSUS

Criterion	Definition	Yes	No	Not evaluated	Unknown
Malar rash [250]	Fixed erythema, flat or raised, over the malar eminences, tending to spare the nasolabial folds	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Discoid rash [251]	Erythematous raised patches with adherent keratotic scaling and follicular plugging; atrophic scarring may occur in older lesions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Photosensitivity [253]	Skin rash as a result of unusual reaction to sunlight, by patient history or physician observation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Oral ulcers [252]	Oral or nasopharyngeal ulceration, usually painless, observed by a physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arthritis [226]	Non-erosive arthritis involving two or more peripheral joints, characterized by tenderness, swelling or effusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Serositis [225]	a) Pleuritis – convincing history of pleuritic pain or rub heard by a physician or evidence of pleural effusion ~OR~ b) Pericarditis – documented by ECG or rub or evidence of pericardial effusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Renal disorder [213]	a) Persistent proteinuria >0.5 grams per day or >3+ on urine dipsCheck if quantitation not performed ~OR~ b) Cellular casts – may be red cell, hemoglobin, granular, tubular or mixed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neurologic disorder [221]	a) Seizures – in the absence of offending drugs or known metabolic derangements; e.g., uremia, ketoacidosis or electrolyte imbalance ~OR~ b) Psychosis – in the absence of offending drugs or known metabolic derangements, e.g., uremia, ketoacidosis or electrolyte imbalance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hematologic disorder [230]	a) Hemolytic anemia – with reticulocytosis ~OR~ b) Thrombocytopenia – <100,000/mm ³ platelets in the absence of offending drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Patient Number in EBMT database (if known):

Criterion	Definition	Yes	No	Not evaluated	Unknown
Immunologic disorder [254]	a) Anti-DNA: antibody to native DNA in abnormal titer ~OR~ b) Anti-Sm: presence of antibody to Sm nuclear antigen ~OR~ c) Positive finding of antiphospholipid antibodies based on (1) an abnormal serum level of IgG or IgM anticardiolipin antibodies, (2) a positive test result for lupus anticoagulant using a standard method, or (3) a false positive serologic test for Syphilis known to be positive for at least 6 months and confirmed by <i>Treponema pallidum</i> immobilisation or fluorescent treponemal antibody absorption test ~OR~ d) False positive serologic test for syphilis known to be positive for at least 6 months and confirmed by <i>Treponema pallidum</i> immobilisation or fluorescent treponemal antibody absorption test	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Antinuclear antibody (ANA) test Normal Elevated Not evaluated Unknown

An abnormal titer of antinuclear antibody by immunofluorescence or an equivalent assay at any point in time and in the absence of drugs known to be associated with "drug-induced lupus" syndrome

FIRST LINE THERAPIES

THERAPIES

- No – Proceed to "Date of transplant"
 Yes:

Date started - -
yyyy mm dd

Drugs:

(including antibodies, GF, hormones, etc.)

- | | | | |
|------------------------------------|------------------------------|-----------------------------|----------------------------------|
| Androgen | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Anti-malarials | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Azathioprine | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Corticosteroids | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Cyclophosphamide | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Cyclosporine | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Mycophenolate mofetil | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Intravenous immune globulin (IVIG) | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Other | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Lymphocytapheresis | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Plasmapheresis | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Other, specify: | | | |

DATE OF HSCT

DATE OF TRANSPLANT : - -
yyyy mm dd

TRANSPLANT TYPE

- Allogeneic: Proceed to STATUS OF DISEASE AT HSCT on page 7
 Autologous: Date of 1st collection or pheresis - -
yyyy mm dd

Patient Number in EBMT database (if known):

Criterion	Definition	Not evaluated				Score
		Yes	No	Unkn	Score	
	changes or a biopsy showing myositis.					
Urinary casts [262]	Heme-granular or red blood cell casts.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Hematuria [263]	>5 red blood cells/high power field. Exclude stone, infection or other cause.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Proteinuria [264]	>0.5 gm/24 hours. New onset or recent increase of >0.5 gm/24 hours.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Pyuria [265]	>5 white blood cells/high power field. Exclude infection.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
New rash [249]	Ongoing inflammatory lupus rash.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Alopecia [266]	Ongoing abnormal, patchy or diffuse loss of hair due to active lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Mucosal ulcers [252]	Ongoing oral or nasal ulcerations due to active lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Pleurisy [267]	Classic and severe pleuritic chest pain or pleural rub or effusion or new pleural thickening due to lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Pericarditis [268]	Classic and severe pericardial pain or rub or effusion or electrocardiogram confirmation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Low complement [269]	Decrease in CH50, C3 or C4 below the lower limit of normal for testing laboratory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Increased DNA binding [270]	>25% binding by Farr assay or above normal range for testing laboratory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Fever [271]	>38°C. Exclude infectious cause.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Thrombocytopenia [272]	<100,000 platelets/mm ³ (x 10 ⁹ /L).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Leukopenia [273]	<3,000 white blood cells/mm ³ (x 10 ⁹ /L). Exclude drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
DISACTIN TOTAL SLEDAI SCORE =						

LABORATORY VALUES

	Units	Not evaluated	Unknown
Haemoglobin	g/dL	<input type="checkbox"/>	<input type="checkbox"/>
Erythrocyte sedimentation rate	mm/hr	<input type="checkbox"/>	<input type="checkbox"/>
Platelets	10 ⁹ /l	<input type="checkbox"/>	<input type="checkbox"/>
WBC	10 ⁹ /l	<input type="checkbox"/>	<input type="checkbox"/>
Serum creatinine	µmol/l	<input type="checkbox"/>	<input type="checkbox"/>
Creatinine clearance	ml/min	<input type="checkbox"/>	<input type="checkbox"/>
Total urinary protein excretion	mg/24hr	<input type="checkbox"/>	<input type="checkbox"/>

	No	Yes	Not evaluated	Unknown
CH50 Complement reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complement component C3 reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complement component C4 reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Patient Number in EBMT database (if known):

Antibodies studied	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Unknown	
If yes:				
anti-dsDNA	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-cardiolipin IgG	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-cardiolipin IgM	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
antinuclear antibody (ANA) test	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-Sm	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-SSA (anti-Ro)	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-SSB (anti-La)	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
lupus-anticoagulant	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown

PATIENT’S SELF ASSESSMENT PRIOR TO MOBILISATION

HEALTH SURVEY

SF-36™ Health Survey completed No Yes Unknown
 If yes, score reported as: Transformed Score Raw score Unknown
(range 0-100)

Partial score: Physical Functioning: -	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Role Functioning-Physical: -	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Role Functioning-Emotional: -	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Social Functioning: -	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Bodily Pain: -	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Mental Health: -	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Vitality: -	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
General Health: -	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown

HEALTH ASSESSMENT QUESTIONNAIRE (HAQ)

	No	Yes	Unknown
Did the patient complete a Health Assessment Questionnaire (HAQ)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient’s score: -		
Worst possible score: -		
Best possible score: -		

Patient Number in EBMT database (if known):

Criterion	Definition	Not evaluated				Score
		Yes	No	Unkn		
	or other cause.					
Proteinuria [264]	>0.5 gm/24 hours. New onset or recent increase of >0.5 gm/24 hours.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Pyuria [265]	>5 white blood cells/high power field. Exclude infection.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
New rash [249]	Ongoing inflammatory lupus rash.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Alopecia [266]	Ongoing abnormal, patchy or diffuse loss of hair due to active lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Mucosal ulcers [252]	Ongoing oral or nasal ulcerations due to active lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Pleurisy [267]	Classic and severe pleuritic chest pain or pleural rub or effusion or new pleural thickening due to lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Pericarditis [268]	Classic and severe pericardial pain or rub or effusion or electrocardiogram confirmation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Low complement [269]	Decrease in CH50, C3 or C4 below the lower limit of normal for testing laboratory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Increased DNA binding [270]	>25% binding by Farr assay or above normal range for testing laboratory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Fever [271]	>38°C. Exclude infectious cause.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Thrombocytopenia [272]	<100,000 platelets/mm ³ (x 10 ⁹ /L).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Leukopenia [272]	<3,000 white blood cells/mm ³ (x 10 ⁹ /L). Exclude drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
DISACTIN TOTAL SLEDAI SCORE =						

LABORATORY VALUES

	Units	Not evaluated	Unknown
Haemoglobin g/dL	<input type="checkbox"/>	<input type="checkbox"/>
Platelets 10 ⁹ /l	<input type="checkbox"/>	<input type="checkbox"/>
WBC 10 ⁹ /l	<input type="checkbox"/>	<input type="checkbox"/>
Erythrocyte sedimentation rate mm/hr	<input type="checkbox"/>	<input type="checkbox"/>
Serum creatinine µmol/l	<input type="checkbox"/>	<input type="checkbox"/>
Creatinine clearance ml/min	<input type="checkbox"/>	<input type="checkbox"/>
Total urinary protein excretion mg/24hr	<input type="checkbox"/>	<input type="checkbox"/>

	No	Yes	Not evaluated	Unknown
CH50 Complement reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complement component C3 reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complement component C4 reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Antibodies studied

	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Unknown
If yes:			
anti-dsDNA	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
anti-cardiolipin IgG	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
anti-cardiolipin IgM	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
antinuclear antibody (ANA) test	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
anti-Sm	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
anti-SSA (anti-Ro)	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
anti-SSB (anti-La)	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
lupus-anticoagulant	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown

PATIENT'S SELF ASSESSMENT PRIOR TO CONDITIONING

HEALTH SURVEY

SF-36™ Health Survey completed No Yes Unknown

If yes, score reported as: Transformed Score Raw score Unknown
 (range 0-100)

Partial score: Physical Functioning: - Not evaluated Unknown
 Role Functioning-Physical: - Not evaluated Unknown
 Role Functioning-Emotional: - Not evaluated Unknown
 Social Functioning: - Not evaluated Unknown
 Bodily Pain: - Not evaluated Unknown
 Mental Health: - Not evaluated Unknown
 Vitality: - Not evaluated Unknown
 General Health: - Not evaluated Unknown

HEALTH ASSESSMENT QUESTIONNAIRE (HAQ)

No Yes Unknown

Did the patient complete a Health Assessment Questionnaire (HAQ)?

Patient's score: -
 Worst possible score: -
 Best possible score: -

FORMS TO BE FILLED IN

TYPE OF HSCT

- AUTOgraft, **proceed to Autograft day 0 form**
- ALLOgraft or Syngeneic graft, **proceed to Allograft day 0 form**
- If Other : , contact the EBMT Central Registry Office for instructions

FOLLOW UP	MED-B SYSTEMIC LUPUS ERITHEMATOSUS (SLE)
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Unique Identification Code (UIC) (if known)

Date of this report
 yyyy mm dd

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

Name of study / trial

Hospital Unique Patient Number

Initials: (first name(s)_surname(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

PATIENT LAST SEEN

DATE OF LAST CONTACT OR DEATH:
 yyyy mm dd

Complications after Transplant (Allografts)

ANSWER IF PATIENT HAS HAD AN ALLOGRAFT AT ANY TIME

ACUTE GRAFT VERSUS HOST DISEASE (AGVHD)

Maximum grade grade 0 (Absent) grade I grade II grade III grade IV Not evaluated

If present: New onset Recurrent Persistent

Reason: Tapering DLI Unexplained

Date onset of this episode:
 (if new or recurrent) yyyy mm dd Not applicable

Stage:

Skin	<input type="checkbox"/> 0 (none)	<input type="checkbox"/> I	<input type="checkbox"/> II	<input type="checkbox"/> III	<input type="checkbox"/> IV
Liver	<input type="checkbox"/> 0 (none)	<input type="checkbox"/> I	<input type="checkbox"/> II	<input type="checkbox"/> III	<input type="checkbox"/> IV
Lower GI tract	<input type="checkbox"/> 0 (none)	<input type="checkbox"/> I	<input type="checkbox"/> II	<input type="checkbox"/> III	<input type="checkbox"/> IV
Upper GI tract	<input type="checkbox"/> 0 (none)	<input type="checkbox"/> I	<input type="checkbox"/> II		
Other site affected	<input type="checkbox"/> No	<input type="checkbox"/> Yes			

Resolution

No Yes: Date of resolution:
 yyyy mm dd

Patient Number in EBMT database (if known):

ANSWER IF PATIENT HAS HAD AN ALLOGRAFT AT ANY TIME
CHRONIC GRAFT VERSUS HOST DISEASE (cGVHD)

Presence of cGVHD

- No
 Yes: First episode
 Recurrence

Date of onset - -
yyyy mm dd

Present continuously since last reported episode

Maximum extent during this period
 Limited Extensive Unknown

Maximum NIH score during this period
 Mild Moderate Severe Not evaluated

Organs affected Skin Gut Liver Mouth
 Eyes Lung Other, specify Unknown

Resolved: Date of resolution: - -
yyyy mm dd

LATE GRAFT FAILURE No Yes

OTHER COMPLICATIONS SINCE LAST REPORT

PLEASE USE THE DOCUMENT "[DEFINITIONS OF INFECTIOUS DISEASES AND COMPLICATIONS AFTER STEM CELL TRANSPLANTATION](#)" TO FILL THESE ITEMS.

INFECTION RELATED COMPLICATIONS

- No complications
 Yes

Type	Pathogen <i>Use the list of pathogens listed after this table for guidance. Use "unknown" if necessary.</i>	Date <i>Provide different dates for different episodes of the same complication if applicable.</i>
Bacteremia / fungemia / viremia / parasites		
SYSTEMIC SYMPTOMS OF INFECTION		
Septic shock		
ARDS		
Multiorgan failure due to infection		
ENDORGAN DISEASES		
Pneumonia		

Patient Number in EBMT database (if known):

Type	Pathogen <i>Use the list of pathogens listed after this table for guidance. Use "unknown" if necessary.</i>	Date <i>Provide different dates for different episodes of the same complication if applicable.</i>
Hepatitis		
CNS infection		
Gut infection		
Skin infection		
Cystitis		
Retinitis		
Other:		
		yyyy mm dd

DOCUMENTED PATHOGENS (Use this table for guidance on the pathogens of interest)

Type	Pathogen	Type	Pathogen
Bacteria	S. pneumoniae	Viruses	HSV
	Other gram positive (i.e.: other streptococci, staphylococci, listeria ...)		VZV
	Haemophilus influenzae		EBV
	Other gram negative (i.e.: E. coli klebsiella, proteus, serratia, pseudomonas ...)		CMV
	Legionella sp		HHV-6
	Mycobacteria sp		RSV
	Other:		Other respiratory virus (influenza, parainfluenza, rhinovirus)
Fungi	Candida sp		Adenovirus
	Aspergillus sp		HBV
	Pneumocystis carinii		HCV
	Other:		HIV
			Papovavirus
Parasites	Toxoplasma gondii		Parvovirus
	Other:		Other:

Patient Number in EBMT database (if known):

NON INFECTION RELATED COMPLICATIONS

- No complications
- Yes

Type <i>(Check all that are applicable for this period)</i>	Yes	No	Unknown	Date
Idiopathic pneumonia syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
VOD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Cataract	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Haemorrhagic cystitis, non infectious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
ARDS, non infectious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Multiorgan failure, non infectious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
HSCT-associated microangiopathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Renal failure requiring dialysis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Haemolytic anaemia due to blood group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Aseptic bone necrosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other: VOTCOMPS	<input type="checkbox"/>			

yyyy mm dd

SECONDARY MALIGNANCY, LYMPHOPROLIFERATIVE OR MYELOPROLIFRATIVE DISORDER DIAGNOSED

- Previously reported
 - Yes, date of diagnosis: - -
yyyy mm dd
- Diagnosis: AML MDS Lymphoproliferative disorder Other

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 SINCE LAST FOLLOW UP
(INCLUDES CELL THERAPY)**

Was any additional treatment given for the disease indication for transplant

- No
- Yes: Start date of the additional treatment since last report:
yyyy mm dd
- Unknown

-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

A boost is an infusion of cells from the same donor without conditioning, in the presence of engraftment (neutrophils > 5 x 10e9), with the same donor being present in a proportion higher than 10%

Is this cell infusion an autologous boost? No Yes

⇒ If cell infusion is not a boost, please complete **CELLULAR THERAPY** on the following page

Patient Number in EBMT database (if known):

CELLULAR THERAPY

One cell therapy regimen is defined as any number of infusions given within 10 weeks for the same indication. If more than one regimen of cell therapy has been given since last report, copy this section and complete it as many times as necessary.

Date of first infusion:
yyyy mm dd

Disease status before this cellular therapy CR Not in CR Not evaluated Unknown

Source of cells: Allo Auto
 (check all that apply)

Type of cells (check all that apply)

- Donor lymphocyte infusion (DLI)
- Mesenchymal cells
- Fibroblasts
- Dendritic cells
- NK cells
- Regulatory T-cells
- Gamma/delta cells
- Other
- Unknown

Number of cells infused by type	
Nucleated cells (/kg*) <i>(DLI only)</i> - x 10 ⁸ <input type="checkbox"/> Not evaluated <input type="checkbox"/> unknown
CD 34+ (cells/kg*) <i>(DLI only)</i> - x 10 ⁶ <input type="checkbox"/> Not evaluated <input type="checkbox"/> unknown
CD 3+ (cells/kg*) <i>(DLI only)</i> - x 10 ⁶ <input type="checkbox"/> Not evaluated <input type="checkbox"/> unknown
Total number of cells infused	
All cells (cells/kg*) <i>(non DLI only)</i> - x 10 ⁶ <input type="checkbox"/> Not evaluated <input type="checkbox"/> unknown

Chronological number of this cell therapy for this patient

Indication (check all that apply)

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

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 grade 0 (absent) grade 1 grade 2
 grade 3 grade 4 present, grade unknown

Patient Number in EBMT database (if known):

-Chemo / radiotherapy

Additional DISEASE treatment given excluding cell infusion?

- No
 Yes: Preemptive / preventive (*planned before the transplant took place*)
 For relapse / progression or persistent disease (*not planned*)

Date started - -
yyyy mm dd

Chemo/drug/agent Unknown
(including MoAB, vaccination, etc.)

Radiotherapy No Yes Unknown

Other treatment No Yes, specify: Unknown

Unknown

FIRST EVIDENCE OF DISEASE WORSENING SINCE LAST HSCT

EVIDENCE OF DISEASE ACTIVITY

- Previously reported
 No
 Yes; date first noted: - -
yyyy mm dd
 Continuous worsening since HSCT

LAST DISEASE AND PATIENT STATUS

SLEDAI (SYSTEMIC LUPUS ERYTHEMATOSUS DISEASE ACTIVITY INDEX) SCORE

Criterion	Definition	Yes	No	Not evaluated	Unkn	Score
Seizures [255]	Recent onset (last 10 days). Exclude metabolic, infectious or drug cause, or seizure due to past irreversible CNS damage.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Psychosis [256]	Altered ability to function in normal activity due to severe disturbance in the perception of reality. Include hallucinations, incoherence, marked loose associations, impoverished thought content, marked illogical thinking, bizarre, disorganized or catatonic behavior. Exclude uremia and drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Organic brain syndrome [257]	Altered mental function with impaired orientation, memory or other intellectual function, with rapid onset and fluctuating clinical features. Include clouding of consciousness with reduced capacity to focus and inability to sustain attention to environment, plus at least 2 of the following: perceptual disturbance, incoherent speech, insomnia or daytime drowsiness or increased or decreased psychomotor activity. Exclude metabolic, infectious or drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Visual disturbance [109]	Retinal and eye changes of SLE. Include cytooid bodies, retinal hemorrhages, serous exudate or hemorrhages in the choroid, optic neuritis, scleritis or episcleritis. Exclude hypertension, infection or drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Cranial nerve disorder [258]	New onset of sensory or motor neuropathy involving cranial nerves. Include vertigo due to lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Lupus headache [259]	Severe, persistent headache: may be migrainous, but must be nonresponsive to narcotic analgesia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
CVA [260]	New onset of cerebrovascular accident(s). Exclude arteriosclerosis or hypertensive causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8

Patient Number in EBMT database (if known):

Criterion	Definition	evaluated				Score
		Yes	No	Not	Unkn	
Vasculitis [234]	Ulceration, gangrene, tender finger nodules, periungual infarction, splinter hemorrhages or biopsy or angiogram proof of vasculitis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Arthritis [226]	More than 2 joints with pain and signs of inflammation (i.e., tenderness, swelling or effusion).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Myositis [261]	Proximal muscle aching/weakness, associated with elevated creatine phosphokinase/aldolase or electromyogram changes or a biopsy showing myositis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Urinary casts [262]	Heme-granular or red blood cell casts.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Hematuria [263]	>5 red blood cells/high power field. Exclude stone, infection or other cause.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Proteinuria [264]	>0.5 gm/24 hours. New onset or recent increase of >0.5 gm/24 hours.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Pyuria [265]	>5 white blood cells/high power field. Exclude infection.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
New rash [249]	Ongoing inflammatory lupus rash.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Alopecia [266]	Ongoing abnormal, patchy or diffuse loss of hair due to active lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Mucosal ulcers [252]	Ongoing oral or nasal ulcerations due to active lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Pleurisy [267]	Classic and severe pleuritic chest pain or pleural rub or effusion or new pleural thickening due to lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Pericarditis [268]	Classic and severe pericardial pain or rub or effusion or electrocardiogram confirmation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Low complement [269]	Decrease in CH50, C3 or C4 below the lower limit of normal for testing laboratory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Increased DNA binding [270]	>25% binding by Farr assay or above normal range for testing laboratory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Fever [271]	>38°C. Exclude infectious cause.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Thrombocytopenia [272]	<100,000 platelets/mm ³ (x 10 ⁹ /L).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Leukopenia [272]	<3,000 white blood cells/mm ³ (x 10 ⁹ /L). Exclude drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
DISACTIN TOTAL SLEDAI SCORE =						

LABORATORY VALUES

	Units	Not evaluated	Unknown
Haemoglobin - g/dL	<input type="checkbox"/>	<input type="checkbox"/>
Platelets 10 ⁹ /l	<input type="checkbox"/>	<input type="checkbox"/>
WBC - 10 ⁹ /l	<input type="checkbox"/>	<input type="checkbox"/>
Erythrocyte sedimentation rate mm/hr	<input type="checkbox"/>	<input type="checkbox"/>
Serum creatinine - µmol/l	<input type="checkbox"/>	<input type="checkbox"/>
Creatinine clearance - ml/min	<input type="checkbox"/>	<input type="checkbox"/>
Total urinary protein excretion - mg/24hr	<input type="checkbox"/>	<input type="checkbox"/>

	No	Yes	Not evaluated	Unknown
CH50 Complement reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complement component C3 reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complement component C4 reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Patient Number in EBMT database (if known):

Antibodies studied No Yes Unknown

If yes:

- | | | | | |
|---------------------------------|---------------------------------|-----------------------------------|--|----------------------------------|
| anti-dsDNA | <input type="checkbox"/> Normal | <input type="checkbox"/> Elevated | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| anti-cardiolipin IgG | <input type="checkbox"/> Normal | <input type="checkbox"/> Elevated | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| anti-cardiolipin IgM | <input type="checkbox"/> Normal | <input type="checkbox"/> Elevated | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| antinuclear antibody (ANA) test | <input type="checkbox"/> Normal | <input type="checkbox"/> Elevated | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| anti-Sm | <input type="checkbox"/> Normal | <input type="checkbox"/> Elevated | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| anti-SSA (anti-Ro) | <input type="checkbox"/> Normal | <input type="checkbox"/> Elevated | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| anti-SSB (anti-La) | <input type="checkbox"/> Normal | <input type="checkbox"/> Elevated | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| lupus-anticoagulant | <input type="checkbox"/> Normal | <input type="checkbox"/> Elevated | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |

PATIENT'S SELF ASSESSMENT AT THIS FOLLOW UP

HEALTH SURVEY

SF-36™ Health Survey completed No Yes Unknown

If yes, score reported as: Transformed Score Raw score Unknown
(range 0-100)

- | | | | |
|--------------------------------------|---------------|--|----------------------------------|
| Partial score: Physical Functioning: | - | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| Role Functioning-Physical: | - | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| Role Functioning-Emotional: | - | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| Social Functioning: | - | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| Bodily Pain: | - | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| Mental Health: | - | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| Vitality: | - | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| General Health: | - | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |

HEALTH ASSESSMENT QUESTIONNAIRE (HAQ)

No Yes Unknown

Did the patient complete a Health Assessment Questionnaire (HAQ)?

Patient's score: -
 Worst possible score: -
 Best possible score: -

PREGNANCY AFTER HSCT

Has patient or partner become pregnant after this HSCT?

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

Patient Number in EBMT database (if known):

SURVIVAL STATUS

- Alive
- Dead

PERFORMANCE SCORE *(if alive)*

- Type of score used** Karnofsky Lansky
- SCORE** 100 (Normal, NED) Not evaluated
 90 (Normal activity) Unknown
 80 (Normal with effort)
 70 (Cares for self)
 60 (Requires occasional assistance)
 50 (Requires assistance)
 40 (Disabled)
 30 (Severely disabled)
 20 (Very sick)
 10 (Moribund)

MAIN CAUSE OF DEATH *(check only one main cause)*

- Relapse or progression / persistent disease
- Secondary malignancy *(including lymphoproliferative disease)*
- HSCT related cause
- Cell therapy (non HSCT) Related Cause *(if applicable)*
- Other:
- Unknown

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

	Yes	No	Unknown
GvHD <i>(if previous allograft)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interstitial pneumonitis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pulmonary toxicity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
bacterial	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
viral	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
fungal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
parasitic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rejection / poor graft function	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
History of severe Venous-Occlusive disorder (VOD)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Haemorrhage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cardiac toxicity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Central nervous system toxicity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gastro intestinal toxicity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin toxicity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Renal failure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Multiple organ failure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other:

ADDITIONAL NOTES IF APPLICABLE

COMMENTS

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IDENTIFICATION & SIGNATURE

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