

LeukemiaNet MDS Registry Datasets

"MED A" – CORE REGISTRATION DATASET

General

Age

Sex

Country of residence

Date of MDS diagnosis (according to the guidelines that we also will discuss)

History / examination

Prior exposure to chemotherapy or radiotherapy

Previous or concurrent malignant disease

Family history of haematological malignancy in first degree relatives

Splenomegaly (yes / no)

Blood parameters at diagnosis

Haemoglobin concentration

MCV

WBC

Neutrophils

Monocytes

Blasts

Platelets

Ferritin

LDH

Creatinine

Erythropoietin (pre-transfusion, preferably before first transfusion)

HLA phenotype (if RA/RCMD, <65y, normal karyotype)

Bone marrow parameters at diagnosis

Aspirate

Blast %

Ring sideroblasts % of erythroid precursors

Trephine

Bone marrow cellularity (%)

Fibrosis increased (y/n)

Cytogenetic analysis

Good / Intermediate / Poor (according to IPSS), / Failed / Not performed

Local biobanking of samples

Yes / no

Pick list – type of sample

Classification / Prognostic stratification

FAB

WHO

[AML following MDS (including FAB / WHO class)]

IPSS score

IPSS group (Low / INT-1/ INT-2/ High)

Initial therapy

Regular transfusion need (yes / no)

Pick list for intervention – current therapies...

Trial number (if in trial)

Study number

“MED B” – EXTENDED REGISTRATION DATSET

History

Pick list for previous chemotherapy details
Pick list for radiotherapy dose / schedule
Smoking history (pack years)

Blood parameters at diagnosis

Reticulocytes (pre-transfusion)
Eosinophils
Basophils
ALT
Alkaline phosphatase
PNH clone (size, type II / III)
Transferrin saturation
Serum B12
Serum folate
Direct Coombs Test

Bone marrow parameters at diagnosis

Aspirate
Erythroid dysplasia (%)
Myeloid dysplasia (%)

Trephine
Megakaryocytic dysplasia (%)

Cytogenetic analysis

Full karyotype
Number of metaphases analysed

Immunophenotypic analysis

(done / not done)

“MED C” – ANNUAL FOLLOW UP DATASET

Detailed transfusion history

- Number of units transfused in a 52 week period
- Frequency of transfusion (last 12 weeks)

Iron chelation

- Yes/no
- If yes, which drug, what dose?

If actively treated with interventional therapy at diagnosis or at last “Med C” follow up, what was the outcome?

- Cheson criteria

If achieved response to active interventional therapy,

- is response continuing?
- If relapsed, date of relapse

Other interventional therapy

- Pick list

Survival

- Alive (yes/no)
- Date of death
- Cause of death

AML transformation

- Yes / no
- Date of transformation
- WHO subtype of AML