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 DATASET

**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