

ERICLL DATABASE (ERICdb)

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Main objectives (I)

Primary:

- To collect prospective and retrospective clinical and biological data of patients with CLL at the time of diagnosis and follow-up on a project basis

Main objectives (and II)

Secondary:

- To develop a data management system and a database for handling and storage of clinicobiological data
- To provide longitudinal data for outcome studies
- To generate hypotheses regarding the association of potential prognostic variables with outcomes in this patient population
- To provide benchmark data about the impact of CLL on European health-systems

Main variables to be collected

- To collect basic information about patients with CLL (e.g. age, gender, comorbidity, performance status)
- To collect disease-related information (date of diagnosis, stage, biological parameters, complete blood cell count)
- To record data about CLL-directed treatment (e.g. types and routes of therapy), response, complications and adverse events
- To record relevant outcome data including survival (overall and progression-free, date of last follow up, death, cause of death)

ERICdb Data collection/current status

Fully characterized cases

Center	N, patients
Milan - San Raffaele	565
Uppsala	527
Barcelona - Hospital de la Santa Creu i Sant Pau	510
Thessaloniki - INAB / CERTH	1280
Athens - LAIKO HOSPITAL	237
Budapest - Semmelweis University	99
Salamanca	667
Valencia	123
Barcelona - HMAR	293
Brno	1086
Belgrade	36
	5386

ERICdb Data collection | upload process

Prospective data collection

- A web interface will be used for real time prospective data collection
- New cases and updates will be stored in a common repository in anonymized way

Retrospective data collection

- A template Excel will be available at ERIC site
- Files with anonymized retrospective data will be collected, reviewed and integrated into the common repository

ERICdb Data collection | next steps

- ERICdb will be open by the end of June to all centers willing to participate with new data or update existing data
- Data will be collected in a retrospective way until the end of November 2019
- A report will be presented on December 2019
- In the meantime the web forms for the prospective registration will be tested by selected users and on January 2020 the prospective registration will also start

Thank you very much!

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