**Background**

- Chronic lymphocytic leukemia (CLL), characterized by a heterogeneous clinical course, is the most frequent type of leukemia among older age population.
- In the past decades the use of markers for CLL patients has provided important disease prognosis information and they have stimulated the development of more appropriate targeted therapies.
- The current standard of care combines cytogenetic results with targeted testing for mutations to determine prognostic subgroups.
- There is no information about the use and impact on these prognostic factors for CLL in Puerto Rico (PR) due to lack of a comprehensive database.

**Objective**

- To develop PR CLL Profile infrastructure in order to assess the epidemiologic and clinical characteristics, treatment patterns, and outcomes of patients diagnosed with CLL in PR.

**Methods**

- A project team was created, including oncologists, Certified Tumor Registrars, IT personnel, epidemiologists, and other medical and research consultants.
- This team evaluated CLL pathology reports and determined prognostic factors, clinical variables, and CLL-specific treatment modalities to be included in PR Central Cancer Registry (PRCCR) database.
- Staff of the PRCCR’s IT unit, together with the project team, developed the layout and the infrastructure of the database to be analyzed.
- CLL cases from 2011 to 2015 were audited through case finding, case processing, and quality control activities to assure completeness and quality of data.

**Results**

- A solution in Visual Studio was created to manage CLL-related variables, integrating data from PRCCR’s cancer database, Electronic Medical Records, Pathology Reports database, and PRCCR Health Insurance Linkage Database.
- Algorithms were created in order to calculate different patients’ comorbidities scores, including NCI Comorbidity Index, Charlson Index, and Elixhauser.
- New variables include CBC results, physical examination, treatment modalities, and genetic tests to identify prognostic factors and mutations such as CD38, trisomy 12, 11q-, 13q-, 17p-, IgHV, TP53, ZAP-70, and Beta2, among others.

**Conclusions and Future Plans**

- This project will strengthen the collaboration between the PRCCR and an external collaborator to develop a unique and robust CLL database of cancer registry data linked to insurance claims data in PR.
- The PR CLL Profile will expand the quantity and quality of data regularly collected by the PRCCR to include additional clinical, biologic, and genetic characteristics.
- The PR CLL Profile will provide the opportunity to develop comparative effectiveness research in the treatment of CLL patients in PR.
- It also will serve as an invaluable component of monitoring and improving CLL-related health outcomes in PR.
- A dashboard will be designed to show demographic and clinical variables dynamically by year of diagnosis, age-group, geography, among others.
- In the future, we plan to expand this project to include Acute Myeloid Leukemia.