Developing the Puerto Rico Chronic Lymphocytic Leukemia Profile

Carlos R. Torres-Cintrón, Omar Centeno-Rodríguez, Karen J. Ortiz-Ortiz, Yadira Román-Ruiz, Guillermo Tortolero-Luna

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 have 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

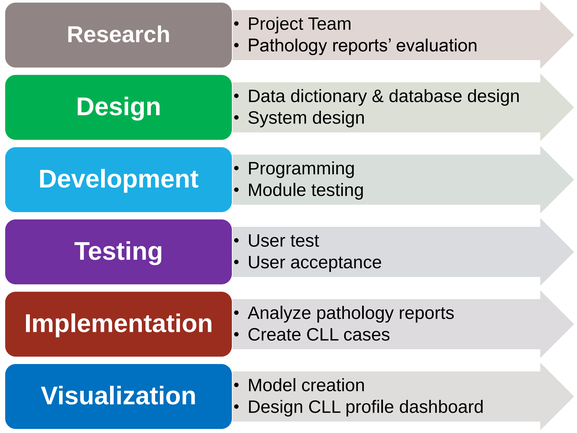
- To develop PR CLL Profile infrastructure in order to assess the epidemiologic and clinical characteristics, treatment patterns, and outcomes of patients diagnosed with CLL in PR.

Methods

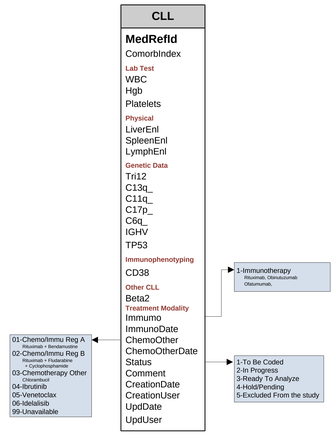
- A project team was created, including oncologists, Certified Tumor Registrars, IT personnel, epidemiologists, and other medical and research consultants.
- This team evaluated CLL pathology reports and determined prognostic factors, clinical variables, and CLL-specific treatment modalities to be included 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.

Methods

CLL Project

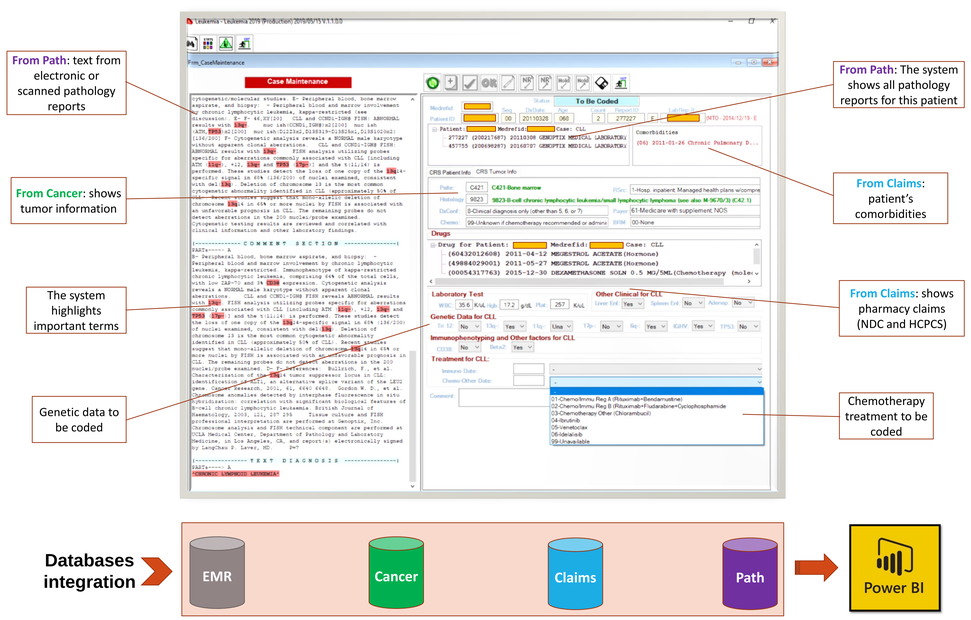


CLL Data Structure



Results

CLL Management System



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.

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