



# National Research Registry

## Interim Progress Report

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# Introduction

Starting on July 1, 2018, LLS worked in collaboration with the International Waldenström Macroglobulinemia Foundation (IWMF) and the CLL Society to invite patients to share their medical records with LLS researchers via a secure medical records submission process.

The following report shows preliminary results regarding metrics of participants and the status of record sharing, as well as the breakdown of whether treatment records originated at an academic or a community practice setting.

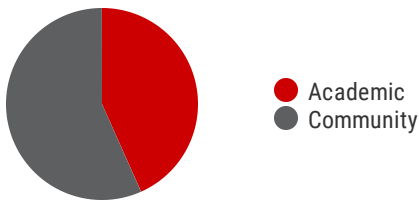


From the total of 244 signed consents, 170 individuals shared their medical records via the secure LLS Registry upload process

**170** total patients

210 **total records** were shared, with an average of 1.2 records per patient

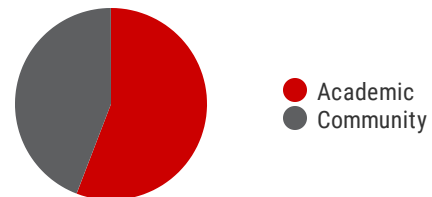
**Academic medical center** - 91 records  
**Community practice** - 119 records



**59** CLL\* patients

77 **total records** were shared, with an average of 1.3 records per patient

**Academic medical center** - 43 records  
**Community practice** - 34 records

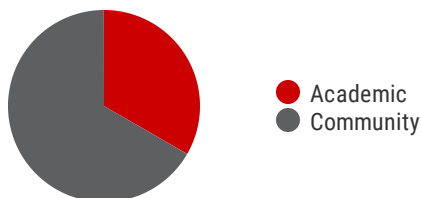


\*Chronic Lymphocytic Leukemia

**27** Records rejected for processing

27 **total records** were shared, with an average of 1.17 records per patient

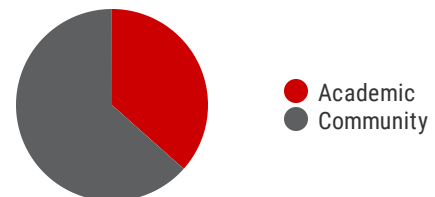
**Academic medical center** - 9 records  
**Community practice** - 18 records



**41** Other bloods cancers not analyzed

41 **total records** were shared, with an average of 1.2 records per patient

**Academic medical center** - 15 records  
**Community practice** - 26 records

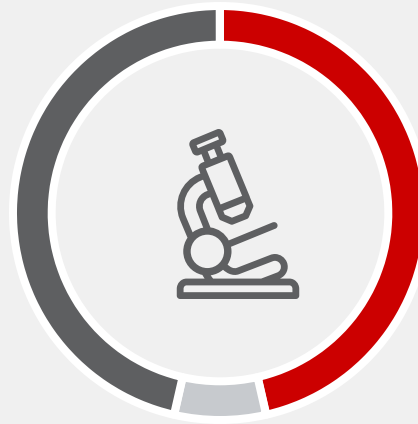


# Chronic Lymphocytic Leukemia

Has cytogenetic analysis been done?



When was cytogenetic analysis performed?



● Day of Diagnosis ● Prior to Diagnosis ● After Diagnosis

41%

patients use or used Ibrutinib

In patients diagnosed since 2017, no FCR or chemo was used for initial treatment. The conclusion is that initial treatment of CLL is currently treated by targeted therapy as opposed to chemotherapy.



Other gene sequencing analysis noted these mutation types:

TP53

ATM

NOTCH  
1

IVGH

MYD88

SF3B1

# Summary

Registry results to date are encouraging. Seventy percent (70%) of patients who agreed who signed consent shared their medical records.

Registry results to date are also encouraging in that the study hypothesis allowed for patients to share more than one portal record available for analysis. The overall ratio was 1.16 records set shared per patient.

Creating a blood cancer registry by asking patients share medical records has been shown to be effective. Direct patient survey follow up has also been shown to be an effective method of gathering data.

Additionally, please note that to date:



There are no reported adverse events or adverse outcomes associated with participation in the LLS Registry



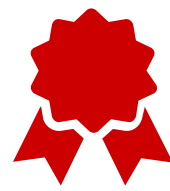
There are no unanticipated problems involving risks to subjects or others



There have been no subject withdrawals



There have been no complaints about the research



There have been no amendments or modifications to the protocol