

BACKGROUND

- An important issue of reliable cancer registry data is the completeness of case ascertainment. It is defined as the percentage of all incident tumors in a registry population that is captured in the registry's database.
- Historically, in the Puerto Rico Central Cancer Registry (PRCCR) we have the concern of a possible underestimation on some cancer types, like leukemia.
- Since most leukemia patients are diagnosed and treated in oncologists/hematologists private offices, these cases are mostly identified from pathology reports.
- One of the constrains to perform an effective casefinding is that the scope of the PRCCR law doesn't cover Out of State Laboratories (OSL).
- Some of the oncologists/hematologists in Puerto Rico send hematologic samples to OSL. These laboratories process cytogenetic and flow cytometry tests, among others.
- High operational costs and low case load make non-cost effective to perform those procedures locally.
- In order to improve the completeness of leukemia case ascertainment, it is essential to capture information from these laboratory sources.

PURPOSE

- To improve the completeness of case ascertainment of leukemia in the PRCCR database using OSL data.

METHODS

- An US mainland specialized OSL, where most of the oncologists/hematologists send their hematologic samples, was contacted.
- The OSL agreed to share information of Puerto Rico cases, establishing an unprecedented event for the PRCCR.

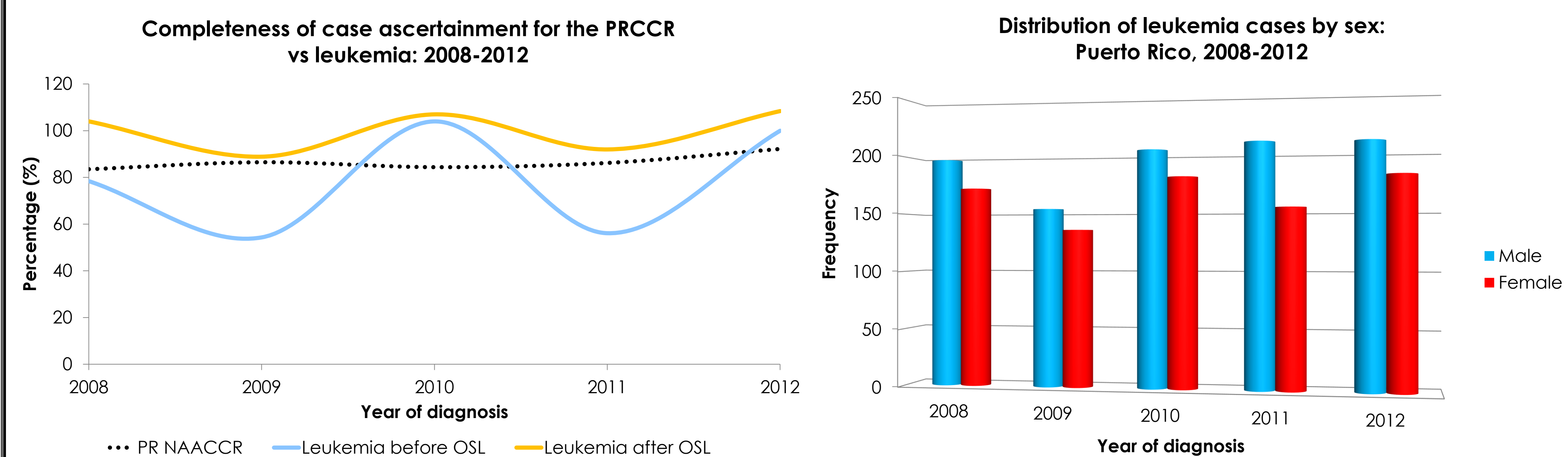
METHODS

- The first step was to establish direct communication with oncologists/hematologists to explain the importance of reporting to the PRCCR as required by law.
- OSL files were received in HL7 format and added to the PRCCR using in-house software called *PathPlus* in order to perform follow up of potential missing cases.
- A list of cases was generated for each oncologist/hematologist, whose cancer information was missing or incomplete.
- These lists and the requested information were exchanged using *WebPlus* as a secure transport method in order to update our cancer database.

RESULTS

- For the period 2008-2012, leukemia cases from the contacted OSL (OSL only) has significantly increased completeness of case ascertainment (approximately 34%).
- For the same period, 59% of leukemia cases had at least one pathology report from the contacted OSL.
- In 2012, 44% of leukemia cases were identified from OSL only.
- In 2012, the PRCCR achieved NAACCR's Silver Certification with a 92.25% completeness estimate.

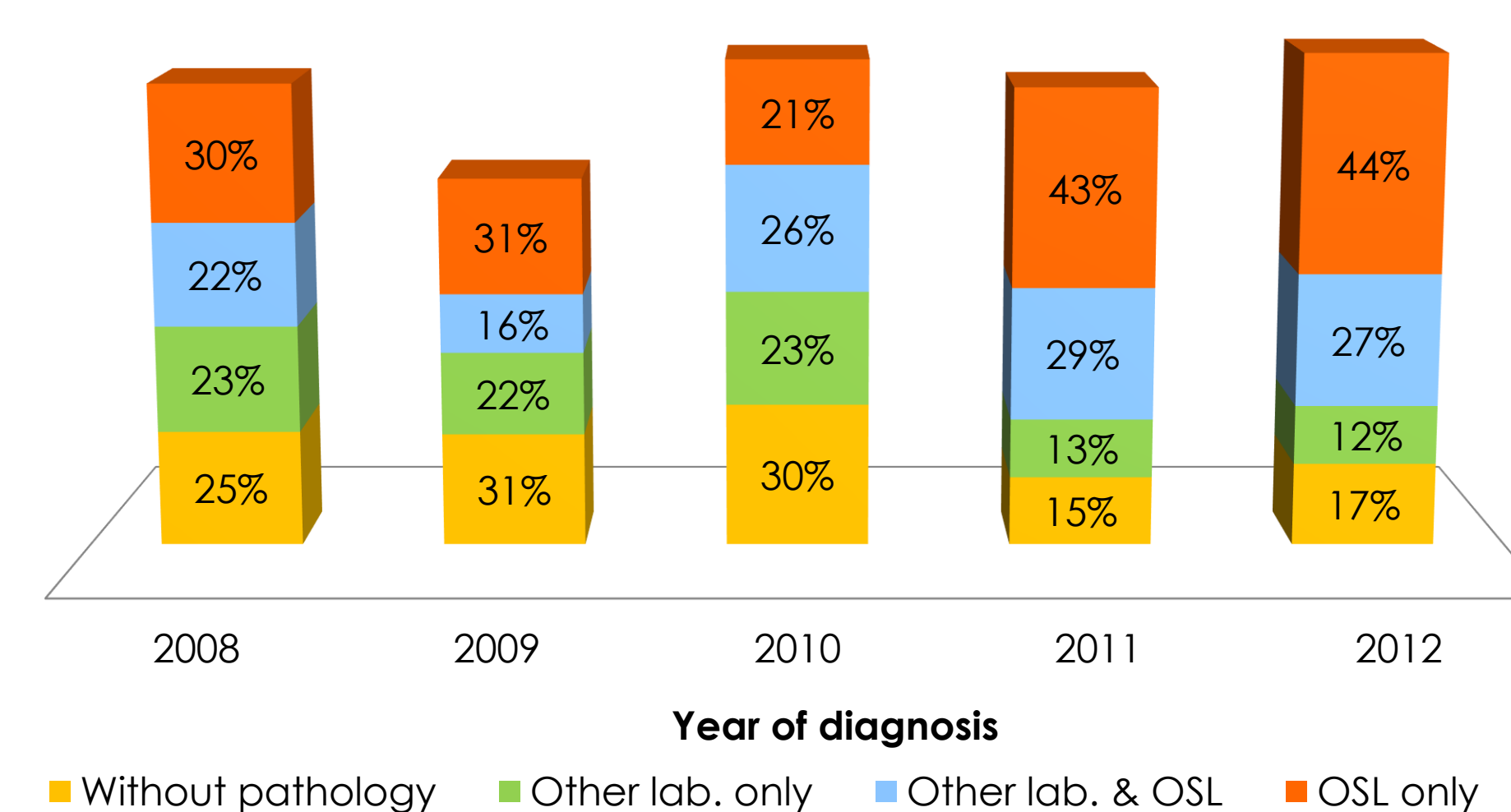
RESULTS



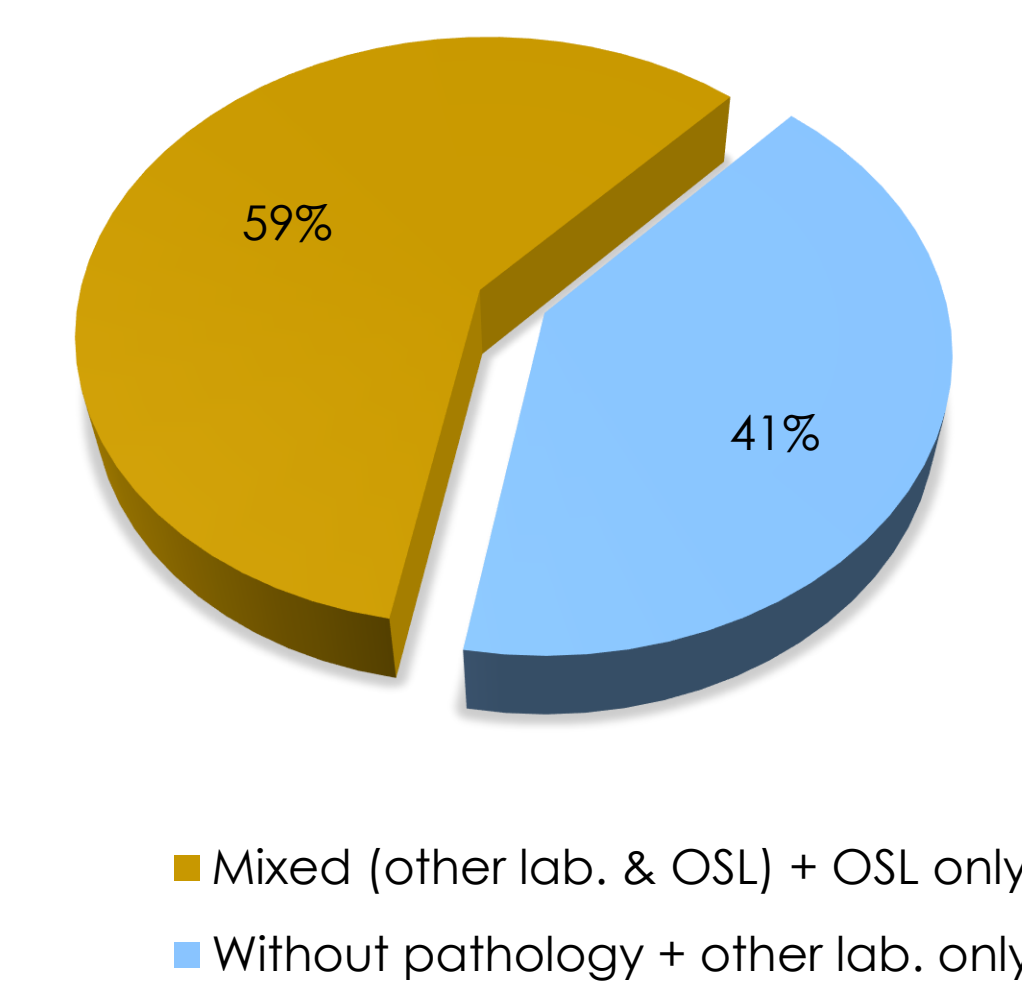
Distribution of leukemia cases by year of diagnosis and pathology source status: 2008-2012

Year	Without pathology	Other lab. only	Other lab. & OSL	OSL only	Total Tumors
2008	92	85	83	110	370
2009	90	66	47	92	295
2010	114	91	101	83	389
2011	55	47	106	159	367
2012	66	47	106	175	394
Total	417	336	443	619	1,815

Leukemia cases: relative distribution of pathology source by year of diagnosis (N = 1,815)



Burden of OSL on leukemia incidence cases 2008-2012 (N = 1,815)



DISCUSSION

- The OSL prove to be an important casefinding source for leukemia cases in Puerto Rico.
- Long term collaboration with the contacted OSL and with local oncologists/hematologists has been established.
- These collaborations will allow PRCCR to optimize its overall processes for years to come and achieve greater level of completeness of case ascertainment.
- There are still OSL's pathology reports to be processed, especially for 2009, so this may explain the low leukemia case load in that year.
- Improvements in case ascertainment will facilitate studies of leukemia epidemiology and health disparities among the population residing in Puerto Rico.
- The results of this work encourage us to explore new sources of data in order to improve the completeness of other sites.

DISCLAIMER

The collection of cancer-incidence data was supported, in part, by the National Program of Cancer Registries of the Centers of Disease Control and Prevention by the PRCCR as part of the statewide cancer reporting program mandated by the Puerto Rico State Law No. 28 of March 20, 1951, and Law No. 113 of July 30, 2010 (Law of the PRCCR).