

# 2021 NPCR RHODE ISLAND SUCCESS STORY

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*Monthly Data Receipts from Neighboring State to Improve Completeness and Timeliness*

## National Program of Cancer Registries SUCCESS STORY

### SUMMARY

Inter-state exchanges play a critical role in completing Rhode Island cancer surveillance. However, it is challenging to verify if Rhode Island resident cases were submitted by the out-of-jurisdiction registries in a complete and timely manner. Rhode Island and a neighboring state mutually agreed to a modification in the data exchange schedule. The Rhode Island Cancer Registry (RICR) could gain leverage in monitoring cases from inter-state exchanges in a timely and predictable manner.

### CHALLENGE

The RICR currently has interstate data exchange agreements in place, either through the NAACCR Interstate Data Exchange Agreement (with 44 states, as of January 2020, Data Exchange Agreement (naaccr.org) or individual state-to-state agreement (with 1 state).

To fulfil RICR's responsibility as a sending registry, the RICR conducts interstate data case searches quarterly, in the months of January, April, July, and October. Non-RI resident cases identified through this protocol are sent to corresponding states that participate in the agreements. Through these agreements, the RICR can collect RI resident cases diagnosed and/or treated from registries with signed agreements. Each state transmits data to the RICR, according to its own data abstraction and exchange policy and protocol. Therefore, timeline and frequency when the RICR receives reports from other states are difficult to predict and

monitor. Although consensus among the bordering states is quarterly exchange, backlogging often occurs for many reasons, such as registry staff shortage/turnover from the sending state, unexpected software changes/glitches, and other reasons.

### SOLUTION

In 2020-2021, the RICR conducted reviews to identify missing and/or reporting delays from several in-state facilities and a neighboring state's registry ("State A"), over the course of a ten-year (diagnosis) span. We found (1) yearly unduplicated case volume from State A varied (from 515 to 1,753 during 2012-2019), (2) timeliness of State A reported cases, measured by "Date of Case Load (in RICR database)" and "Date of First Contact," was 400-500 days on average, and (3) frequency of data receipts from State A was not consistent year to year (once-three times a year).

It was a challenging task to verify if Rhode Island resident cases submitted by the out-of-jurisdiction registry were complete and timely. Two registries, RI and State A, met virtually in February 2021, and shared the above findings. Having discussed how to improve data exchange procedures and outcomes, the two registries agreed that the most workable and quick-fix strategy was modification of the data exchange schedule that would help RICR gain leverage in monitoring cases from State A in a timely and predictable manner. State A was willing to transmit RI resident cases monthly to RICR.

### RESULTS

Since March 2021, RICR receives State A data every 15th day of the month. Frequency of data receipts changed from one-three times a year in previous years to monthly in 2021. Accordingly, staff workload to review and process State A cases were evenly distributed since March. Impact on completeness and timeliness are being monitored.

### SUSTAINING SUCCESS

Inter-state exchanges play a critical role in completing Rhode Island cancer surveillance. Data sourced from out-of-state contributed approximately 10% of all abstract records for cases diagnosed in 2010-2019 (10,600 records per year, on average). Out-of-state reports mainly came from States A, B, C and D; small number of cases (less than 5 per year) were from 27 other states across the nation. Case reporting from State A is particularly significant to the RICR, attributed to RI residents' physical proximity and accessibility to state-of-the-art cancer centers in State A. For the cases diagnosed in 2010-2019, 900 to 1,000 (unduplicated) records, each year, were State A-sourced cases, accounting for 86% of all out-of-state reports. Besides, 50% of these State A records were not accompanied with other source(s), such as reports from in-state facilities or pathology labs, meaning that a significant number of the RICR case reporting was created from a single source – the State A report. Monitoring and verification of out-of-state reports are critical activities that help RICR submit complete, timely and quality reporting.

### REGISTRY CONTACT INFORMATION

401-222-4577

[https://health.ri.gov/programs/detail.php?pgm\\_id=124](https://health.ri.gov/programs/detail.php?pgm_id=124)



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