

2021 NPCR NEW YORK SUCCESS STORY

New York State Cancer Registry: Margaret Gates Kuliszewski, ScD; Jovanka N. Harrison, PhD; Maria J. Schymura, PhD

Importance of Electronic Pathology Reporting for Rapid Case Ascertainment in Patient Contact Studies

National Program of Cancer Registries SUCCESS STORY

SUMMARY

The New York State Cancer Registry (NYSCR) worked with reporting facilities to increase the percentage of cases reported by electronic pathology report (ePath) from 15.7% in 2014 to 44.8% in 2019. This increase has allowed the NYSCR to collaborate with researchers on patient contact studies involving rapid case ascertainment (RCA), such as studies with prospective assessment of clinical and treatment-related factors and studies seeking to assess pre-diagnostic exposures as close as possible to the time of diagnosis. Additional improvements in the percent of cases reported to cancer registries by ePath will further enable patient contact research studies and will ensure the representativeness of the patients contacted.

CHALLENGE

For studies of patient outcomes, researchers often are interested in contacting and enrolling cancer patients in a study soon after diagnosis. Potential benefits of RCA include assessment of pre-diagnostic exposures closer to the time of diagnosis, which may decrease recall bias, and prospective assessment of clinical and treatment-related factors including treatment decision-making, barriers to treatment, and quality of life. In addition, in studies of highly fatal cancers and transient populations, RCA may maximize participation and reduce the number of patients who are unable to be reached.

Electronic pathology reporting to cancer registries can help facilitate research studies involving RCA and build collaborations with researchers. Maximizing the number of facilities with ePath reporting capabilities increases the number of patients available for contact soon after diagnosis and the representativeness of the sample. However, the onboarding process is slow and requires commitment and dedicated resources by the facility for implementation and continued support of ePath reporting.

SOLUTION

The NYSCR Pathology Laboratory Reporting Team has worked with reporting facilities over the past seven years to increase the number of facilities with ePath reporting capabilities. Although additional work remains, these efforts have increased the percent of cases reported by ePath and has allowed the NYSCR to collaborate with researchers on studies requiring RCA. For these studies, the NYSCR has also used additional case identification approaches to include cases not reported by ePath and to help improve the representativeness of the study sample, such as working directly with reporting facilities without ePath capabilities to identify additional cases soon after diagnosis or extending the time window for identification and enrollment of cases.

RESULTS

As a result of these efforts, the percent of cases reported to the NYSCR by ePath within three months after diagnosis increased over time from 15.7% in 2014 to 44.8% in 2019. The percent of cases reported by ePath varied by cancer site, and case characteristics including age, race/ethnicity, and stage at diagnosis differed for cases reported and those not reported by ePath. These results indicate that additional work on the part of both the NYSCR and reporting facilities is needed to continue to increase the number of facilities with ePath reporting capabilities, as well as to sustain current ePath reporting efforts. In the meantime, approaches to include cases not reported by ePath in RCA studies will help to improve the representativeness of the study sample.

SUSTAINING SUCCESS

The NYSCR is continuing to work with additional facilities to enable them to submit ePath reports. However, this onboarding process is slow and requires commitment and dedicated resources by the facility for implementation and continued support of ePath reporting. This long-term commitment can be cost prohibitive for smaller or under-resourced reporting facilities. Approaches to streamline the ePath reporting process and to minimize the cost of ePath reporting will benefit cancer registries and the entire cancer research community.

REGISTRY CONTACT INFORMATION

518-474-2255

<https://www.health.ny.gov/statistics/diseases/cancer/>



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