

2019 NPCR KENTUCKY SUCCESS STORY

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Adapting to the implementation delays of the 2018 changes and their impact on the timeliness of reporting to the KCR

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: The submission of complete and timely cancer registry data to the National Program of Cancer Registries is a required activity for Program participants. These activities are critical to CDC's analytic data sets and web-based query systems used to support evidence-based cancer prevention and control initiatives. Changes in data collection requirements, coding guidelines and instructions, staging systems, and treatment procedures are necessary over time, in order for the data to remain relevant to current medical practice. However, major changes to cancer surveillance data standards must be well planned, coordinated, and carefully executed in order to be effective and constructive. Vast changes in 2018 data standards rank among the most significant single year change in recent history. In order to minimize the impact on timely reporting of 2018 data, the Kentucky Cancer Registry (KCR) leveraged all available resources and opportunities to implement the changes, in spite of numerous delays in documentation and necessary software tools.

CHALLENGE: KCR requires hospitals to report cancer cases to the central registry within 6 months of the date of first contact of the patient with that facility. The delay in availability of the 2018 coding manuals from the Commission on Cancer and the NCI-SEER Program, as well as the EDITS metafile, registry software and other online resources was expected to have a significant impact on hospital reporting to KCR. In addition, Kentucky is unique in that it must obtain reports for residents seen in seven contiguous states and is engaged in data exchange with greater than twenty additional states. The proportion of Kentucky resident cases which are reported solely through out-of-state data sources averages over 5% annually. These cases may be significantly delayed by the 2018 changes, and KCR has little or no control over the timeliness of reporting to the other state registries.

SOLUTION: The KCR is unique in another way, in that its enabling legislation requires that all healthcare providers report to KCR using its internally developed Cancer Patient Data Management System (CPDMS). KCR has a dedicated software development team that continually develops and maintains its registry reporting system. When the 2018 changes were initially proposed in early 2017, KCR made a strategic decision to use the draft manuals and deeply engage in national work groups and committee meetings in order to anticipate the changes that would be needed in the CPDMS software to enable hospital reporting. Since many of the specifications for the changes were not finalized by January, or even March of 2018, the software team adapted the CPDMS to allow data entry of 2018 cancer cases in the existing (2016) format. CPDMS held these cases as 'incomplete' until August of 2018, when the first version of the 2018 EDITS metafile became available. During March and April, KCR's Education and Training managers used the draft coding manuals to develop training materials and presented them to hospitals throughout the state. In August 2018, KCR fully implemented the 2018 changes in CPDMS for all Kentucky

cancer reporting facilities and enforced the completion of all the 'incomplete' cases that had been entered in the 2016 format. While the national cancer standard setters have continued to update documents and guidelines, and roll out implementation requirements, KCR operations staff have continuously been updating the training materials, software, and data collection requirements.

RESULTS: KCR's planning and innovative approaches to hospital reporting resulted in remarkably complete reporting, despite the major standard setter delays and challenges for 2018 reporting. Table 1 shows the number of cases reported to KCR at 1-month and at subsequent 6-month intervals beyond the close the diagnosis years 2016-2018.

Cases Reported within Interval						
Diagnosis Year	1 month (Jan)	7 months (July)	13 months (Jan)	19 months (July)	25 months (Jan)	31 months (July)
2016	14458	22923	26911	30217	30665	36772
2017	15175	24364	27872	30032		
2018	10915	21130				

Table 1.
Cases Reported within 1-Month and Subsequent 6-Month Intervals by Diagnosis Year

The last row of Table 1 indicates that the reporting of 2018 cases, one month after the close of the year, was 25% lower what had been reported in the previous two years (highlighted in yellow). However, by the end of following 6-month interval in July, the 2018 cases were only 11% lower than in the previous two diagnosis years (highlighted in blue).

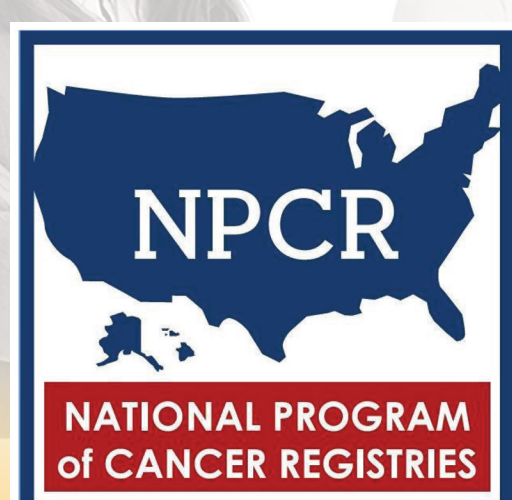
The NPCR-CSS Completeness Estimates for KCR 2016 and 2017 data at 12 months was 93.2% and 93.1%, respectively. KCR appears to be on track to achieve the NPCR standard of 90% completeness for 12 month reporting of its 2018 data.

SUSTAINING SUCCESS: Adapting to change is constant and necessary in cancer registration. Careful planning and coordination is the key to mitigating the risks associated with constant change, especially when timely information and resources to support those changes aren't provided. KCR recognizes that active registry participation in the committee meetings, work groups, and training sessions provides opportunities to prepare for the changes and may offer opportunities to influence the nature and timing of future changes.

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