

2019 NPCR OKLAHOMA SUCCESS STORY

Oklahoma Cancer Registry: Alexandra Feld, MPH and Christy Dabbs, AA, CTR

Clear and Timely Communication with Oklahoma Cancer Reporters to Survive the 2018 Changes

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: Among a plethora of changes and unanticipated delays, the Oklahoma Central Cancer Registry (OCCR) developed a plan to allow Oklahoma cancer reporters to stay informed about the implementation of known changes for 2018 and the unanticipated delays that followed. Communicating with reporters on a monthly basis and implementing the plan to allow abstraction of cases diagnosed in 2018 prior to all reporters' software being converted to the North American Association of Central Cancer Registries (NAACCR) record layout v18.0, allowed cancer reporters to continue to abstract cancer cases without a delay. This process also allowed for earlier submission of 2018 cases than what otherwise would have been a significant delay if cases were not abstracted until after conversion. The 2018 changes were, at times, difficult to manage but by creating a plan of action and making adjustments to the normal reporting schedule, we were able to implement all the required changes, update central registry software, and begin accepting 2018 diagnosed cases in the second quarter of 2019.

CHALLENGE: There were several major changes to data items, the format in which some data items are entered, and expanded treatment data collection for radiation therapy across the United States in 2018. Because there was so much change, the coding manuals had to be re-written. In addition, the Surveillance, Epidemiology and End Results (SEER) Summary Stage Manual was updated for the first time since 2000 and the American Joint Commission on Cancer (AJCC) released the eighth edition of the AJCC Cancer Staging manual to be used with 2018 diagnosed cases. Each of these changes individually and as a collective whole caused major delays in release dates for reporting and coding manuals, applications developed by the CDC and used by registry software vendors, and registry software.

Specifically, the NAACCR 2018 implementation guidelines and recommendations were released in September of 2018, nine months after 2018 cancer cases began to be diagnosed and three months after the first group of 2018 cases would have normally been reported to the central registry. The NAACCR 18 conversion specs, Northcon18, NAACCR site-specific data item (SSDI) application programming interface (API), and the TNM (tumor, node, metastasis) API 8th ed. were all available around November of 2018 and registry software vendors were only then able to start updating their programs. Reporting for almost 400 cancer reporters across Oklahoma was delayed by approximately nine months.

Another major change in 2018 was the discontinuation of Collaborative Stage (CS), a unified data collection system that had been in use since 2004. With that came the discontinuation of site-specific factors and a changeover to SSDIs, in which field length is not limited to 3 digits, decimals are allowed, and different coding conventions are used to record actual values, percentages and ranges. Radiation therapy coding also changed in format, information collected, and data coded. Finally, the SEER Summary Stage was updated, and a new manual was published.

Challenges with coordination and communication in making change revisions and implementation recommendations caused some delays with the data submission timeline for the cancer registry community as a whole. In addition to these challenges, the OCCR faced a registry software update, separate from the 2018 changes updates, which further complicated case reporting and delayed our ability to accept reported cases in the new NAACCR record layout (version 18, v18).

SOLUTION: The OCCR Data Manager (DM) spearheaded the OCCR program's response to the plethora of changes and delays. First, the program sent a letter to reporting facilities to keep them informed of delays and the plan going forward. The DM and Education and Compliance specialist created a guidelines document for Oklahoma cancer reporters to allow them to begin abstracting

2018 cancer cases in the current (version 16, v16) NAACCR record layout. This allowed reporters to begin abstracting cancer cases without waiting for all changes to be implemented into their software or the central registry; however, they were not allowed to submit these cases for several reasons. Their software had yet to be updated, the v18 edit metafile had not yet been released, and the central registry software had not yet been updated. Additional communication and documents were created and distributed to cancer reporting facilities throughout the next few months, including a "2018 submission schedule" (Picture 1), a "what you need to know" document (Picture 2), as well as many update emails with instructions on how to proceed and any new information (Picture 3).

One key suggestion of the OCCR was that reporters record specific new data items, provided to them in a list, in the text documentation fields of the abstract. By recording accurate information as recommended, they could avoid reviewing patient medical records again when the new (v18) NAACCR record layout was released. As the 2018 coding manual version updates and software updates were released, communication continued monthly with reporters with the latest information, next steps to take, and reminders. For example, once the v18 NAACCR record layout was released and integrated into the central registry and hospital software applications, the DM reminded reporters that cases abstracted using v16 needed to be updated and pass the v18 edits before submission to the OCCR. Finally, the OCCR staff provided two in person trainings to go over the general rules for SSDI, Oklahoma-required SSDIs, and Solid Tumor Rules.

RESULTS: The unanticipated time and difficulty in rewriting coding manuals and upgrading software led to major delays in 2018 reporting of cancer cases in Oklahoma and across the country. Despite the major difficulties, reporting facilities of Oklahoma were able to move forward with data submission because of the constant clear communication with and from the OCCR. While case submission would normally begin in July of the reporting year, the OCCR did not begin accepting 2018 diagnosed cases until late May 2019, almost a year behind. By September 2019, we estimate that approximately just over half, 53%, of the 2018 cases have been submitted to the OCCR. In just four months, half of the cases for the entirety of 2018 have been submitted, which can only be attributed to the outstanding organization, communication, and dedication from the DM, the OCCR staff, and most importantly, the reporting facilities of Oklahoma.

SUSTAINING SUCCESS: The 2018 changes were difficult to manage. By creating a plan of action and making adjustments to the normal reporting schedule, we were able to implement all the required changes and begin accepting 2018 diagnosed cases in the second quarter of 2019. There is still more work to be done and communication must continue. We send out quarterly newsletters with important updates and documents, such as the links to the 2018 coding manuals for reference. We also provide feedback to reporters on their compliance. As more cases are submitted and questions arise, reporters are able to directly contact OCCR staff for additional help and feedback.

Sources

1. Ruhl, J, Ward, E, Hofferkamp, J, et al. (September 2019). Site-Specific Data Item (SSDI) Manual. NAACCR, Springfield, IL 62704-4194. Accessed 25 September 2019. <https://www.naacr.org/SSDI/SSDI-Manual.pdf?v=1533680119>.

CONTACT INFORMATION:

Tel.: (405) 271-6225
https://www.ok.gov/health/Disease_Prevention_Preparedness/Chronic_Disease_Service/Cancer/Oklahoma_Central_Cancer_Registry/

Picture 1: Revised Submission Schedule for OK Cancer Reporters

REVISED Submission Schedule Diagnosis Year 2018	
CASES DIAGNOSED/ ADMITTED IN:	SHOULD BE REPORTED ON OR BEFORE:
January / February / March 2018	March 2019
April / May 2018	April 2019
June / July 2018	May 2019
August / September 2018	June 2019
October 2018	July 2019
November 2018	August 2019
December 2018	September 2019

Due to 2018 v18 software delays, the OCCR has granted all healthcare facilities an additional grace period as indicated above.

Picture 2: Example "What you need to know" email sent to Cancer Reporters

From: Christy X Dabbs
Sent: Friday, December 22, 2017 8:10 AM
To: Christy X Dabbs
Subject: 2018 Cancer Diagnosis Reporting - What You Need to Know
Attachments: Letter to Reporters.pdf; 2018-Implementations-and-Timeline-V1.5_20171215.pdf; 2018-Concurrent-Abstracting-Overview-Statement_20171210.pdf

Dear Oklahoma Cancer Reporters,

The Oklahoma Central Cancer Registry (OCCR) has created a document to update you on reporting changes that will be implemented for cancers diagnosed in 2018 and forward. Please read the Letter to Reporters carefully and save for future reference. I have also attached two additional documents that provide more detailed information, 2018-Implementations-and-Timeline and 2018-Concurrent-Abstracting-Overview-Statement. These documents can also be found on the North American Association of Central Cancer Registries (NAACCR) website. I have provided the link below and encourage you to look through all the great information that is provided regarding changes for 2018.
<https://www.naacr.org/2018-implementation/>

Education and Training webinars for AJCC 8th edition staging are being provided by OCCR as presented by NCCRA. These are provided at two sites, one in Oklahoma City and one in Tulsa. If you are not receiving the invitations to these webinars and would like to, please contact Susan Nagehouth at 405-271-9444, ext 57121 or susan@health.ok.gov. Additionally AJCC is also providing training webinars. You can find them here: <https://cancerstaging.org/CSC/Pages/8thEditionWebinars.aspx>

Note: You may receive this notification more than once if you are listed in multiple mailing lists at OCCR.

Thank you,

Christy Dabbs, AA, CTR
Data Manager
Oklahoma Central Cancer Registry
Center for Health Statistics
Oklahoma State Department of Health
cdabbs@health.ok.gov
Phone: 405-271-9444, ext 57121
Fax: 405-271-6315

Picture 3: Example Update email sent to Cancer Reporters

From: Christy X Dabbs
Sent: Monday, March 04, 2019 8:38 AM
To: Christy X Dabbs
Subject: "IMPORTANT NOTIFICATION" Reporting Updates

Good morning Oklahoma Cancer Reporters,

The Oklahoma Central Cancer Registry (OCCR) has been made aware of two types of abstracts that should be kept in suspense for Rocky Mountain Cancer Data System users until an update to the TNM API is released from the CDC. These are rare instances and you should not have many of these cases. At this time the CDC has not given a release date for the update.

- **Melanoma of the Anus (C210)**
This should belong to the Anus schema and not the Melanoma schema. This affects schema assignment for SS2018 and EOD. These cases will need to be identified and manually reviewed prior to submission to OCCR once the update has been applied.
- **Unknown Primary (C809) with Histology 8041**
There will be a change to the AJCC ID and Schema ID. It will be moved to ill-defined other and unstaged for TNM and will no longer be included in Merkel Cell. These cases will need to be identified and manually reviewed prior to submission to OCCR once the update has been applied.

Oklahoma cancer reporters that use a software other than Rocky Mountain Cancer Data System, please check with your software vendor for further instruction regarding the above two scenarios.

Thank you,

Christy Dabbs, AA, CTR
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Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion