# A Summary of Interactive Best Practices Workshops Findings and Tools to Guide Registries to Improve Data Reporting and Registry Operations

March 2021

#### **Acknowledgment**

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# Interactive Workshops Designed to Identify Tools and Best Practices to Improve and Support Central Cancer Registries' Operations

#### **Overview and Background**

Based on the recommendations for next steps from the first year of the project, *Identifying and Implementing Best Practices for Cancer Registry Operations*, the North American Association of Central Cancer Registries (NAACCR) planned and implemented a series of virtual interactive workshops aimed at identifying best practices and tools to improve and support registry reporting and operations. Although the workshops all focused on different challenges within central registry operations, a common purpose focused on allowing registry staff to share experiences and knowledge around these topics and compare different registry operational approaches to learn which methods were the most effective in diverse settings. Workshops were virtual due to COVID 19 constraints, but they were developed to allow maximum engagement among participants. All National Program of Cancer Registries (NPCR)-supported registry staff were invited to participate in any and all of the workshops.

The purpose of this project was to plan and implement interactive workshops to facilitate discussion around best practices and tools for the following:

- 1. Developing and monitoring data management reports
- 2. Establishing strong communications and relationships with hospitals
- 3. Improving reporting from nonhospital sources
- 4. Managing best practices around the COVID-19 response

Because of COVID-19 and other time constraints, fully developed and vetted best practices could not be developed within the framework of this project. In NAACCR's experience, the development of best practices guidelines requires extended discussion and negotiation among a broad constituency. Consensus on best practices is often difficult to reach and not attainable within the framework of a brief virtual workshop. Nonetheless, these workshops produced substantial information on current and successful best practices used across NPCR registries. This information is summarized below, and tip sheets are offered containing ideas from registry directors. The summaries provided will serve as an excellent base to further develop these topics in the future.

A top salient benefit of these workshops was allowing the registries to exchange ideas freely on a selected topic. (See Appendix C, Workshop Evaluations.) Registries are always eager to share experiences, explain their approach to problems, and learn from others. In every breakout and workshop session creative ideas were shared, and registry directors heard about methods tried in other environments that might be useful in their own situation. We strongly recommend that the Centers for Disease Control and Prevention (CDC) continue to facilitate such opportunities for exchange of ideas among the registries.

### **Workshop III: Improving Reporting from Nonhospital Sources**

The third workshop was designed to identify tools, strategies, and best practices to improve the quality and timeliness of nonhospital reporting by sharing success stories. It was structured differently from the previous two workshops to facilitate exchange of information and generate strategic ideas through participant interaction (Table 5).

Table 5. Structure of Workshop III

Workshop Structure		
Session One - 10/14/2020	Session Two 10/14/2020	
Abstract Plus Cancer Reporting for Non- Hospital Reporters—Oregon	Sharing Other Success Stories	
Web Plus Focused Abstract Experience Demonstration—New Jersey	Discussing Challenges	
Improving Melanoma Physician Reporting with the Help of a Task Force—Arizona	Identifying Strategies and Next Steps	

The morning session featured presentations from three registries that had developed specific strategies for improving or facilitating nonhospital reporting, and the afternoon session was reserved for discussing challenges and opportunities. Recommendations to improve nonhospital reporting (tools or communication strategies) were discussed and tabulated during the afternoon session. Participants attended both sessions.

Registries in 24 states and Washington, D.C., participated (Table 6).

Table 6. Registries participating in Workshop III

Alaska	Minnesota	Rhode Island
Arizona	Missouri	South Carolina
Arkansas	Montana	Tennessee
Colorado	New Jersey	Texas
Hawaii	New York	Utah
Idaho	North Carolina	Vermont
Kentucky	North Dakota	Washington, D.C.
Louisiana	Ohio	
Maryland	Oregon	

#### **Workshop Recommendations**

#### **Recommendations for CDC**

 Build abbreviated, targeted abstracts, with corresponding edit sets in Web Plus and Abstract Plus for registries to implement with dermatologists, urologists, radiation oncologists, and hematology oncologists.

- Design the Web Plus and Abstract Plus user interface with intuitive field names and descriptive tool tip callouts.
- Provide up-to-date training materials and videos for using targeted abstracts in Web Plus and Abstract Plus.
- Develop tools for effective reportability screening.
- Enhance Web Plus with the ability to attach documents as PDF files.
- Develop strategies and best practices for central registries to identify nonhospital reporters.
- Hold a workshop on using linkages to enhance nonhospital sources.
- Conduct a cost-benefit analysis of the effort involved in increasing reporting from low-volume reporters.
- Provide registries with guidance on how to access health information exchanges.

#### **Recommendations for Central Registries**

- Contact state and local medical societies for opportunities to educate their members about cancer reporting requirements.
- Work with the state comprehensive cancer control program to build relationships with providers.
- Use pathology reports to identify physician offices that are not currently reporting.
- Partner with other programs within the health department that may have relationships and or access to providers.
- Process nonhospital reports after reporting from hospitals is complete or near complete.
- Consider regulatory changes to require electronic reporting from nonhospital facilities.

#### **Session One**

The first session involved presentations by three central cancer registries on their innovative best practices around improving reporting from nonhospital reporters.

#### **Oregon State Cancer Registry**

Refer to Appendix D for presentation slides.

The Oregon State Cancer Registry (OSCaR) decided to shift nonhospital reporters to electronic case submission and eliminate incoming paper reports. Registry staff collaborated with NPCR to develop a customized template using Abstract Plus software to capture the minimum information necessary for required cases. OSCaR implemented Abstract Plus on a Citrix server, rather than on an individual workstation. Although this allows a multiple-user environment, it also requires IT support. Because of the lack of IT staff supporting the registry, requested

upgrades often take a year or more to implement once they are available from CDC. Overall, the rollout took 2 years. Of the 93 ambulatory sites approached, six are now reporting regularly using this method.

#### Benefits

- Reduce the number of paper reports received from ambulatory facilities.
- Receive physician reports in NAACCR format, which allows seamless integration with registry software and reduces the need for manual data entry and processing.
- Abstract Plus software is free for the central registry and the reporting physician.
- Abstract Plus has customizable templates to reduce the number of data items required from physicians.
- Software development is managed by CDC and is independent of OSCaR.
- Templates/Edits work well.
- The OSCaR Citrix server can be used to enable multiple users.
- Reduce the need for abstracting contractors to handle manual data entry.

#### Challenges

- Implementation took 2 years and required significant staff time.
- Templates/edits are not intuitive, and customization requires investment of staff time.
- Internal IT support is required to enable a multiuser environment.
- Some concepts can be hard to teach to reporters (i.e., exporting cases)
- Manuals and other materials available from CDC are outdated and do not apply to the most recent version of the software.
- Onboarding and training materials must be designed specifically for each state.
- A comprehensive outreach and communication plan is necessary to make providers aware of electronic reporting options.
- Adoption by ambulatory facilities is low, with only 6 out of 93 facilities having implemented reporting by Abstract Plus.

#### **New Jersey State Cancer Registry**

In 2019, the New Jersey State Cancer Registry (NJSCR) revised its cancer reporting regulations to require electronic reporting by nonhospital reporting facilities, including laboratories and physician practices. The NJSCR provides physician practices with Web Plus for electronic reporting. To reduce the time and effort required for reporting and to improve the quality and completeness of the data reported, NJSCR developed customized abstract layouts

in Web Plus software to facilitate reporting from about 100 nonhospital sources. Customization includes layouts specific to radiation oncologists and hematology oncologists, as well as a general layout for all other providers. Each layout includes a limited required data set and edits. Data item names have been modified to be clear and descriptive, and tool tip call-out boxes provide detailed descriptions of each data item.

#### Key Takeaways

- Rename data items to be more intuitive to non-CTR reporters.
- Modify tool tip call out boxes for each field (including text fields) to provide detailed instructions.
- Provide a confirmation report to each facility, including date ranges for cases entered and the number of cases received.

#### **Arizona State Cancer Registry**

Refer to Appendix D for presentation slides.

National data revealed that in 2004 U.S. incidence rates of melanoma began to increase, while the rate in Arizona was declining. The Arizona Cancer Registry (ACR) was concerned melanoma cases were not being fully captured at the registry because of an increase in patients seen in outpatient settings. It was believed that nonhospital facilities may be underreporting to the ACR. Because there are no penalties within the Arizona law for physician reporting non-compliance, there is a need to work cooperatively with reporting sources. A pilot project to assess reporting at 15 dermatology practices in Tucson and Phoenix showed 71 percent underreporting of melanoma. A task force was created to identify barriers and develop strategies to improve melanoma reporting by physicians in Arizona. The strategies identified included the following:

- A survey of physicians to identify barriers to reporting and create a database of physician email address.
- Presentations to dermatology societies on reporting to the central registry.
- Redesign of report form to make it melanoma specific.
- Dermatopathologists now include a statement on melanoma pathology reports regarding state reportability.
- A newsletter including physician names and number of cases reported distributed biannually.
- Development of a melanoma profile
- Data Quality Indicator Report for physician reporters (depth of lesion, most common sites of melanoma).

Task force efforts have resulted in a 147.5 percent increase in physicians reporting from 2009 to 2019. Most physician reported cases are paper case reports received through efax or email; however, in 2020 ACR changed regulations to require electronic reporting for any physician with more than 50 cases per year. ACR has developed a Web Plus melanoma module for physician

reporting, along with electronic onboarding and user guides. The registry also has created four recorded training modules to assist in navigating Web Plus.

#### **Session Two**

The afternoon session focused on sharing other strategies and challenges registries encountered working with nonhospital reporting sources. Discussions were focused and used to identify recommendations for training, tools, and best practices.

#### **Strategies**

- Develop a video and materials to send to potential reporters to educate them about the registry and reporting process.
- Participate in the state cancer control plan to connect with cancer specialists from throughout the state.
- Use remote access to provider medical records to facilitate follow-back.
- Use pathology reports to identify physician offices that are not currently reporting.
- Partner with other programs within the health department that may have relationships and or access to providers.
- Develop relationships with the individuals who are reporting the cases for each practice.
- Modify Abstract Plus to collect a smaller number of variables.
- Hold nonhospital cases until most of the hospital treatment cases, then link that to the cases collected from the hospitals.

#### **Challenges**

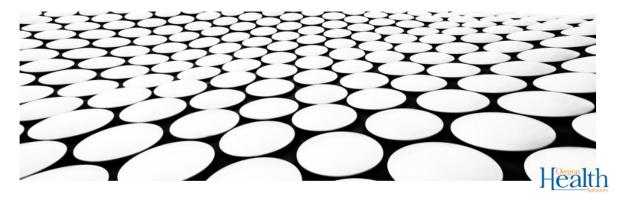
- Cancer reporting rules and regulations do not always support enforcing reporting by nonhospital facilities.
- Maintaining a current list of practices required to report is challenging, given the frequency of changes.
- Education and outreach to nonhospital reporters requires staff and time.
- Physician offices often do not collect or report patient race and social security number.
- Monitoring physician reporting to identify when reporting stops or slows is important.

## **Appendix D: Workshop 3: State Presentation Slides**

### THE OREGON STATE CANCER REGISTRY (OSCAR)

ABSTRACT PLUS CANCER REPORTING FOR NON -HOSPITAL REPORTERS

OCTOBER 2020



### OSCAR'S DECISION TO MOVE NON-HOSPITAL REPORTERS TO ELECTRONIC REPORTING WITH ABSTRACT PLUS

#### Pros:

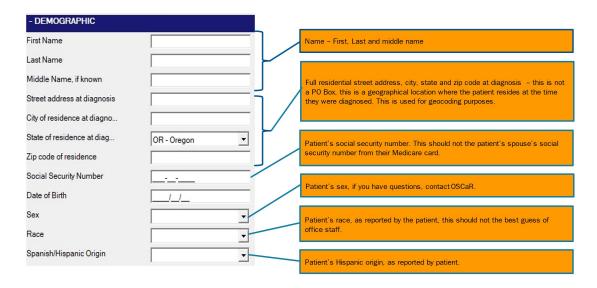
- · Reduce the number of paper reports
- Receive reports in NAACCR format
- Software is free
- Software has customizable templates
- Software is independent of OSCaR
- · Templates/Edits work well
- OSCaR Citrix server to enable multiple users
- · Reduced need for abstracting contractors

#### Cons

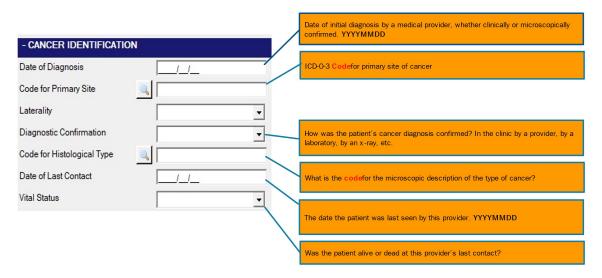
- Templates/edits are not intuitive
- IT support is required for a multi -user environment.
- Some concepts can be hard to teach (exporting cases)
- Onboarding & Training materials must be designed for your State (v16 available from CDC)
- · Comprehensive outreach and communication plan



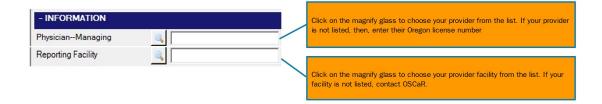
#### ABSTRACT CONTENT - DEMOGRAPHICS



#### ABSTRACT CONTENT - CANCER IDENTIFICATION

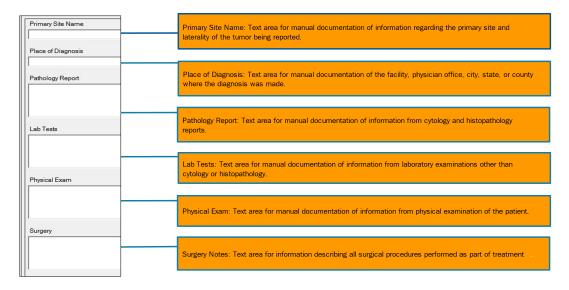


#### ABSTRACT CONTENT - INFORMATION





#### ABSTRACT CONTENT - TEXT FIELDS

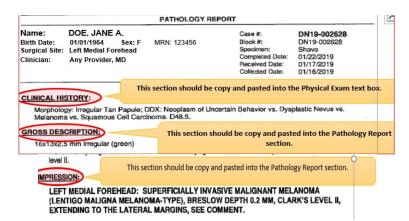


OSCAR'S ORIGINAL MELANOMA PAPER REPORTING FORM

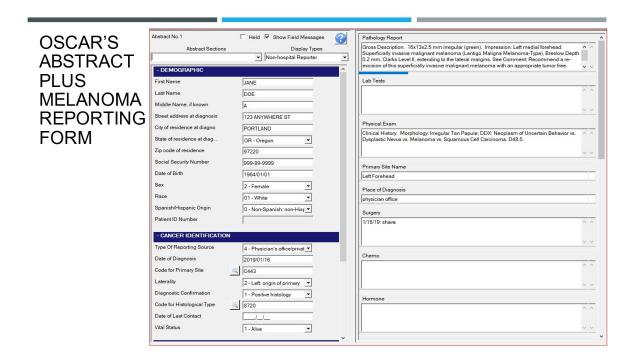




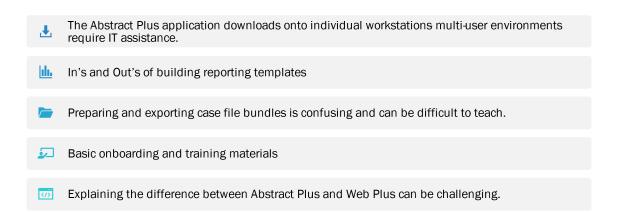
#### PAPER MELANOMA PATHOLOGY REPORT



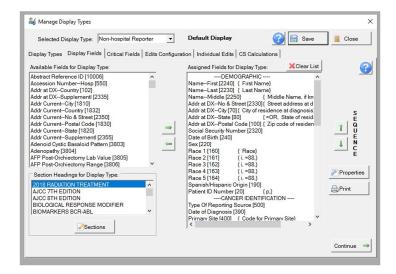




#### OPPORTUNITIES TO IMPROVE THE USER EXPERIENCE

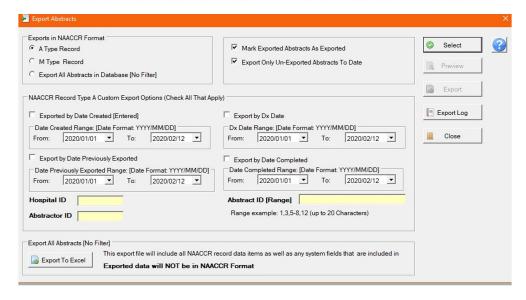


#### OPPORTUNITIES FOR IMPROVEMENT - TEMPLATES/EDITS





#### OPPORTUNITIES FOR IMPROVEMENT - EXPORTING ABSTRACTS









OSCAR'S

ABSTRACT PLUS

TRAINING

AND

ONBOARDING

MATERIALS



#### INFORMATIONAL OUTREACH LETTER TO AMBULATORY SURGERY CENTERS

10/6/2018

To Whom It May Concern:

Every year, thousands of Oregonians are diagnosed with cancer. The Oregon State Cancer Registry (OSCaR) was established in August 1995, after the Oregon Legislature unanimously passed legislation making cancer a reportable disease.

Under Oregon Revised Statute, all cases of cancer diagnosed on or after January 1, 1996, must be reported to the Oregon State
requires the participation of many reporting sources including hospitals, ambulatory surgical centers (ASC), physicians/practiti
oners, pathology labs, and other cancer treatment

Cancer is under -reported in Oregon. In an effort to reach cancer reporters who may not be aware of reporting requirements or understand how to report to OSCaR, we are directly contacting ambulatory surgical centers, physicians/practitioners, pathology labs and other cancer treatment centers we have identified with possible reporting obligations.

#### Ambulatory surgical centers and Cancer treatment centers :

- must report to OSCaR each case of reportable cancer or reportable non-malignant condition, in patients admitted for diagnosis or any part of the first course of treatment for that cancer.
- must report cases of reportable cancer or reportable non-malignant conditions to OSCaR within 180 days of the date the case first receives cancer diagnostic or treatment services at the facility.
- may elect to contract with a private vendor or contractor to report cases of reportable cancer and reportable nonmalignant conditions to OSCaR.
- may report to a health system cancer registry, discharging their reporting responsibilities provided that the health system r
  requirements for health care facilities.

Please find text and links to the applicable Oregon statutes and administrative rules, attached. OSCaR maintains a website which explains the cancer incidence reporting process, reportable diagnosis list, and case finding lists. <a href="https://www.oregon.gov/oha/PH/DISEASESCONDITIONS/CHRONICDISEASES/CANCER/OSCAR/Pages/index.aspx">https://www.oregon.gov/oha/PH/DISEASESCONDITIONS/CHRONICDISEASES/CANCER/OSCAR/Pages/index.aspx</a>

If you have any questions about Abstract Plus and/or your Cancer reporting obligation please do not hesitate to contact Shannon Evangelista at 971- 673-0986 or by email at SHANNON.D.EVANGELISTA@dhsoha.state.or.us.



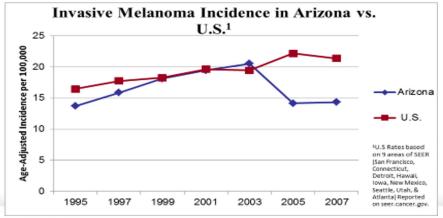


# Increasing Physician Melanoma Reporting with the Help of a Task Force

Arizona Cancer Registry
NAACCR Best Practices Workshop
Improving Non-Hospital Reporting
October 2020



### **Challenges Melanoma – Decreasing or Under-reported?**





#### **Challenges**

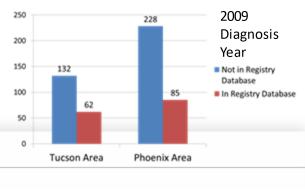
- Patients seen in outpatient settings increasing
- CDC NPCR Standards
  - Annually increase case reporting by urologists, dermatologists, and gastroenterologists, medical oncologists, radiation oncologists, and hematologists
  - For non-hospital facilities reporting to the CCR, increase percentage reporting electronically every year
- Internal challenges
  - Staffing/budgetary constraints
  - Arizona regulations
- Assumption Arizona has the highest rates of melanoma



#### **Process Development**

- Assumption Arizona has the highest rates of melanoma
- First meeting with researchers and physicians
  - To address: Declining rates of melanoma / under -reporting by physician offices
  - · Pilot Project: To assess reporting

Melanoma Task Force Members Multiple Disciplines		
AZ Cancer Registry	Dermatologists/Dermatopatholog	
Arizona SunWise Cancer Prevention Program	University: College of Public Health/Skin Cand Institute Dermatologist Epidemiologist Graduate Student	

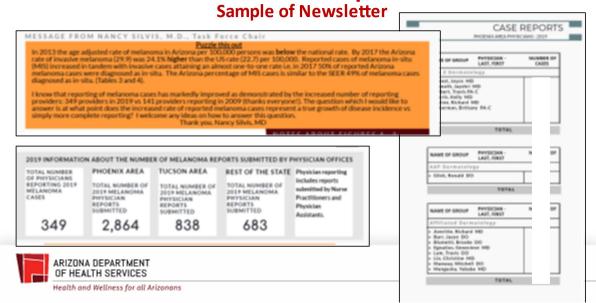


#### **Process Development**

- Worked with University to survey physicians to identify barriers to reporting / create a database of physician email addresses
- Educational presentations to dermatology societies
- Redesign of report form
- Dermatopathologists include statement on melanoma pathology reports
- Newsletter (physician names)
- Melanoma Profile
- Data Quality Indicator Report

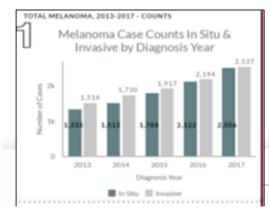


**Process Development** 



#### **Impact of Registry Operations**

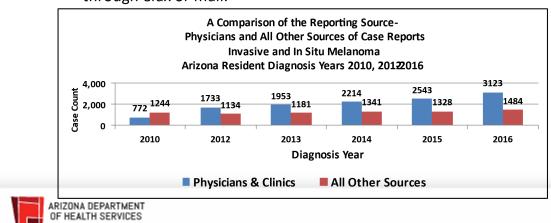
- Number of physicians reporting
  - 2019 Diagnosis Year = 349
  - 2009 Diagnosis Year = 141





#### **Impact of Registry Operations**

Most physician reported cases are paper case reports received through efax or mail.



#### Training, feedback and Communication with Users

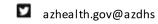
- **New Challenges** 
  - How does the registry keep up with melanoma reporting but also engage other physician specialties in cancer reporting
  - Continue engagement of physician reporting
  - How do we know we have all the melanoma cases?
- ACR Regulations
- Continue activities described (newsletter/periodic reports/direct physician reports)
- Arizona Cancer Plan Melanoma Task Force involvement
- Development of a Web Plus melanoma module for physician reporting
  - Many documents created: Onboarding, user guides, etc.
  - How to engage physician reporting during a pandemic: Created 4 recorded modules to assist in navigating Web Plus



Health and Wellness for all Arizonans

#### **THANK YOU!**

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#### **Tips to Improve Reporting from Nonhospital Sources**

Physician practices and other outpatient facilities rarely employ Certified Tumor Registrars; reporting to the central cancer registry often falls to office staff with little to no oncology training. It is important for central registries to provide them with tools to ensure data are as complete and accurate as possible.



#### Software Development

- Build abbreviated, targeted abstracts in Web Plus and Abstract Plus for dermatologists, urologists, radiation oncologists, and hematology oncologists.
- Modify field names and descriptions to be more intuitive for reporters.
- Develop training manuals and videos for nonhospital reporters.



#### **Education and Outreach**

- Contact state and local medical societies for opportunities to educate their members about cancer reporting requirements.
- Work with the state comprehensive cancer control program to build relationships with providers.
- Use pathology reports to identify physician offices that are not currently reporting.
- Partner with other programs within the health department that may have relationships and or access to providers.
- Provide data quality reports back to physician reporters.
- Survey physician practices to identify barriers to reporting.
- Maintain a contact list of nonhospital facilities and their reporting status.



#### Other

- Process nonhospital reports after reporting from hospitals is complete or near complete.
- Consider regulatory changes to require electronic reporting from nonhospital facilities.
- Request remote access to facility medical records to facilitate follow-back.