REGISTRAR PIP

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The Talking Heads Speak
(Cancer Surveillance Roundtable Highlights)

There were many interesting topics presented at the North American Association of Central Cancer Registries (NAACCR) annual meeting held in New Orleans between June 20-22, 2023. Initially, it was difficult to choose one topic to highlight for this issue of the Registry PIP. However, after thinking about what might interest most Washington State registrars, the choice was much easier to make. Most of us are likely very interested in the national leaders 'assessment of the current state of registry operations and what they envision going forward. Our reality is that what they think impacts how they choose to invest their resources, provides insight into the direction for the various programs, and ultimately how our jobs might be impacted.

The roundtable participants were Dr. Vicki Benard Chief of Cancer Surveillance Branch, Centers for Disease Control and Prevention (CDC); Dr. Heidi Nelson, Medical Director for Cancer Programs, for the American College of Surgeons (ACoS); Dr. Lynne Penberthy, Associate Director Surveillance Research Program (SRP), National Cancer Institute (NCI); and Betsy Kohler, Executive Director, NAACCR.

In the NAACCR program brochure, this session was being promoted as a planned informal discussion of the challenges related to capturing data from electronic health records, artificial intelligence, changes in cancer care as it relates to surveillance, patient privacy concerns and the complexities of data sharing. The moderator posed three specific questions to the group and each was given an opportunity to respond providing their personal and organizational perspectives. Note: These responses have been edited for length and clarity. They are not direct quotes.

First Question, "What are the significant threats to cancer surveillance?"

- **Dr. Nelson:** Maintaining the quality and security of the data is important and challenging given the increasing accelerated pace of change in clinical treatment and the access to electronic sources of information.

    Facilities will need to increase their involvement in Qualified Health Information Networks (QHIN), which are networks of organizations that work together to share data. These organizations connect directly with each other as a way to promote interoperability between the networks they are a part of. A QHIN has the ability to present cancer data in the literature quickly.

- **Ms. Kohler:** We will be unable to keep pace with change if we continue to cling to data collection methodology developed in the 1970's-1980's. Future data collection will require increased use of automation, expanding our datasets in order to be responsive to research and clinical needs, and adequate funding provided to registries to keep pace with these changes and requirements.

- **Dr. Benard:** Our focus needs to be on improving the timeliness of reporting by taking advantage of making changes to our infrastructure in order to do what we want in a quicker way.
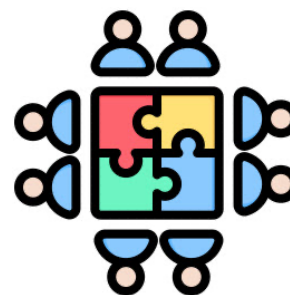
- **Dr. Penberthy:** The healthcare delivery system in the country is extremely chaotic in the sense that many of those on a patient's care team are not on the same electronic medical record system. In one sample review of the data, it was observed that over 40% of the data was missing. We need to gain access to all data sources both inpatient and outpatient.

  In addition, we know there is a diminishing number of well-trained CTRs. We need to figure out how to improve this profession and make it more exciting in order to attract new people to the field. We need to understand that no matter how much automation we have, we will always need CTRs.

Second question, **"What can we do to respond to these threats to cancer surveillance?"**

- **Dr. Penberthy:** We need to be aggressive in gaining access to new data sources, incorporating automation into our workflow, and promoting the use of data linkages to improve the quality and completeness of our data. Data linkages can also bring different types of sources together involving cancer patients to create new, richer datasets which will allow researchers to use the expanded cancer registry data in novel ways.

- **Ms. Kohler:** It's all about more education - - training and retraining. We need more education especially in the area of biomedical medicine. We also need to enhance generalized training to recruit good people into the profession. We need to do a better job of promoting what we do to the general public. We need to emphasize the need and value of data sharing in order to enhance research efforts, validate results, disseminate knowledge, and increase the pace of discovery.

- **Dr. Benard:** We need to look at other medical data collection systems to learn how we might improve our processes. For example, can we use the same data feed methodology, such as that used by physicians to report their HIV positive patients to the state department of health, to enhance pathology report transmission to the cancer registries more quickly?

  We need to work toward pulling data directly off the medical record to increase the speed of reporting, reducing the cost of data collection in order to improve the value of the registry data.

- **Dr. Nelson:** We need to reduce the cost of data collection while improving the quality of the data collected by standardizing how data is captured and coded. For example, we should consider using ICD-10 surgery codes rather than developing our own coding schemes and promote the use of synoptic patho reporting. This should help reduce the need for data interpretation.
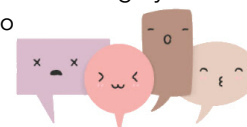
Third question, **"What makes you optimistic about the future of cancer surveillance?"**

- **Dr. Benard:** I think the most important thing is all the leaders of our organizations are working together and learning from one another. Everyone has a seat at the table.

- **Dr. Penberthy:** The NAACCR community (which includes registrars, clinicians, and researchers) are hardworking and committed to expanding our knowledge about cancer epidemiology and treatment outcomes by capturing and analyzing genomic data and population-based quality of care measures. Genomic data helps researchers better understand hereditary cancer burden and identify populations that would benefit from enhanced cancer screening and outreach efforts. Analyzing quality measures in health care can prevent the overuse, underuse, and misuse of health care services and can identify disparities in healthcare delivery and outcomes.

- **Dr. Nelson:** We need to shift from abstracting cancer data to auditing cancer data. Deep learning and data extraction tools have been developed and are continuing to be enhanced that will allow this shift to happen. We need to move to standardize data collection by the physicians to expedite this process (e.g., more widespread use of synoptic forms of data capture). The next generation of clinicians will embrace this type of

medical record documentation because it is quicker to do and continually reminds them of the information they need to record.

- **Ms. Kohler:** When I look around the room and I see so many new faces and hear the passion they have for this profession and the new ideas they are eager to share, I can't help but be optimistic about our future. (Note: There were 81 first time attendees at this NAACCR meeting.)

Those from CSS in attendance at this NAACCR meeting had their pens scribbling notes as fast possible in order to capture as much of the details shared by the leaders in our profession. After all, where they lead, we will need to follow. Bottomline, it seems we need to do more than merely accept change is coming. We need to embrace it so everyone can take advantage of these opportunities that will promote research discovery, improve patient outcomes, and enhance our role in this profession. What is clear from this meeting is that significant financial and intellectual resources are being invested at the national level to create this reality sooner rather than later. The forward thinking vision of the "talking heads" should prove to be a win-win-win all around when it materializes.

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