# Understanding Cancer Registries

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**Becca Battisfore:**

Welcome to the latest edition of the College of American Pathologists' CAPcast. I'm Becca Battisfore, Content Specialist with the CAP. On this episode, I'm joined by Dr. Lara Harik and Mildred Jones, who will discuss cancer registries. This is the first in a series of conversations about how cancer registries improve patient outcomes using the CAP's Cancer Protocols.

The Cancer Protocols help ensure that all pathology reports contain the necessary data elements for optimal patient care. By requiring specific data elements synoptic reporting increases accuracy and communicates findings in a clear standardized format to health officials, researchers, and clinicians.

Cancer registries also depend on the protocols for accurate standardized data collection. The curated data within a cancer registry provides essential information to better monitor and advance cancer treatments, conduct research, and improve cancer prevention and screening programs.

Before we get into the questions, let's learn more about our guests. Dr. Harik, would you like to introduce yourself?

**Dr. Lara Harik:**

Yes. Thank you so much, Becca. Hi, everyone. My name is Lara Harik. I'm a pathologist at Emory University Hospital in Atlanta, Georgia. And I'm the medical director of the Clinical Laboratories Hospital Service Line. I'm also the vice chair of the College of American Pathologists, or CAP, Cancer Committee. Happy to be here with you.

**Becca Battisfore:**

And Ms. Jones?

**Mildred Jones:**

Yes. Hi, my name is Mildred Jones and I'm the manager of the Cancer Registry Department at the hospital system in Atlanta, Georgia. And I'm also the liaison for the National Cancer Registrars Association for the CAP Cancer Committee.

**Becca Battisfore:**

Great. Thank you both for joining the podcast today. Dr. Harik, I'll let you take it from here.

**Dr. Lara Harik:**

Thanks so much, Becca. Mildred, I'm really excited to learn about cancer registries from you today. Let's start with the basic, what is a cancer registry?

**Mildred Jones:**

That's a great question. We really are in sort of in a niche area and a whole lot of people don't know who and what we do. So a cancer registry is an information system designed to collect, maintain, manage, and analyze the data for patients with a malignant or neoplastic disease. So over 1.7 million cases are collected annually, and if you've ever wondered how those statistics are compiled on cancer, whether it's incidents, stage, or outcomes, cancer registrars are at the forefront of that system. They're the data management experts behind that collection system.

**Dr. Lara Harik:**

That's great. Are there different kinds of cancer registries?

**Mildred Jones:**

Yes, there are. We have primarily three different kinds of registries, hospital registries, state or central registries, and special purpose registries. The hospital registries are probably what pathologists are most familiar with because they're in their community-based programs, their academic centers, and so they're likely to have run into a cancer registrar working behind the scenes in their program. Central registries are population-based registries which maintain data on all patients within a certain geographic area. And then special purpose registries are not as common, but they're certainly very important, they're maintaining data on a particular type of cancer. So for example, the Commission on Cancer, the National Cancer Database is a special purpose registry, as is the American Academy of Orthopedic Surgeons, their Musculoskeletal Tumor Registry.

**Dr. Lara Harik:**

That's very interesting. I've had rare phone calls from cancer registry personnel, who are the professionals who are working in this industry?

**Mildred Jones:**

So you may have heard of the term Certified Tumor Registrar or CTR. In order to be able to sit for that credential, candidates have to have completed an associate degree or at least 60 college-level credits and successfully completed a cancer registry management program, or a certificate program through the National Cancer Registrars Association.

**Dr. Lara Harik:**

Thank you. What type of data do they collect in the registrars? Or is it different types of data depending on the registrars?

**Mildred Jones:**

Primarily it's the same kind of data. It's very standardized, the way that we submit information to the national and really the international organization. So the various data points that are collected are demographics, treatment, clinical information on the cancer itself, follow-up. So for example, the demographics is the kind of information you'd imagine, the age of the patient, the gender, the race, birthplace. Clinical data is going to consist of tests and procedures that are used to diagnose that cancer. Dates and results are collected as well. Now, the cancer information is very specific, it includes not just the primary site and the histology, but very particular information on the extent of disease. And that varies, primary site to primary site. Treatment information is gathered as well, radiation, surgery, systemic therapy, and follow-up. Not everyone is aware, but annual follow-up on these patients does occur and that includes whether the patient has a recurrence, is disease free, what their patient status is.

**Dr. Lara Harik:**

It looks like part of the data that is collected is some of the data that we generate as pathologists. So how do the pathologists contribute to the registry data?

**Mildred Jones:**

That's a great question. We rely as CTRs a great deal on the pathology reports that come through. So those CAP Protocol Templates are critical for our data collection. For example, the colorectal template has about 36 elements on it, and of those 65% are collected by cancer registrars, 26 of them. And so it's really important for us to be able to rely on that path report as a source of truth for our data collection that ultimately not just gets populated in your hospital, it goes to the central registry and is the information that is used nationally.

**Dr. Lara Harik:**

Wow, that's pretty impressive for the Rectal Synoptic Worksheet or Cancer Protocol. Any other interesting facts you would like pathologists to know about cancer registries?

**Mildred Jones:**

One other thing I wanted to make mention about with the pathology report and just that we really do consider pathologists to be the cornerstone of that diagnosis and treatment for the cancer patient. It's not just determining the primary site and the morphology, but all of those molecular testing, and it's so important to have that information to be able to treat the patient and all of that information is really collected by the cancer registrars.

**Dr. Lara Harik:**

So Mildred, do you have any tips for pathologists on how they can shape their reports so that they are more helpful to the cancer registry personnels?

**Mildred Jones:**

That is a really great question. Really, as I mentioned before, we depend on that template a lot. That's our bread and butter if you will.

**Dr. Lara Harik:**

The Cancer Protocols?

**Mildred Jones:**

Yes, the Cancer Protocols. But when the pathologists are doing some text and narration, it is really important for registrars to minimize the amount of interpretation that we're doing in order to collect that data. And so the more standardized that language can be, the better for the data collection, not just on a local level, but again on a national level. We rely on that language consistency to determine even reportability of the cases and accurately coding those data fields.

**Dr. Lara Harik:**

Thanks so much, Mildred.

**Mildred Jones:**

Thank you.

**Becca Battisfore:**

Thank you both for joining the podcast to talk about cancer registries. And I want to thank you all for listening to this CAPcast. For questions about cancer registries and the Cancer Protocols, please email us at CancerProtocols@cap.org. And for more information about the CAP visit cap.org.