

# REGISTRAR PIP

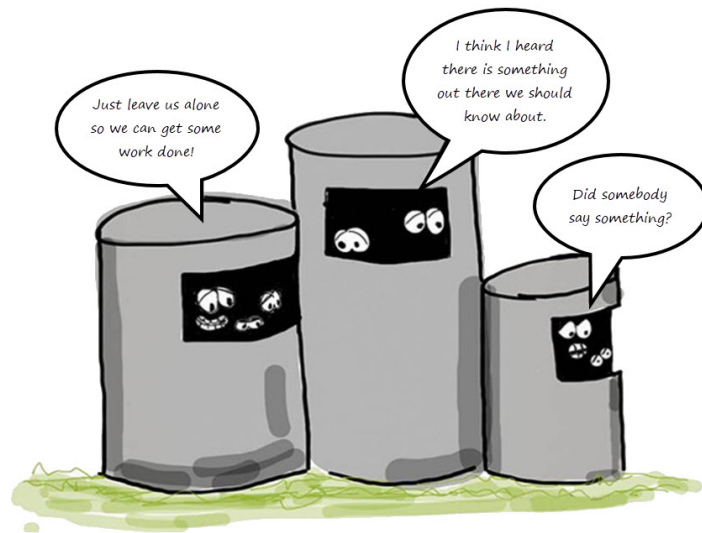
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## January 2025 Registrar PIP Follow the Money

### Background

Avoid the silo! Without realizing it, we may have inadvertently adopted a siloed mentality or created a siloed work environment. Ask yourself, "Am I solely focused on either my own "to do" list or addressing the needs and goals of only my registry?" Then ask yourself, "How does the registry help my organization reach some of its goals? Do I know what is important to the standard setters?" Depending on your answers, you may have taken up residency in a silo without realizing it. If so, the result is less visibility and appreciation for the work performed by the registry staff.

If we learn we might be a "silo resident," we will likely also discover we have become too busy to be productive in ways that matter most to our organization's leaders and the standard setters. We are too focused on our own registry operation and getting through our daily required tasks. Learning what matters most to those who currently use the data we collect needs to be a priority. That's how we move from being merely data collectors to becoming more valued, indispensable, and **funded!**



**Avoid the Silo Mindset**

### Introduction

When considering topics for these bimonthly newsletters, it's not uncommon for me to check the standard setters' websites to see if I run across a subject that might be of general interest to others. Is there something shared that relates to new goals, procedures, or applications that CSS could adopt to streamline registry operations, improve the quality of the data, or enhance the visibility of the registry?

Organizational, state, or national meeting presentations are other sources of topics for these articles. During such meetings, company leadership and standard setter representatives often discuss their short- and long-term goals. This represents the "more" they wish to achieve, the direction they'd like to see the organization move. After such meetings, even after returning to our offices to work on the "must do's" outlined in our job descriptions, we should prioritize at least thinking of ways the registry might be able to tackle the "more" wishes of others. It is likely that our success will be tied to our ability to effectively address stakeholders' critical requests for "more" who will be better positioned for longevity.

### The Google Reveal

While visiting the homepages of our standard setters, I can't tell you how many times I thought to myself, "Wow, that's interesting. Am I the only one who didn't know about this?" Granted, it was more often a case of "Oh, I remember someone mentioning this at a meeting once or twice." I must say, after today's searches my next thought was, "Wonder

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why they didn't mention it more often? Clearly, the "it" on the webpage was a bigger deal than I thought it was when I first heard or read about it!" You have to admit that over the course of multi-day conferences, so many things are discussed. After decades in this business, I can tell you some things currently being discussed have been brought up, dropped, and revisited more than once. So, I understand how difficult it might be to keep track of everything that might impact us personally in the either the short- or long-term that we should "prepare" for.

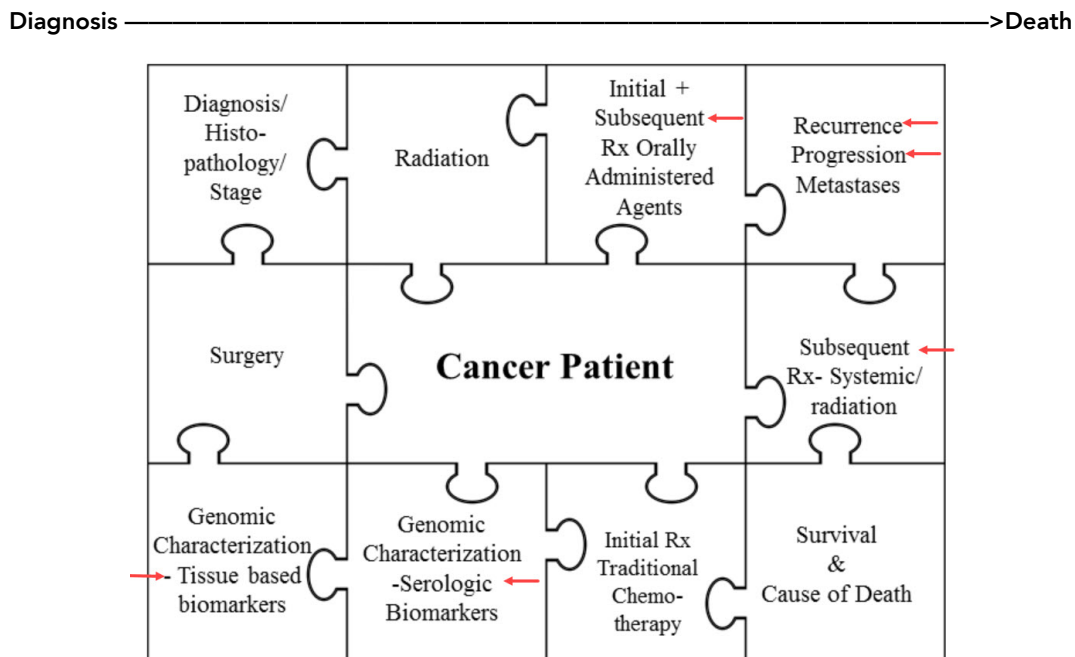
Thinking the most recently announced expectations of the registry standard setters might have escaped, I decided to do a little googling to see if I could locate anything describing how the standard setters need registries to evolve. Depending on what I found, sharing what I learned might help all of us best position ourselves and our registry to meet the challenges they outlined. I decided to view this as an exercise in self- and registry-preservation.

It probably won't surprise anyone to read that while scanning the standard setters' webpages and reviewing recent articles by their leaders, I found many similarities in the goals and expectations across the programs. But would you be surprised to learn the 2025 vision for the future seemed to echo that expressed a decade ago? It was impossible not to be smacked in the face with the realization that **their** goals and expectations **will** impact us because they **have** already started to impact us. The Surveillance, Epidemiology, and End Results (SEER) Program, for example, has been nothing if not consistent in terms of outlining the needs of registry data users (i.e., patients, clinicians, public health agencies, and researchers) and direction they'd like the SEER Program to position itself in order to be responsive to those user needs.

Figure 1 is a 2015 graphic I stumbled across while roaming the web. I decided it was worth sharing because it relates so closely to something written by Dr. Lynne Penberthy, former Associate Director for the Surveillance Research Program at National Cancer Institute (NCI), which was released only four months ago in a **JNCI Monograph**.

**Figure 1**  
**Cancer Surveillance: What do we need to collect?**  
 Putting the puzzle together for each patient

NCI Circa 2015



To those who don't have time to track down the monograph in order to read the eight-page article, I'll summarize the highlights. In her opinion, while registries do a great job of collecting data that describes cancer at diagnosis and capturing information needed to help produce incidence, survival and mortality rates, which is no longer enough to address the needs of all our users. Most registries' data collection efforts are insufficient to address the "whys" associated

with the differences in outcomes observed among patients with the same diagnosis, stage of disease, and treatment. Some of the “whys” could potentially be explained by studying molecular characteristics, genetic factors, and the patients’ responses and outcomes to various treatments. However, there is little reliable data available in the registry on tumor progression or recurrence and how such clinical developments were treated over time. We’ve only scratched the surface when it comes to collecting the molecular and genetic factors currently available.

According to Dr. Lynne Penberthy, she wants registries to be able to support clinically relevant population-based research by not only expanding **what** is collected, but she indicated it is also important to **move toward concurrent reporting** from diagnosis until death. Information is needed within a timeframe that could assist a physician and patient with finalizing both the initial treatment plan and any subsequent treatment plans that need to be considered due to initial treatment failure, subsequent tumor progression, or recurrence of disease.

### Follow the Money

Well, who among us wouldn’t want to be in a position to expand the “**what**” we collect to help address the “**why**” of every patient, clinician, and researcher and to do so **concurrently**? The issue from registrars’ perspective isn’t that we don’t want to do it. The issue is “**how**” do we do it without being given additional resources? I’m pretty sure we are willing to give up some of our manual (and even some of our less efficient automated) processing if there was a faster way of doing not only what is currently expected, but to be able to do more. However, I think we all recognize that more electronic methodology needs to be developed and then made widely available to the registries at little or no cost to be able to do the “**more**” everyone wants with the same number of staff.

In my humble opinion, the standard setters need to assume the financial responsibility associated with such development activities because individual registries likely lack the availability and capacity to do this. In addition, the standard setter either needs to centralize such development, or adopt the initial development they fund a single registry to create and then take charge of deploying it nationally.



You might be wondering at this point, “How did NCI’s Division of Cancer Control & Population Sciences divide the “grant” pie of research dollars?” I did learn there are currently over twenty statistical modeling projects funded which attempt to learn whether there is a mathematical relationship that might explain and help us understand how random and non-random variables are connected. Clearly, figuring out what a sample of the data we collect might mean and using that knowledge to predict what is going on in the real world is a priority at NCI. However, I didn’t see how those projects would help us in our effort to do more without increasing our staff size.

As I continued down the list of projects that received grant funding, I also discovered there are a number of projects looking at different ways to expand what we collect and suggestions for doing so. Luckily, most involve linkage and Natural Language Processing (NLP) electronic methods to capture this data. As you review the projects mentioned below, notice that most are evaluating different ways to capture molecular, additional treatment, and outcome data including recurrence, which appears to be the biggie. When standard setters spend money on something, it is a priority for them.

- **Keven Ward (Emory University)** – The **C**ancer **R**ecurrence and **I**nformation **S**urveillance **P**rogram (CRISP) will be the first registry of cancer recurrences. They will be using six data streams to identify potential recurrences occurring among cancer survivors originally diagnosed with breast, prostate, colorectal, and lymphoma primaries. They plan a review of medical records to validate true recurrences. Once the infrastructure is established and the methods are optimized, the recurrence registration protocols will be transportable to cancer registries with similar infrastructure and legal authority. (**Georgia** central registry involved.)
- **Ruth Etzioni (Fred Hutchinson Cancer Center)** - The goal of the **R**ecurrence from **C**laims and **P**ROs for **S**EER Enhancement (RECAPSE) proposed study is to develop a scalable approach for population-based ascertainment of cancer recurrence with a specific focus on breast cancer using ongoing research agreements with Puget Sound payers. She will develop an algorithm for detecting a first recurrence by combining medical claims with patient reported outcomes (PROs). The algorithms will be validated against gold-standard recurrence information based on

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electronic medical records from two major local providers. ([Seattle-Puget Sound](#) and [Kentucky](#) central registries involved.)

- **Imon Banerjee (Mayo in Arizona)** - A Natural Language Processing (NLP) toolkit will be developed to automate identifying outcomes for breast cancer patients to avoid the expense of manual abstraction. The toolset would be executed locally at the institution level and will select and organize the clinical and patient-centered outcomes of breast cancer patients by parsing clinic notes, radiology and pathology reports over time. Georgia SEER and California state cancer registry will be involved in testing the generalizability of the tools and to initiate their deployment for data collection using the outcome data of the past 10 years of breast cancer patients from two institutions. ([Emory University Hospital](#) (Georgia) and [Stanford Medical Center](#) (California) registries involved.)
- **Guergana Savova (Boston Children's Hospital)** – Current manual abstracting is time-consuming and only feasible for smaller datasets. In addition, it's difficult to correlate phenotypic data (e.g., tumor morphology, co-morbid conditions, laboratory findings, specific tumor behaviors [e.g., progression and metastasis] and response to treatment) with genomic data, which is being produced at an increasingly faster pace. This team of investigators is working to enhance **DeepPhe**, an NLP system, to extract cancer phenotype variables from electronic medical records for breast cancer, melanoma, ovarian cancer, diffuse large B-cell lymphoma and colorectal cancer cases to provide a resource of having the potential to provide new insights about cancer initiation, progression, metastasis, and response to treatment.
- **Mara Epstein (University of Massachusetts Chan Medical School)** - The project will include 1,128 aggressive diffuse large B-cell lymphoma (DLBCL) and 519 follicular lymphoma (FL) patients aged 18 years and older at diagnosis (2000-2018) with follow-up through 2021. They will create algorithms to detect recurrence using a rule-based approach involving expert knowledge and a machine learning approach that is data-driven. Post-diagnosis data including detailed treatment history, tumor characteristics, and healthcare utilization will be collected for all study participants, along with text-based clinical notes and reports. The goal is to: 1) develop and evaluate rule-based algorithms integrating data from health claims, electronic health records (EHRs), and tumor registries, including specific treatment data and results from relevant procedures; and 2) adopt a machine learning approach integrated with natural language processing to improve algorithm performance. ([Henry Ford Health System](#) (Detroit, MI) and the [Meyers Primary Care Institute/Reliant Medical Group](#) (Worcester, MA involved)).
- **Mia Hashibe (University of Utah)** – Recognizing cancer recurrence data are difficult to capture and require the evaluation of multiple data sources to accurately identify cancer recurrences, the Utah Cancer Registry (UCR) registry data already linked its data to the **Utah Population Database (UPDB)**, which includes electronic medical records (EMR), statewide healthcare facility data (inpatient, ambulatory surgery and emergency department), and claims data (All Payer Claims Database (APCD), Medicare). In this project they want to compare their currently available UPDB linkage by assessing linkages done in other registries using data sources more commonly available (e.g., Commission on Cancer recurrence variables, electronic pathology reports, and death certificates) for breast and prostate cases. In addition, they also plan to validate the breast recurrence identification algorithm recently developed in the Seattle-Puget Sound registry within the Utah breast cancer population. Doing so would allow this team to investigate the added value the UPDB linkage done at the UCR. ([Utah Cancer Registry](#) involved.)

### Conclusion:

Data is a registry's asset. Its value increases as we expand its ability to meet the needs of those who either currently use, **or could use**, the data if they were made aware of its existence and potential. It is important to learn more about our data including its strengths and limitations, and how we might address its limitations to meet the needs of our current and future users. To do so, we need to step outside our "silo" and check out what others are doing. We need to be open to making necessary changes because this is how we better position ourselves to do the "more" others continually want and expect us to provide.

It is key to recognize as cancer registrars we are simultaneously part of both local and national organizations. As such, avoiding the "silo" requires cross-team and cross-organizational communication and collaboration to recognize what should change and when to do it. Checking out what is available and promoted on the standard setter websites **and** the topics featured during their workshops and annual conferences provide clues as to their priorities. Another strong indicator

of the likely future direction of the national programs is learning how our standard setters allocate grant funding in pursuit of their goals and which projects could impact our registry operations. By paying attention to these clues and trying to implement what we can as it becomes available, we will optimize the potential of our registry and raise its profile within and outside the organization. This will help us stay not only relevant, but critical to others in the future.

