REGISTRAR PIP

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Cancer PathCHART Rollout Begins January 2024

Introduction

Some might be asking themselves; will someone explain to me what Cancer **Pathology Coding Histology And Registration Terminology** (Cancer PathCHART) is and why I should care about it? Here's the **big picture** response to that question. We've all seen terms that continue to be used by pathologists which are supposedly obsolete. Or we've noticed a new term in a pathology report that we've never seen before and we can't find that term in any of our coding references. How are we supposed to code primary site, histology, and behavior for these cases? Cancer PathCHART is promoted as a tool that will help us in these situations. In other words, it will be the bridge between cancer surveillance data collection standards we are expected to follow **and** what we actually see reported in the pathology reports.



The application will provide a map between the "expected and reality" so we know how to reflect the cases in our database. This sounds like something that has the potential to reduce what we at CSS refer to as the "dither factor" when it comes to coding difficult cases. Hopefully, we will no longer have to spend our limited time searching for pathology terms in multiple manuals. Nor will we need to consult with someone we think is smarter than we are when it comes to assigning the appropriate primary site/histology/behavior codes in these situations. More confident and consistently applied decision making will replace the needless dithering we currently experience when handling some of our tricky cases. This application certainly seems to have the potential to make our work a lot easier, right?

Background

The Cancer PathCHART initiative is aimed at having subspecialty subject matter expert (SME) pathologists, certified cancer registrars, and epidemiologists review tumor site-histology combinations and associated histology terminology and coding. Through this project the Site-Type Validation List, the Impossible Combinations List, and other cancer registration resources will be vetted by SMEs and updated more rapidly than it currently is. The updated information will be used in the edit packages made available by our national standard setters and will be provided to cancer registration software vendors for implementation. A companion webtool will subsequently be developed to allow searches of this validated information. The primary goal of this initiative is to improve data quality captured through cancer registration.

According to Allison Van Dyke, MD, PhD, FCAP of the Surveillance Research Program (SRP), "Major problems in data quality result from variations in terminology across standards and stakeholders' products creating confusion among pathologists, especially pathologists who are not subspecialty subject matter experts. There is a lot of

variation in terminology used over time and a lack of consistent reporting for heme, lymphoid, bone, and soft tissue malignancies. The consequence is a variation in understanding even among pathologists as well as cancer registrars, oncologists, researchers, and public health officials."

Inconsistent terminology over time (and even at the same time) can result if it is biased in a certain direction, resulting in important data quality issues that need to be addressed. The intent of Cancer PathCHART is to address data quality issues by improving the data alignment between the cancer surveillance group and pathologists and also help us code cases if there are changes over time or across standards in how various reportable cases are described.

Cancer PathCHART is a collaboration involving staff at the following organizations:

- World Health Organization (WHO)
- National Cancer Registrars Association (NCRA)
- North American Association of Central Cancer Registries (NAACCR)
- Surveillance, Epidemiology, and End Results (SEER) Program
- Commission on Cancer (CoC)
- National Program of Cancer Registries (NPCR)
- Statistics Canada
- International Association of Cancer Registries (IARC)
- International Collaboration on Cancer Reporting (ICCR)
- American Joint Commission on Cancer (AJCC)
- College of American Pathologists (CAP)



In Dr. Van Dyke's Cancer PathCHART presentations at both NCRA and NCRA, she indicated the clear vision that includes the following lofty goals associated with this initiative:

- → Coordinate standards across stakeholders for histology terms and for codes (histology, behavior, and primary site)
- → Function as the single source for cancer surveillance site/histology terms and codes
- Reduce the time between when new standards are released and when they can be implemented in the field in order to reduce the chance of creating differences in how tumors are reported by various parties
- ➡ Enhance public health data-driven research and statistics using higher quality recorded elements in our registry databases

Not all content is new ...

Part of coordinating this huge effort to insure consistency and accuracy in reflecting critical data items in the database is pulling together the various resources we use into a **single** product. This will facilitate the retrieval and updating of the necessary information associated with terms and codes for histology, behavior, and primary site.

There will be three **Updated Site/Histology Lists**. The core elements of the first two lists have been around for decades. Edits fail if we try to use site/histology combinations that do not exist. The third one is new.

- **⇒ Site/Histology Validation** (valid site/histology combinations)
- **Impossible** (biologically impossible site/histology combinations)
- → **Unlikely** (not on either of the lists above but we have these site/histology combinations with override flags associated to indicate we have reviewed the cases and the weird combinations were actually used by pathologists in the pathology reports)

There are also a couple of Histology Look-up Tables.

- → Valid codes
- → Comprehensive terminology used over time for each code

The updated lists associated with these site/histology standards will be freely available on the SEER website in multiple formats including a human-readable format for our vendors to use, and they will be integrated into the data quality edits.

Will this change how we do what we do every day?

Basically, in this initial rollout planned for January 2024 cases, there will be virtually no impact on who does what in any of our registries. For the majority of cases, these lists and edit updates provided to the vendors will all be operating behind the scenes as part of our registry software.

What will Cancer PathCHART achieve?

The primary objective is to improve the timeliness of integrating new standards to shortly after they have been released by the WHO. This will facilitate the concurrent abstracting process because it will allow us to code data items as they should be coded the first time we touch the case. Currently, if standards change, they typically cannot be implemented for a couple of years. As a result, we are forced to decide whether or not we should take the time to review the cases impacted by the changed standard that was actually released a couple of years beforehand. With Cancer PathCHART we will be able to avoid a lot of rework that we currently perform because of current implementation delays associated with the released WHO standards.

The longer-term plan is that the coding rules will subsequently be aligned with the Solid Tumor Rules, Hematopoietic Database, and other coding resources. The goal of this initiative is to ensure there is not conflicting information among the various resources.

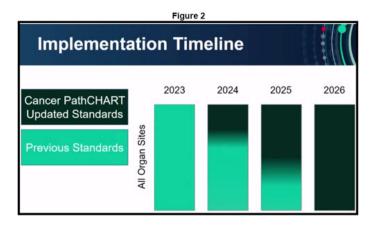
What has been accomplished so far?

Getting all eleven international organizations together to begin the review process was a huge undertaking. It may not surprise any of us to learn this is the first extensive update of the site/histology/behavior standards in over 15 years. While a lot of new terms have been added, it was discovered that outdated terms were not cleaned up. As a result, the outdated terms were still inadvertently being used in medical practice. It became clear to those involved in this project that additional guidance is needed to ensure the most current and accurate standards are being used by everyone.

Implementation Timeline

The previous standards will apply to all organ sites for 2023. Beginning in 2024, the implementation of Cancer PathCHART's updated standards by primary site will be phased in. The reason for a phased-in implementation approach is explained by what triggers the updates to the standards to occur **and** for the review process to begin. The trigger is the WHO's staggered release of new books associated with its **5th Edition of the WHO Classification of Tumours** series. After that occurs and it is determined the

After that occurs and it is determined the terms and the site/histology code combinations in the book are accurate, then the Cancer PathCHART team of pathologists start their review to incorporate the changes into the various lists, tables and edits.



The 5th edition, guided by the WHO Classification of Tumours Editorial Board, has established a single cancer classification presented across a collection of individual volumes. It is organized on the basis of anatomical site (digestive system, breast, soft tissue and bone, etc.) and structured in a systematic manner, with each tumor type listed within a taxonomic classification: site, category, family (class), type, and subtype. Figure 1 is a screenshot from the WHO website of the currently released volumes. Figure 2 is a copy of the slide from Dr. Van Dyke's NCRA presentation which graphically displays the implementation timeline over the next few years.

Registrar Education

The Cancer PathCHART team recognizes that their presentations during annual national meetings may not be enough to help everyone understand the full impact of the planned changes following operationalization of this initiative in the field by all of us. Let's face it, initial discussions regarding future planned changes occurring far before implementation often fall on deaf ears. The reason? They lack relatability until we are faced with seeing and trying to use something new. Many of us need and want relevant training to occur closer to when implementation occurs.

While some of us have been hearing about this initiative for a few years now, how many of us can answer the following questions regarding Cancer PathCHART?

Figure 1 **WHO Classification of Tumours Genetic Tumour Syndromes Skin Tumours Eye Tumours Haematolymphoid Tumours Endocrine Tumours Head and Neck Tumours Urinary and Male Genital Tumours Paediatric Tumours Central Nervous System Tumours Thoracic Tumours Female Genital Tumours Soft Tissue and Bone Tumours Breast Tumours Digestive Tumours**

- → What is Cancer PathCHART
- → Why is it needed?
- → What will change for registrars and registries?
- → What will not change?
- → How will Cancer PathCHART work with Solid Tumor Rules, Heme Database, etc.?
- ➡ What do we do if a site-histology combination is unlikely or impossible?
- ➡ What is the advantage for registrars in using Cancer PathCHART?

During our SEER Managers Meeting held in mid-July, Dr. Van Dyke indicated that they plan to develop initial training materials that will address these specific questions. She also outlined some of the following suggested methods to educate us on the basics when it comes to Cancer PathCHART:

- ➡ Short recording will be prepared to post on the SEER website making it readily available to us
- → Two page factsheet will be drafted to also post on the SEER website
- NAACCR will prepare an educational session to discuss how the changes made by the Cancer PathCHART impact the site/type histology tables and how those changes impact edits
- → A member of the Cancer PathCHART team will be available for a live Q&A session following the playing of a prerecorded presentation at any state association Fall meeting to which they are invited
- → Presentation is planned for the December 2023 SEER Advanced Workshop
- → NCRA Education Center for Cancer Registry Education will prepare a training module
- → Publications will be prepared

Second Timeline: Registrar Education Rollout

The training will begin this month. After the January 2024 scheduled implementation date, training will continue but shift focus to address questions and issues submitted by hospital and State cancer registrars through the **Ask** a **SEER Registrar** website. We at CSS will submit our questions and issues through the **SINQ** website. Throughout 2024, initial presentations will also keep us informed about the status of the development of what will be a freely

available searchable interface of 2024 Cancer PathCHART ICD-O-3 Site Morphology Validation List standards. This webtool is scheduled to be available in 2015.

Conclusion

Tumor site, histology, and behavior are the most basic data items collected during cancer registration. Site-specific tumor terminology and valid tumor site-histology combinations have changed over time and have been observed to differ between those used in medical practice and cancer registry operations. This has resulted in a variation in terminology usage and understanding among physicians, researchers, tumor registrars, and public health officials. Unless addressed, the potential for inconsistent cancer surveillance data would continue.

To the rescue . . . the Cancer PathCHART initiative working group intends to better align cancer registry operation standards for tumor site-histology combinations and associated terms/codes with current medical practice. This initiative is the first of its kind that includes multilevel reviews conducted by subspecialty matter expert pathologists and registrars to update tumor site-histology standards for cancer registration.

So . . . if this is what it takes to make our coding life a little easier at CSS, we're all in!