REGISTRAR PIP

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The Future: A One Stop Shop for Primary Site and Histology Coding

Introduction

For those of us who have been frustrated trying to figure out how to code pathology terms we've never seen before or the increasing length of time it takes to find the correct histology code for a given primary site or wondering why it takes so long for the World Health Organization (WHO) to keep their ICD-O editions in sync with the WHO Blue Books, help is on the way. The Data Quality, Analysis, and Interpretation Branch (DQAIB) in the National Cancer Institute's (NCI) Surveillance Research Program (SRP) is responsible for designing and developing methods and tools to tackle such issues. One goal of this team is to ultimately integrate pathology, genomics, genetics, and medical imaging sources with traditional cancer registry data. In doing so, this branch of the government hopes to position itself at the forefront of efforts to release clinically relevant data in support of cancer control research.

Background

When it comes to cancer, the classification of tumors is essential to making a correct diagnosis. The accurate classification of tumors also informs research into cancer epidemiology, prevention, and treatment, making a consensus critical for pathologists around the world. That's the help the World Health Organization (WHO)'s Classification of Tumors series, also known as the Blue Books, has been providing the medical community since 1967. The fifth edition of the series was released in 2019.

The Blue Books, published by the WHO's International Agency for Research on Cancer (IARC), consist of a series of 15 books compiled by expert consensus, each of which focuses on a major tumor group and defines the cause, mechanism, sign and symptoms, basic structure, diagnosis, epidemiology, and outcomes of types of tumors. Traditionally, cancer classification has been based on consensus of histopathological opinion. Terms included in the Blue Books appear in the International Classification of Diseases for Oncology (ICD-O). However, in a rapidly evolving field we can no longer rely solely on histopathological features to classify tumors because there is a need for more frequent updates to our coding systems that can accommodate the improved understanding of tumors at the molecular level and the impact of digital pathology and image analysis.

SEER Manager Quality Improvement Experts (QIE) Meeting Highlights

The purpose of these annual meetings is to improve and maintain the Surveillance, Epidemiology and End Results (SEER) Program registry operations and the quality of SEER data. During the September 2021 meeting, we learned about the status of current projects under development. In breakout sessions, we discussed their potential impact on our understanding of tumor histology classification, which will also impact the manner in which coding histology will be done with the resulting goal of maintaining and potentially improving the data quality for cancer surveillance.

Two interesting projects mentioned during the meeting were the **Tumor Site-Histology Term Finder** project presented by Ngoc Tran MD, MS and Alison Van Dyke, MD, PhD which will hyperlink into the much larger **Cancer Pathology Coding Histology And Registry Terminology (Cancer PathCHART)** project presented by Kathleen (Thoburn) Loomis, CTR.

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√ Tumor Site-Histology Term Finder Project

Ultimately, this project will provide an open source web-based interactive platform for us to explore tumor histology terms based on the WHO's 5th edition Blue Books with associated existing and proposed ICD-O codes classified by anatomic regions and organ systems. Currently, only the following five books covering these topics are available:

- Digestive system tumors
- Breast tumors
- Soft tissue and bone tumors
- Female genital tumors
- Thoracis tumors

While this tool is intended to help us learn the tissue origin of each Blue Book topic's tumors such as breast tumors (e.g., epithelial, mesenchymal, hematolymphoid, etc.) and list tumors that fall into each of those categories (e.g., mesenchymal tumors include various adipocytic, smooth muscle, vascular, etc. tumors) along with their corresponding histology codes, the scope of this particular project is narrowly defined and is not intended:

- to be a complete reference source for site and histology terms given it only covers tumors discussed in the 5th edition Blue Books released
- as a replacement for the Solid Tumor Rules
- to determine tumor reportability

Given that this tool can't be used to code primary site/histology, you might be asking yourself, "What is value in using the product?"

This tool will be released before Cancer PathCHART, the tool we will ultimately find more helpful when abstracting and coding. However, between the release of the **Tumor Site-Histology Term Finder** and **Cancer PathCHART** tools, when we see a pathology term we've never seen before and we want to know whether it is listed in a WHO Blue Book and how it is classified, this web-based tool can point us in the right direction. This tool is being created to include preferred terms with hyperlinks that will ultimately take us to Cancer PathCHART where we will find more information on related terms, synonyms, and codes.

Not a lot of us have access to the voluminous and expensive Blue Books so we aren't able to easily figure out whether the terms we run across in pathology reports are currently being considered as reportable at the international level or what the preferred term is for the diagnosis per the WHO. This tool provides us a sort of "Blue Books lite" edition of the manuals which is tailored to our needs as registrars.

√ Cancer PathCHART Project

This was clearly one of the more exciting projects discussed during the meeting and one that we suspect will be a tool we can use to not only improve our accuracy but our speed at determining whether the given histology is reportable, the number of primaries, and the correct primary site and histology to assign. The Cancer PathCHART tool is intended to be a "one stop" resource that uses an integrated, relational database to link histology terminology with tumor topography, morphology, behavior codes and descriptions across versions of:

- WHO Classification of Tumors (Blue Books)
- WHO International Classification of Diseases for Oncology (ICD-O-3.2)
- College of American Pathologists (CAP) protocols and electronic Cancer Checklists (eCCs)
- American Joint Commission on Cancer (AJCC) histology terms and codes included in AJCC Cancer Staging Manual editions and systems

According to Ms. Loomis, the Cancer PathCHART collaborative effort, as well as the development and implementation of the Cancer PathCHART tool and API (Application Programming Interface) will:

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- Coordinate the data products of participating organizations drawing from the database as a standard
- Improve public health data quality obtained through cancer surveillance
- Decrease the timeline for implementation of changes in histologic diagnosis by the registry community from the point of release of the source information
- Bridge the gap between clinical language and surveillance codes

As we've all experienced, when the latest versions of the Blue Books were released in 2019, we started seeing new terms we couldn't necessarily (or at least easily) code. It has proven problematic that an ICD-O4 edition has yet been released. We are limited to the codes available in ICD-2 and 3.

It is also known different organizations have some different terms others do not use. In addition, the hope is that with the development and release of this these products we will see a reduction in the time between when a term is released by WHO and when it appears in vendor abstracting software for our use. While the project seems a herculean task, the collaborative effort brings together the talent and expertise of the following organizations to standardize and harmonize terminology:

- American College of Surgeons, Commission on Cancer
- American Joint Committee on Cancer
- Centers for Disease Control and Prevention, National Program of Cancer Registries
- College of American Pathologists
- World Health Organizations/International Agency for Research on Cancer
- International Association on Cancer Registries
- International Collaboration on Cancer Reporting
- National Cancer Institute, Surveillance Research Program
- National Cancer Registrars Association
- North American Association of Central Cancer Registries.

1 **Phase 1: January 1, 2023 Implementation**

Three outputs expected from the Cancer PathCHART project:

- **Histology Look-up Table**

  The histology look-up table will allow vendors to incorporate this information into dropdowns we can use in our abstracting software. The look-up table will be the definitive list of ICD-O histology codes and acceptable terminology for each code (i.e., all alternate terms/synonyms) standardized and harmonized across current coding resources (e.g., WHO Blue Books, ICD-O, CAP, AJCC). The histology look-up will include updates for diagnosis year 2023 and will go back through time across diagnosis year.

- **Updates Site/Histology Lists and Edits**

  Currently, several lists with corresponding edits exist to identify the valid, unlikely/rare, impossible, and inaccurate combinations of site, histology, behavior, and/or diagnosis date data items. These lists and edits will need to be updated after the histology look-up table has been finalized.

ADVANTAGE: The ***inaccurate category*** will include a new list and corresponding edits with error messages to the abstractor indicating a recommendation as to how to correctly code the case when we initially use an inaccurate combination of site, histology, behavior, and/or diagnosis date.

- **Tumor Site-Histology Term Finder**

  A web-based, visual, interactive tool for tumor registrars to explore the current histology terms and ICD-O code in connection with selected sites. Those working on the development of this tool stated it may be

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released prior to January 1, 2023 because the information used to develop the content for this tool comes directly from the Blue Books which are currently available.

2 Phase 2: Post 2023 Implementation . . . What's next?

Registrars will be able to search the Cancer PathCHART database directly via an open-source web-based graphical user interface.

Features: Cancer PathCHART vs. Tumor Site-Histology Term Finder

During her presentation, Ms. Loomis provided a summary (Table 1) that compares the two tools in terms of scale, standard setter involvement, work groups, content, goals, search parameters, and target users. The summary is a concise and effective means to highlight the currently planned features of each tool.

Table 1
Tool Feature Summary: Cancer PathCHART and Tumor Site-Histology Term Finder

Feature Comparison	Cancer PathCHART	Tumor Site-Histology Term Finder
Scale	Large	Small
Standard Setter Involvement	Many organizations/standard setters involved	No standard setters involved (includes content from WHO Blue Books only)
Workgroups	Four work groups comprised of volunteers from all standard setting organizations including CAP, WHO, and IACR: - Standards and Harmonization - Content - Database Development - Implementation and Logistics IMS (Database and Web Tool development staff)	A content extraction group of individuals (3 current members with one contractor)
Content and Change Tracking	Harmonizing ***old***, ***current***, and ***proposed*** histology terms and codes across **WHO Blue Books, ICD-O, CAP** and **AJCC** for implementation in North America	Using only histology terms extracted from **WHO Blue Books** with associated ***current*** and ***proposed*** ICD-O codes, as they are released
Goals	**Phase I** 1. Providing histology look-up table for consumption by cancer registry software vendors 2. Providing updates to Site/Histology Validation Lists (edits) **Phase II** Providing a database search function for end users via a Web Tool	Providing both a search function and an interactive visual navigation of the clinical relationship of primary site with associated existing and proposed histology terminology and ICD-O codes
Search Parameters	Multiple parameters with multiple search result sections	Search by histology term, code, or primary site with a behavior filter
Target Users	**Primarily cancer registrars**	

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The various workgroup roles include the following responsibilities and activities:

Standards and Harmonization Workgroup – Will look at implementation timelines for the various products used in the development of these tools and try to harmonize the timelines across the various organizations so it possible to move as quickly as possible once a new WHO term is identified to having it implemented in North America.

Content Workgroup – Responsible for identifying content for inclusion in the Cancer PathCHART database. Currently, members are extracting Blue Book content which is over and above what will be needed for the Tumor Site – Histology Term Finder tool.

Database Development Workgroup - There is a large Scratch Database hosted by CAP in use today. All currently available resources involving site/histology coding are being entered into it. The Scratch Database will support the Content Workgroup's effort of reviewing site/histology combinations. Once all the resources have been included, templates will be created for the pathologists to review. It is anticipated there is obsolete and duplicative information currently in the Scratch Database that will need to be deleted or consolidated. Following this activity, this committee will outline the specifications for the production database.

Implementation and Logistics Workgroup - Currently this group is gathering user interface specifications for this tool.

Early Draft of Potential Search Result Screen Displays for Cancer PathCHART

To illustrate why we are so excited about the impact of this project on abstractors, we have included an example of the search results screens that would appear if we opted to look up the term *pleomorphic lobular carcinoma in situ* in Cancer PathCHART. These screen display mock-ups (1-3) were also presented during the meeting by Ms. Loomis.

Screen Display Mock-up 1
Pleomorphic lobular carcinoma in situ

Definition: Pleomorphic lobular carcinoma in situ is a non-invasive neoplastic proliferation of dyscohesive cells, originating in the terminal duct lobular unit showing significant pleomorphism**.**

Alternate Names:

WHO classification of breast, series 5 acceptable: Pleomorphic lobular neoplasia

WHO classification of breast, Series 5 not recommended: non-classic lobular carcinoma in situ; variant lobular carcinoma in situ; lobular intraepithelial neoplasia

Member(1) of: In situ lesions of breast; lobular carcinoma in situ; epithelial in situ lesions

WHO Classification of Tumours(2)

Breast, Series 5, 2019
Breast, Series 4, 2012

(1) Member refers to the tumor family indicated in the Blue Books

(2) Blue Book in which the term appears with links to the pages in the series included

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Screen Display Mock-up 2 Coding: Pleomorphic lobular carcinoma in situ			
Coding System	**Code**	**USA Valid Dates**	**IACR Valid Dates**
ICD-O 3.2	8519/2	2021	2020
ICD-O 3.1	8520/2	Not applicable; See 2014-2017 & 2018-2020 NAACCR ICD-0-# Implementation Guidelines	2012-2019
ICD-O 3.0	8520/2	2001-2013	2000-2011
ICD-O topography	C501-C509		
ICD11	2E65.0 & XH6EH0		
ICD10 (2010)	D05		
ICD10 (2008)	D05		
Birch	Not applicable		
ICCC3	Not applicable		
Tips for Cancer Registrars: Pleomorphic lobular carcinoma of the breast was first described in the 2012 WHO classification of breast tumors and is considered a sub-type of lobular carcinoma in situ.			

Screen Display Mock-up 3 Staging: Pleomorphic lobular carcinoma in situ			
Staging System	**Chapter**	**USA Valid Date**	**IACR Valid Dates**
AJCC8	Chapter 48/Not staged	2018+ (SEER EOD)	
AJCC7	Breast	2010-2017 (SEER CS)	
UICC8	Breast		2018
UICC7	Breast		2014-2017
College of American Pathologists Datasets: Breast v8: C Key: 812738172 Breast v7: C Key: 1289371982			

Conclusion

Cancer PathCHART is one initiative led by the Data Quality, Analysis, and Interpretation Branch that has a goal to ensure data quality and usability while simultaneously expanding pathology resources for population-based cancer research. This tool is being designed to address the primary data quality and data usability issues that impact registrar coding of tumor site and histology. It is being developed collaboratively between standard-setters in in the hope that it will map tumor histology terminology and coding across all standard-setter resources. Ultimately, Cancer PathCHART will include a suite of resources for tumor registrars, end users of cancer registry data, and tumor registry software vendors. The future suite of webtools will allow users to view mapped histology terminology and cancer coding and will permit searches of histology terminology and codes, their reportability, standard sources, valid site-histology combinations, and diagnosis years for which they are valid.

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