North American Association of Central Cancer Registries, Inc.

GUIDELINES FOR ICD-O-3 UPDATE IMPLEMENTATION

Effective January 1, 2014

Prepared by the

NAACCR ICD-O-3 Update Implementation Work Group

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ICD-O-3 WORK GROUP MEMBERS

April Fritz, Chair
A. Fritz and Associates, LLC
april@afritz.org

Lois Dickie
National Cancer Institute
dickielo@mail.nih.gov

Donna Gress
American Joint Committee on Cancer
dgress@facs.org

Ann Griffin
UCSF Comprehensive Cancer Center
Ann.Griffin@ucsfmedctr.org

Annette Hurlbut
Elekta
annette.hurlbut@elekta.com

Linda Mulvihill
Centers for Disease Control and Prevention
LMulvihill@cdc.gov

Gail Noonan
Manitoba Cancer Registry
gail.noonan@cancercare.mb.ca

Steven Peace
Florida Cancer Data System
speace@med.miami.edu

Jerri Linn Phillips
American College of Surgeons
Commission on Cancer
jphillips@facs.org

Lynn Ries
National Cancer Institute
rieslynn@mail.nih.gov

Winny Roshala
Cancer Registry of Greater California
wroshala@crgc-cancer.org

Carol Russell
Alberta Cancer Registry
carol.russell@albertahealthservices.ca

Shannon Vann
NAACCR
svann@naaccr.org

1 INTRODUCTION

These implementation guidelines, developed by the North American Association of Central Cancer Registries, Inc. (NAACCR) ICD-O-3 Implementation Work Group and approved by the Cancer Registration Steering Committee (CRSC) Change Management Board (CMB), address implementation of ICD-O-3 Update terms and codes for cases diagnosed on or after January 1, 2014. Members of the work group represent standard setting organizations, central registries, and cancer registry software vendors.

On an international level, the need was recognized in 2010 for updating the morphology section to accurately code contemporary diagnoses described in the terms of the fourth editions of the World Health Organization's Classifications of Hematopoietic and Lymphoid Neoplasms, Tumors of the Central Nervous System, and Tumors of the Digestive System. In September 2011, the International Agency for Research on Cancer (IARC) and the World Health Organization (WHO) released the document *Updates to the International Classification of Diseases for Oncology, third edition (ICDO-3)* (http://www.who.int/classifications/icd/updates/ICDO3Updates2011.pdf). According to that document, the changes were valid for implementation with cases diagnosed January 1, 2012, and later. Many countries adopted the new terms and codes immediately; others, along with the United States, have taken a more stepwise approach to implementation.

The CRSC in North America recommended that NAACCR member registries not incorporate the updates until the impact of these changes could be evaluated. CRSC requested that NAACCR create a work group to determine how and when NAACCR member registries should implement the ICD-O-3 changes. The ICD-O-3 Update Implementation Work Group, with April Fritz as chair, began meeting in July 2012. The Work Group forwarded their implementation recommendations to the CMB in June 2013. The CMB reviewed the recommendations and accepted them with implementation dates as shown below. The CMB instructed the ICD-O-3 Update Implementation Work Group to prepare a communication plan to disseminate the information to NAACCR members. This implementation document is one step in disseminating the information. The changes and effective dates follow.

The ICD-O-3 Implementation Work Group was charged with developing the implementation document and they will also act as the clearinghouse for review and resolution of ICD-O-3 implementation questions. If there are any questions, email them to April Fritz (april@afritz.org) as chair of this Work Group. Updates will be posted on NAACCR's web site (www.naaccr.org). The Work Group will also be communicating updates via email using the NAACCR listserv and mailing lists of all organizations involved.

2 BACKGROUND AND IMPLEMENTATION ISSUES

Implementation of new standards is never 100 percent problem-free. In anticipation of questions that may arise in this update, the Work Group has developed the following explanations.

2.1 Why is there an update to ICD-O-3 at this time?

WHO has been publishing updates to the WHO Classification of Tumors (Blue Book) series for several years. As part of each new edition, subject matter experts review current literature pertaining to the organ or body system covered in the WHO Classification and make recommendations regarding revised histologic terminology. These revisions are reviewed pre-publication by the WHO/IARC Committee on ICD-O-3 to make sure that recommended code changes and additions are appropriate. When each new Blue Book edition is published, the terminology and codes are introduced into contemporary pathology terminology to be used in pathology reports. Malignant diagnoses from these books that find their way into cancer registries may not be listed in ICD-O-3, the standard reference for reportable conditions. This becomes an issue if there is no histology code available to register a case.

The IARC and WHO responded to this by creating a list of terms and codes that were added or modified in the new edition of the Blue Books in print as of 2010. In September 2011, WHO published the first update to the ICD-O-3 since its publication in 2000. The 2011 Update list incorporated terms from the Blue Books published at the time:

WHO Classification of Tumors of the Central Nervous System (2007)
WHO Classification of Tumors of the Hematopoietic and Lymphoid Tissues (2008)
WHO Classification of Tumors of the Digestive System (2010)

It should be noted that the terms and codes pertaining to the *WHO Classification of Tumors of the Hematopoietic and Lymphoid Tissues* (fourth edition, 2008) had already been reviewed and accepted by NAACCR and were implemented for use in North America effective with cases diagnosed on or after January 1, 2010. These hematopoietic and lymphoid terms comprised almost half of the terms on the 2011 WHO ICD-O-3 Update List.

2.2 How sweeping are the changes?

The CMB has approved 36 new terms to be added to existing codes in ICD-O-3 for use in the United States and Canada beginning with cases diagnosed on or after January 1, 2014. Of these terms, 21 are malignant (/3) terms, and one is a new borderline (/1) tumor of the central nervous system. All of these are reportable. The remaining 14 are benign (/0) or uncertain malignancy (/1) and are not reportable conditions. Table 1 displays the terms approved for use with 2014 diagnoses and forward.

It is important to understand that cancer registry reportability rules based on behavior code still apply. With the exception of primary intracranial and central nervous system benign and borderline tumors, the addition of a /0 or /1 coded term to ICD-O-3 does not imply that it is now reportable.

For 2015, 16 new codes and terms were proposed for addition to ICD-O-3. Of these, 7 are reportable malignant (/3) tumors and 4 are reportable borderline (/1) tumors of the central nervous system (see Table 2). The implementation of these updates was postponed until 2015 because these are new codes, and the terms cannot be used until the codes have been added to registry manuals, software, edits, and documentation. Most of these new codes and terms are rare or very site-specific. The newly reportable malignant codes were not incorporated into CS version 02.05 and thus cannot be used at this time because no CS Stage Group will be derived. Until the new codes can be used, the Work Group has prepared a coding guideline (Table 2) for the terms with new codes on the WHO Update List, (which may appear in pathology reports) showing which existing codes to use.

Also proposed for 2015 is a behavior and reportability change for carcinoid of the appendix (See section 4). This change was made in the *WHO Classification of Digestive System Tumors* published in 2010. The Work Group supports this reportability change, since current terminology for "carcinoid" – well-differentiated neuroendocrine tumor – is coded to 8240/3 and most 'former' carcinoids of the appendix are already being accessioned under the new terminology. Based on an analysis of data from a large university hospital pathology department and cancer registry, the Work Group believes there will be only a minimal effect on casefinding and abstracting if all carcinoids of the appendix are made reportable. Canada adopted this behavior and reportability change for carcinoid of the appendix as of 2012 diagnoses.

2.3 Why is the 2014 list of approved terms so limited compared to the WHO ICD-O-3 Update List?

As mentioned above, the CRSC wanted to proceed deliberately and study the implications of adding new codes and terms. The first terms approved by the CMB (for 2014) are additions (synonymous terms) to existing codes so there should be no problems with invalid codes or edit conflicts. The next set of terms to be implemented in 2015 includes new codes and terms. The delay in implementing terms with new codes is to allow software vendors and others who work with ICD-O-3 codes in their databases to have more time to add new codes, check code ranges and test any software revisions. The discontinuation of Collaborative Staging has further delayed the use of the new malignant codes until 2016. The remaining terms may or may not be implemented for cancer registries in the United States because of the terminology used and potential reportability issues. Please refer to the remaining ICD-O-3 issues in section 5 of this guide.

2.4 What about training for data collectors?

Short articles/announcements have been issued in blast emails from standard setting organizations and in the *Journal of Registry Management* to highlight some of the changes, and more are planned. Educational materials/presentations are also planned.

2.5 What are the conversion issues?

To the Work Group's knowledge, there are no conversion issues with the list of terms in Table 1, as they are terminology additions to existing codes. There is one recode required in 2015, which will have minimal impact on cancer registries and could be done manually (see section 4).

2.6 Will a new version of the ICD-O-3 manual be available?

WHO has announced a "first revision" of ICD-O-3. It is important to note that this new printing includes all of the terms added to ICD-O-3 in the 2011 WHO Update. Consequently, purchasers of the "ICD-O-3 First Revision" may be confused by terms added internationally but not yet implemented in the United States and/or Canada. At this time, the Work Group recommends using the original publication of the ICD-O-3 book (Copyright 2000) since only the terms in Table 1 have been approved in the United States and Canada for 2014 and forward.

Until all update terms are approved for use in the United States and Canada, print Tables 1 and 2 and include those terms in the original ICD-O-3 book.

3 TABLE 1. ICD-O-3 CHANGES EFFECTIVE JANUARY 1, 2014

Use the following new terms, synonyms, and related terms for existing ICD-O-3 codes.
Bold indicates a preferred term. Sans-serif font indicates a new reportable term.

New preferred term	8150/0	**Pancreatic endocrine tumor, benign (C25._)**
Move former preferred term to synonym	8150/0	Islet cell adenoma (C25._)
New related term	8150/0	Pancreatic microadenoma (C25._)
New preferred term	8150/1	**Pancreatic endocrine tumor, NOS (C25._)**
Move former preferred term to synonym	8150/1	Islet cell tumor, NOS (C25._)
New preferred term	8150/3	**Pancreatic endocrine tumor, malignant (C25._)**
Move former preferred term to synonym	8150/3	Islet cell carcinoma (C25._)
New related term	8150/3	Pancreatic endocrine tumor, nonfunctioning (C25._)
New related term	8152/1	L-cell tumor
New related term	8152/1	Glucagon-like peptide-producing tumor (C25._)
New related term	8152/1	Pancreatic peptide and pancreatic peptide-like peptide within terminal tyrosine amide producing tumor
New synonym for related term	8152/1	PP/PYY producing tumor
New preferred term	**8154/3**	**Mixed pancreatic endocrine and exocrine tumor, malignant (C25._)**
New related term	8154/3	Mixed endocrine and exocrine adenocarcinoma (C25._)
New synonym for related term	8154/3	Mixed islet cell and exocrine adenocarcinoma (C25._)
New related term	8154/3	Mixed acinar-endocrine-ductal carcinoma
New related term	8201/3	Cribriform comedo-type carcinoma (C18._, C19.9, C20.9)
New synonym	8201/3	Adenocarcinoma, cribriform comedo-type (C18._, C19.9, C20.9)
New synonym to primary term	8213/0	Traditional serrated adenoma
New related term	8213/0	Sessile serrated adenoma
New related term	8213/0	Sessile serrated polyp
New related term	8213/0	Traditional sessile serrated adenoma
New related term	8240/3	Neuroendocrine tumor, grade 1
New related term	8240/3	Neuroendocrine carcinoma, low grade
New related term	8240/3	Neuroendocrine carcinoma, well-differentiated
New preferred term	**8244/3**	**Mixed adenoneuroendocrine carcinoma**
Move former preferred term to synonym	8244/3	Composite carcinoid
New synonym	8244/3	Combined/mixed carcinoid and adenocarcinoma
New synonym	8244/3	MANEC

New synonym	8249/3	Neuroendocrine tumor, grade 2
New related term	8249/3	Neuroendocrine carcinoma, moderately differentiated
New synonym	8263/0	Tubulo-papillary adenoma
New related term	8290/0	Spindle cell oncocytoma (C75.1)
New related term	8490/3	Poorly cohesive carcinoma
New related term	8811/0	Plexiform fibromyxoma
New related term	8970/3	Hepatoblastoma, epithelioid (C22.0)
New related term	8970/3	Hepatoblastoma, mixed epithelial-mesenchymal (C22.0)
New related term	9471/3	Medulloblastoma with extensive nodularity
New related term	9474/3	Anaplastic medulloblastoma
New related term	9506/1	Extraventricular neurocytoma

NOTE: It is important to understand that cancer registry reportability rules based on behavior code still apply. With the exception of primary intracranial and central nervous system benign and borderline tumors, the addition of a /0 or /1 coded term to ICD-O-3 does not imply that it is now reportable.

TABLE 2. ICD-O-3 CHANGES EFFECTIVE FOR JANUARY 1, 2015

ICD-O-3 change	New code in ICD-O-3	Description	Comment	Use this code in 2015
New term and code	8158/1	Endocrine tumor, functioning, NOS	Not reportable	
New related term	8158/1	ACTH-producing tumor	Not reportable	
New term and code	8163/3	Pancreatobiliary-type carcinoma (C24.1)	DO NOT use new code	8255/3
New synonym	8163/3	Adenocarcinoma, pancreatobiliary-type (C24.1)	DO NOT use new code	8255/3
New term	8213/3	Serrated adenocarcinoma		8213/3*
New code and term	8265/3	Micropapillary carcinoma, NOS (C18._, C19.9, C20.9)	DO NOT use new code	8507/3*
New code and term	8480/1	Low grade appendiceal mucinous neoplasm (C18.1)	Not reportable	
New term and code	8552/3	Mixed acinar ductal carcinoma	DO NOT use new code	8523/3
New term and code	8975/1	Calcifying nested epithelial stromal tumor (C22.0)	Not reportable	
New term and code	9395/3	Papillary tumor of the pineal region	DO NOT use new code	9361/3*
New term and code	9425/3	Pilomyxoid astrocytoma	DO NOT use new code	9421/3
New term and code	9431/1	Angiocentric glioma	DO NOT use new code	9380/1*
New term and code	9432/1	Pituicytoma	DO NOT use new code	9380/1*
New term and code	9509/1	Papillary glioneuronal tumor	DO NOT use new code	9505/1
New related term	9509/1	Rosette-forming glioneuronal tumor	DO NOT use new code	9505/1
New term and code	9741/1	Indolent systemic mastocytosis	Not reportable	

** ICD-O-3 rule F applies (code the behavior stated by the pathologist). If necessary, over-ride any advisory messages.*

4 REPORTABILITY AND RECODE CHANGES EFFECTIVE IN 2015

Make the following reportability change.
Behavior code change

- ☐ Delete code and term, 8240/1, Carcinoid tumor, NOS, of appendix (C18.1).
- ☐ Code carcinoid tumor, NOS, of appendix to 8240/3. (Change made in Canada in 2012).

Recode the following conditions as shown.

- ☐ Recode all cases of enteroglucagonoma, NOS, as 8152/1. *Enteroglucagonoma is now a related term for glucagonoma.*
- ☐ Then delete code 8157/1 Enteroglucagonoma, NOS.
- ☐ Recode all cases of enteroglucagonoma, malignant as 8152/3. *Enteroglucagonoma, malignant is now a related term for glucagonoma, malignant.*
- ☐ Then delete code 8157/3 Enteroglucagonoma, malignant.

NOTE: It is important to understand that cancer registry reportability rules based on behavior code still apply. With the exception of primary intracranial and central nervous system benign and borderline tumors, the addition of a /0 or /1 coded term to ICD-O-3 does not imply that it is now reportable.

5 REMAINING ISSUES

The publication of this implementation guideline document containing the list of approved new terms and its dissemination through the United States standards setters does not mean that the job of the ICD-O-3 Update Implementation Work Group is complete. A number of other issues remain.

The review of other terms that were included in the WHO Updates List has not been completed. While the WHO "Blue Books" reflect current thinking and current terminology among pathologists and specialists, reportability to population-based cancer registries is not clear in many instances. NAACCR is taking a close look at some of the terms and the potential challenges in implementing them as reportable neoplasms in the United States. Most of the problematic terms include the words "high grade neoplasia" or "high grade dysplasia" or "severe dysplasia" in digestive system sites and breast. These dysplasia terms are not included in most states' reporting legislation. The implications of accepting these terms as reportable are being carefully studied as they may affect not only reporting legislation, but also workload in case ascertainment (casefinding), abstracting, follow-up (as applicable) and incidence reporting. The ICD-O-3 Work Group is cooperating with CRSC and the College of American Pathologists (CAP) (among others) to make recommendations on the adoption of various dysplasia terminologies for future inclusion in cancer registries. (Note: Canada has recommended the adoption and collection of all reportable high grade dysplasia tumors in the digestive system beginning with cases diagnosed on or after January 1, 2012).

In addition, other issues regarding morphology coding have been identified. These are not within the original scope of the Work Group but should be addressed soon.

- The *WHO Classifications of Soft Tissue and Bone, Breast, and Female Genital Organs* have been published since 2011. These pathology references include more new terms and codes but they have not been organized into updated lists for future adoption. More updated volumes of WHO Classification are planned, and WHO is planning further update lists as new editions of the classifications are published.
  Suggested Next steps: North American standard setting organizations provide guidance on how to handle new codes, obsolete codes, other changes, and timing of implementation. In conjunction with the assessments of the impact of additions and changes on incidence, there should be assessments of the impact on the Multiple Primary and Histology coding rules.
- Although the new edition of the Lung WHO Classification is not expected until 2015, updated terms for bronchioloalveolar carcinoma – including changes in behavior codes – are already in use by pathologists around the United States and Canada.
  Suggested Next steps: Review new terminology and provide recommendations for interim codes to disseminate for consistent use in registries long before the WHO Lung Classification is published.
- Reportability guidelines for GIST tumors has been partially addressed in a sentence added to *FORDS* 2013 and the *SEER 2013 Coding Manual*, which indicate that GIST tumors and thymomas are reportable when there is evidence of multiple foci, lymph node involvement, or metastasis.
  Suggested Next steps: North American standard setters provide additional guidance for GIST tumors, such as formal interpretation of the "risk assessment" categories as benign, borderline, or malignant.