

**NAACCR**

**2004 Implementation Guidelines:  
Collaborative Staging and Benign/Borderline  
Intracranial and CNS Tumors**

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**NORTH AMERICAN ASSOCIATION OF  
CENTRAL CANCER REGISTRIES**

# 2004 Implementation Guidelines

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## Acronyms and Abbreviations Used

ACoS	American College of Surgeons
AJCC	American Joint Committee on Cancer
API	Application Program Interface
CCCS	Canadian Committee for Cancer Staging
CDC	Centers for Disease Control and Prevention
CNS	Central Nervous System
CoC	Commission on Cancer
CS	Collaborative Staging
EOD	Extent of Disease
FAQ	Frequently Asked Questions
I&R	Inquiry and Response
ICD-O-3	International Classification of Diseases for Oncology, Third Edition
NAACCR	North American Association of Central Cancer Registries
NCI	National Cancer Institute
NCRA	National Cancer Registrars Association
NPCR	National Program of Cancer Registries
SEER	Surveillance, Epidemiology, and End Results Program
TNM	Tumor, Nodes, and Metastasis
WHO	World Health Organization

# **1 Introduction**

Consensus standards developed through the North American Association of Central Cancer Registries, Inc. (NAACCR) involve all standard setting organizations, as well as representatives from the National Cancer Registrars Association (NCRA). Data recording and transmission standards should be consistently maintained among all hospital and central registries and should be implemented in a planned and timely manner. As with the introduction of any new set of standards, and its potential consequences, implementation must be evaluated by each individual program during the planning process.

The NAACCR 2004 Implementation work groups, Collaborative Staging (CS) Implementation Work Group and Benign Brain Tumor Implementation Work Group, have been working with the American College of Surgeons (ACoS) Commission on Cancer (CoC), Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR), National Cancer Institute (NCI) Surveillance Epidemiology and End Results Program (SEER), NCRA, Canadian Council of Cancer Registries, central cancer registries, and cancer registry software vendors to develop a model implementation plan to assist cancer registries and to help ease the introduction of:

- 1) The Collaborative Staging System
- 2) The Federal mandate requiring the reporting of benign and borderline intracranial and central nervous system (CNS) tumors.

The NAACCR 2004 Implementation Guidelines are based on the adaptation and use of the NAACCR record layout version 10.1 (effective with cases diagnosed January 1, 2004 and later). Version 10.1 accommodates the data elements necessary to support the CS schema and specifies the standard setters' reporting requirements for benign and borderline intracranial and CNS tumors.

Revisions to data collection and data system design require close attention in order to transition to NAACCR version 10.1 in an efficient and timely manner. Recommendations for the implementation of the CS schema and the new reporting rules for benign and borderline intracranial and CNS tumors should be reviewed carefully. Refer to individual program and central registry requirements for additional information and guidance.

Information system design modifications and limited data conversion will be necessary for all data systems to meet the 2004 requirements. NAACCR record layout version 10.1 and the data collection, data conversion and file maintenance issues must be addressed by hospital and central cancer registries in addition to vendors who support these registries.

## **1.1 Collaborative Staging**

CS is a group of data items set up by a joint task force including representatives from the American Joint Committee on Cancer (AJCC), CoC, NAACCR, NCRA, NPCR, and SEER, designed to provide a single uniform set of codes and rules for collecting extent of disease and stage information to meet the needs of all of the participating organizations. The CS schema incorporates all of the fields from SEER 10-digit EOD, in a modified form, and adds several additional fields. When CS data items are coded, a computer algorithm allows generation of AJCC Sixth Edition Tumor, Nodes, and Metastasis (TNM) stage, SEER Summary Stage 1977, and SEER Summary Stage 2000. Separate CS fields are provided in the NAACCR record for these outputs. This document is intended to provide guidance for reporting facilities, central cancer registries, standard setters, and cancer registry software vendors as each moves forward with the implementation of the CS schema.

## **1.2 Benign and Borderline Intracranial and Central Nervous System Tumors**

The Benign Brain Tumor Cancer Registries Amendment Act passed both the Senate and the House and was signed by the President in October 2002. Public law 107-260 requires the collection of benign and borderline intracranial and CNS tumors by NPCR. CoC and SEER added benign and borderline intracranial and CNS tumors to their case definition. Reporting begins with cases diagnosed January 1, 2004 and later. This document is intended to provide guidance for reporting facilities, central cancer registries, standard setters, and cancer registry software vendors as each moves forward with the implementation of the reporting of benign and borderline intracranial and CNS tumors.

## **2 Collaborative Staging System**

NAACCR has formed a work group to make recommendations for the implementation of the Collaborative Staging System which has been developed cooperatively between the following organizations: AJCC, CoC, Canadian Committee for Cancer Staging (CCCS), NAACCR, NCRA, NPCR, and SEER. Each organization has recognized the benefit and value of supporting the development of a standardized set of data items that will support a uniform staging schema that can be easily and uniformly utilized by cancer registrars across North America.

The NAACCR Collaborative Staging Implementation work group has been charged with the task of providing the cancer registry community with a concise set of guidelines that 1) provide guidance to the registry community with respect to the technical aspects of adopting CS; 2) highlight documentation resources available to registry professionals and the software vendor community; and 3) outline the educational efforts underway to support this new registry based staging tool.

### **2.1 Standard Setting Organization Collaborative Staging Reporting Requirements**

A complete list of data collection requirements for CS items, as identified by the CoC, NPCR and SEER, appears in *NAACCR Standards for Cancer Registries Volume II, Data Standards and Data Dictionary, Version 10.1*, Chapter IX: Required Status Table. Where necessary, refer to individual program or central cancer registry requirements for additional information.

Changes have been made to the allowable values for Derived AJCC T [2940], Derived AJCC N [2960], Derived AJCC M [2980], and Derived AJCC Stage Group [3000] (see tables in section 2.10 – 2.14). These changes are effective with cases diagnosed January 1, 2004 and later, and must take precedence over the tables included in *NAACCR Standards for Cancer Registries Volume II, Data Standards and Data Dictionary, Version 10.1*.

In October 2003 two new data items, CS Version 1<sup>st</sup> and CS Version Latest, (see section 2.15 and 2.16) were approved by the NAACCR Uniform Data Standards and Information Technology committees with a recommendation that these new data items be stored for cases diagnosed January 1, 2004 and later.

For pre-2004 diagnoses reporting facilities will be required to continue to code those staging items, using previously published guidelines and rules, required by each respective standard setter. Registrars need to check with local state/central registries for data requirements.

Derived CS fields should be viewable only and the ability to edit should not be provided to the end user. In the event that CS data item(s) are revised, the CS algorithm must be recalculated to update the derived CS data items. CS derived data items should not be independently changed.

#### **2.1.1 CoC Reporting Requirements**

Beginning with cases diagnosed on or after January 1, 2004, the CoC will require full implementation of all CS data items for hospital cancer registries at CoC approved cancer programs. The CoC will require registries to record all the CS data items necessary to derive AJCC T, N, M, Descriptor, Stage Group, Summary Stage 1977, and Summary Stage 2000 data items for all cases entered into local registries (Derived AJCC T [2940], Derived AJCC T Descriptor [2950], Derived AJCC N [2960], Derived AJCC N Descriptor [2970], Derived AJCC M [2980], Derived AJCC M Descriptor [2990], Derived AJCC Stage Group [3000], Derived SS1977 [3010], Derived SS2000 [3020], Derived AJCC-Flag [3030], Derived SS1977-Flag [3040], and Derived SS2000-Flag [3050]). Coded items and derived values will be required to be transmitted to the National Cancer Data Base as part of its annual call for data.

With the diagnosis year 2004 the CoC will continue to require CoC approved cancer program registries to collect and report physician staging information recorded in the following items:

<b>Table 1. COC Required Physician Staging Data Items</b>	
<b>Item Name</b>	<b>Item Number</b>
TNM Path T	880
TNM Path N	890
TNM Path M	900
TNM Path Stage Group	910
TNM Path Descriptor	920
TNM Path Staged By	930
TNM Clin T	940
TNM Clin N	950
TNM Clin M	960
TNM Clin Stage Group	970
TNM Clin Descriptor	980
TNM Clin Staged By	990

### 2.1.2 NPCR Reporting Requirements

Beginning with cases diagnosed on or after January 1, 2004, NPCR will require the collection of the CS data items necessary to derive Summary Stage 2000 (Derived SS2000 [3020]), these include:

<b>Table 2. NPCR Required Collaborative Staging Data Items</b>	
<b>Item Name</b>	<b>Item Number</b>
CS Extension	2810
CS Lymph Nodes	2830
CS Mets at DX	2850
CS Site-Specific Factor 1	2880
CS Site-Specific Factor 3	2900
Derived SS1977-Flag	3040
Derived SS2000-Flag	3050

Collection of all CS data items is recommended for NPCR registries. For cases diagnosed between January 1, 2001 and December 31, 2003 direct coding of SEER Summary Stage 2000 [759] will be required. For cases diagnosed prior to January 1, 2001 SEER Summary Stage 1977 [760] will be required.

### 2.1.3 SEER Reporting Requirements

Beginning with cases diagnosed on or after January 1, 2004, SEER will require the collection of the CS data items necessary to derive AJCC T, N, M, Stage Group, Summary Stage 1977, and Summary Stage 2000 (Derived AJCC T [2940], Derived AJCC N [2960], Derived AJCC M [2980], Derived AJCC Stage Group [3000], Derived SS1977 [3010], and Derived SS2000 [3020]). These items are:

<b>Table 3. SEER Required Collaborative Staging Data Items</b>	
<b>Item Name</b>	<b>Item Number</b>
CS Tumor Size	2800
CS Extension	2810
CS Lymph Nodes	2830
Regional Nodes Positive	820

Regional Nodes Examined	830
CS Mets at DX	2850
CS Site Specific Factor 1	2880
CS Site Specific Factor 2	2890
CS Site Specific Factor 3	2900
CS Site Specific Factor 4	2910
CS Site Specific Factor 5	2920
CS Site Specific Factor 6	2930

#### **2.1.4 Canadian Council of Cancer Registries**

For cases diagnosed January 1, 2003 and later, the standard staging classification for use in Canada, as directed by the Canadian Council of Cancer Registries Data and Quality Management Committee, is the AJCC *Cancer Staging Manual 6<sup>th</sup> Edition*.

For cases diagnosed January 1, 2004 and later, the recommended staging data set is the CS system and work is being initiated to incorporate the appropriate data elements into the national data set.

## **2.2 Collaborative Staging Implementation Issues and Recommendations for Central Cancer Registries, Reporting Facilities and Software Vendors**

### **2.2.1.1 Central Cancer Registries**

Changes have been made to the allowable values for Derived AJCC T [2940], Derived AJCC N [2960], Derived AJCC M [2980], and Derived AJCC Stage Group [3000] (see tables in section 2.10 – 2.14). These changes are effective with cases diagnosed January 1, 2004 and later, and must take precedence over the tables included in *NAACCR Standards for Cancer Registries Volume II, Data Standards and Data Dictionary, Version 10.1*.

### **2.2.1.2 Transmission of Collaborative Staging Variables**

Central cancer registries should expect that both the derived values and the input items be transmitted from their respective reporting sources. Software vendors are expected to implement CS such that end users cannot edit the derived values.

### **2.2.1.3 Re-Calculating Derived Values**

CS derived values are calculated based upon an algorithm implemented by the Collaborative Staging Task Force and then adapted by various software vendors. It should be anticipated that over time the algorithm may change, the Task Force implementation may change, and/or various vendor adaptations may change. Therefore, the central cancer registry should plan to implement the capability to recalculate the derived variables. This issue should be addressed with the central registry's software vendor. It is recommended that the computer algorithm be re-run on data before the creation of an analysis file and before submission of data to standard-setting organizations. If the central cancer registry requires any of the following items be reported by reporting facilities (Derived AJCC Stage Group [3000], Derived SS1977 [3010], and Derived SS2000 [3020]), then it is recommended that the associated flag items (Derived AJCC-Flag [3030], Derived SS1977-Flag [3040], and Derived SS2000-Flag [3050]) be reported too, and that software vendors should automatically code these items with the value "1" for each of the respective items.

#### **2.2.1.4 Validation of the Task Force and Vendor Implementations**

In order to validate the Task Force and vendor implementations, the Collaborative Staging Implementation Task Force has provided two test files that are designed to assist with the validation of CS input items and derived valid and invalid values. Because of the exponential combination of valid and invalid input combinations, the test files are not exhaustively comprehensive. At the very least these test files should allow a software vendor or central cancer registry to reasonably test their particular implementation to ensure that their results are consistent with the test cases. See section 2.9 of this document.

#### **2.2.1.5 Remaining Current with the Collaborative Staging Implementation**

All updates and modifications to the CS implementation should be documented and resources updated respectively. CS resources can be found on the following web site: <http://www.cancerstaging.org>. See section 2.7 of this document.

### **2.2.2 Reporting Facilities**

Changes have been made to the allowable values for Derived AJCC T [2940], Derived AJCC N [2960], Derived AJCC M [2980], and Derived AJCC Stage Group [3000] (see tables in section 2.10 – 2.14). These changes are effective with cases diagnosed January 1, 2004 and later, and must take precedence over the tables included in *NAACCR Standards for Cancer Registries Volume II, Data Standards and Data Dictionary, Version 10.1*.

#### **2.2.2.1 The implementation of CS will require reporting facilities to carefully manage their case abstracting procedures.**

For pre-2004 diagnoses, reporting facilities will be required to continue to code those staging items, using previously published guidelines and rules, required by each respective standard setter. Registrars need to check with local central registries for data requirements. To reduce confusion, registrars should prioritize their 2003 abstracting, ideally completing the abstracting of these cases before commencing with cases diagnosed January 1, 2004 or later.

The implementation of the CS algorithm into cancer registry software systems should not affect a registry's ability to continue to code cases diagnosed prior to January 1, 2004 following the applicable registry guidelines. Registries need to check with their software vendor to confirm that “straggler” (pre-2004) cases can be coded using the appropriate staging rules and data items when these cases are encountered.

#### **2.2.2.2 For cases diagnosed January 1, 2004 or later, reporting facilities will be required to abstract, code and report staging items per the appropriate standard setter requirements documented in section 2.1.**

It is recommended that the computer algorithm be re-run on data before the creation of an analysis file and before submission of data to standard setting organizations. If the reporting facility is required to report any of the derived items (Derived AJCC Stage Group [3000], Derived SS1977 [3010], and Derived SS2000 [3020]) then it is recommended that the software vendors automatically code the associated flag items (Derived AJCC-Flag [3030], Derived SS1977-flag [3040], and Derived SS2000-Flag [3050]) with the value “1” for each of the respective items.

### **2.2.3 Software Vendors**

Changes have been made to the allowable values for Derived AJCC T [2940], Derived AJCC N [2960], Derived AJCC M [2980], and Derived AJCC Stage Group [3000] (see tables in section 2.10 – 2.14). These changes are effective with cases diagnosed January 1, 2004 and later, and must take precedence over the tables included in *NAACCR Standards for Cancer Registries Volume II, Data Standards and Data Dictionary, Version 10.1*.

Important points for consideration when supporting clients' transition to NAACCR Standards Volume II Version 10.1 standards 2004 implementation of CS are listed below. NAACCR Version 10.1 necessitates change in the following:

#### **2.2.3.1 Timeliness**

- 2.2.3.1.1 Software vendors must prepare to comply with new standards in advance of implementation dates. As a result software vendors need to revise/develop, test, distribute, and install software prior to implementation dates set by standard setting organizations and central cancer registries. If there are delays to the standards or errata that have not been identified, the software vendor programs will be at risk of delay. Software vendors should build this factor into their timelines.
- 2.2.3.1.2 CS warrants a test phase review due to the complexity and requirement for accuracy of linking all the tables and deriving values for SEER Summary Stage and AJCC stages. This will also help identify and minimize the necessity for errata correction. Software vendors should participate in routine teleconferences with the CS algorithm developers and Collaborative Staging Task Force for assistance in integrating the application file into software programs. Software vendors have the ability to test the algorithm using the Test-O-Matic module on the CS web site.

#### **2.2.3.2 Database Conversion**

Regional Lymph Nodes Positive field is to be converted. Conversion mapping is to be performed throughout the legacy database based on section 2.4, Conversion Specifications for Regional Nodes Positive [820]. This is the only conversion necessary for implementation of CS.

#### **2.2.3.3 Data Collection**

- 2.2.3.3.1 CS fields are to be exported in NAACCR Version 10.1 layout beginning with cases diagnosed January 1, 2004 and later.
- 2.2.3.3.2 Registry software programs are to implement CS based on cases diagnosed January 1, 2004 and later.
- 2.2.3.3.3 Encourage clients to wait until they have entered their 2003 cases prior to product installation that contains the CS fields. For clients performing concurrent abstracting, it is recommended that 2004 diagnosed cases be placed into suspense until the software is available.
- 2.2.3.3.4 Software vendors should use the CS package programs provided; vendor specific pick lists should not be created for the CS fields.
- 2.2.3.3.5 Algorithms provided from the AJCC/CS web site should be applied to vendor software programs without any additional coding except to 'call' the algorithm.



2.2.3.3.6 Derived CS fields should be viewable only and the ability to edit should not be provided to the end user. It is strongly advised that correction of the derived CS fields not be possible in order to assure accuracy/consistency over time.

2.2.3.3.7 If errata are found, and updates are required to the CS algorithm, they will need to be implemented in a timely manner.

#### **2.2.3.4 Field Validation and Edits**

2.2.3.4.1 NAACCR EDITS metafile for NAACCR Version 10.1 includes single field and some interfield edits on all CS items.

2.2.3.4.2 This will also impact any state-specific metafiles currently in use at the time of implementation. These metafiles may require replacement with updated files.

#### **2.2.3.5 Reports**

CS fields should be added to the data set and incorporated into clients' ad-hoc report writing capabilities, including the ability to filter on these data items.

#### **2.2.3.6 Transmission of Records to Central/State Registry**

2.2.3.6.1 NAACCR Version 10 introduced the CS fields. Data collection and reporting is required to begin with cases diagnosed January 1, 2004 or later and to be written to NAACCR Version 10.1 layout.

2.2.3.6.2 It is recommended that the computer algorithm be re-run on data before the creation of an analysis file and before submission of data to standard-setting organizations.

2.2.3.6.3 If any of the following items are required to be transmitted (Derived AJCC Stage Group [3000], Derived SS1977 [3010], and Derived SS2000 [3020]) then it is recommended that the associated flag items (Derived AJCC-Flag [3030], Derived SS1977-Flag [3040], and Derived SS2000-Flag [3050]) be reported too, and that software vendors automatically code these items with the value "1" for each of the respective items.

#### **2.2.3.7 On-Line Help Systems**

On-line Help systems, where available, should consider the addition of special instructions for CS, with links to the CS web site for algorithm and manuals.

#### **2.2.3.8 Technical Support and Education**

Standard setters will provide the necessary registry education activities to support the correct interpretation, coding, and use of the CS system by central cancer registries and reporting facilities. Software vendors will be expected to support their software changes and assist reporting facilities and central cancer registries in data collection and reporting requirements. Software vendors should provide training on the software upgrades, which includes reference to the source for information on year 2004 changes.

### 2.3 Collaborative Staging Implementation Needs

The following documentation and conversion tools have been made available to facilitate the implementation of CS in NAACCR Version 10.1:

<b>Table 4. Implementation Needs for Collaborative Staging</b>		
<b>Implementation Needs</b>	<b>Anticipated Availability</b>	<b>Suppliers</b>
<i>Collaborative Staging and Coding Manual, part 1</i> (electronic) – contains the full electronic version of the documentation for Collaborative Staging, an introduction to Collaborative Staging, descriptions of concepts, and general instructions to coders. <www.cancerstaging.org>	July 2003	SEER
<i>Collaborative Staging and Coding Manual, part 2</i> (electronic) – a collection of about 1400 HTML pages, organized by schema, containing the site-and-histology-specific tables for coding Collaborative Stage. <www.cancerstaging.org>	July 2003	SEER
<i>Collaborative Staging and Coding Manual, part 1 and 2</i> (hard copy)	Fall 2003	AJCC, NPCR, SEER
<i>CS Schema-Selection Algorithm</i> (rules and conversion codes) – uses histology and site codes to choose one of the 94 Collaborative Staging schemas. <www.cancerstaging.org>	July 2003	NPCR
<i>CS Application Program Interface</i> – is a file in Rich Text Format describing the API for use by programmers and software vendors. <www.cancerstaging.org>	July 2003	NPCR
<i>CS Computer Algorithm Program-Beta Version.</i> Final version of the CS Algorithm program will be released after Beta Version tested and software vendors comments/concerns/questions addressed (includes CS Validation Test File). <www.cancerstaging.org>	September 2003	NPCR
<i>Change Log and Known Issues</i> – lists recent changes and issues discovered by pre-release testers. <www.cancerstaging.org>	July 2003	AJCC, NPCR, SEER
<i>FORDS</i> – CS Revisions	November 2003	COC
<i>SEER Program Manual</i> – CS Revisions	December 2003	SEER
<i>CS Education/Training Material</i> <www.training.seer.cancer.gov> <www.facs.org/cancer/coc/coceduc.html>	July 2003	COC, SEER
<i>Collaborative Staging Web Based Training Module</i> <www.training.seer.cancer.gov>	July 2003	SEER
<i>EDITS</i>	November 2003	NAACCR

## 2.4 Collaborative Staging Conversion Specifications for Regional Nodes Positive [820]

Regional Nodes Positive data item [820] is part of the CS data set. Definition changes were made to codes 90-97. For cases diagnosed prior to January 1, 2004 codes 01-95 definition was “1-95 nodes are positive (Code exact number of nodes positive)”; code 96 definition was “96 or more positive nodes”; and, code 97 was defined as “Positive nodes – number unspecified”. Effective January 1, 2004 the code 90 definition changes to “90 or more positive nodes” and code 95 definition changes to “positive aspiration of lymph node(s).” This will require a conversion of the Regional Nodes Positive data item [820] when NAACCR Version 10.1 is implemented. The following table shows the conversion specifications.

<b>Table 5. Collaborative Staging Conversion Specifications for Regional Nodes Positive</b>	
<b>Code for cases diagnosed prior to January 1, 2004</b>	<b>Converted code</b>
00-90	Copy
91-96	90
97, and Regional Nodes Examined [830] = 95	95
97, and Regional Nodes Examined [830] <> 95	97
98	98
99	99

There are no other conversion requirements necessary to implement the CS system.

## 2.5 Collaborative Staging EDITS

The version 10 NAACCR EDITS Metafile will be updated to handle the CS data items. This includes single and some interfield edits on all CS items. Edit sets will also be updated per each standard setter’s requirements. The Metafile, when completed, will be available from the NAACCR web site. Anticipated date of availability is November 2003.

## 2.6 Collaborative Staging Training and Educational Resources

The CS maintenance activities outlined below have been developed to ensure ongoing support for the CS system. Since this is a “collaborative” system, the standard-setting organizations involved in its development are responsible for certain aspects of system maintenance. The responsible party is identified for the following maintenance activities:

## 2.7 Training and Educational Resources

Training and educational activities are provided by and/or in collaboration with the following agencies: AJCC, CoC, NPCR, and SEER.

The following training and educational resources are available on the AJCC web site at [www.cancerstaging.org](http://www.cancerstaging.org):

- *Collaborative Staging and Coding Manual*, part 1
- *Collaborative Staging and Coding Manual*, part 2
- Schema-Selection Algorithm
- Collaborative Staging Practicum available via CoC Speakers Bureau
- CS Training provided via SEER/NPCR staff
- CS Web Based Training Module
- CS Questions and Answers/Inquiry and Response System

The electronic version of the *Collaborative Staging and Coding Manual*, Parts 1 and 2, is available for download from the AJCC web site at [www.cancerstaging.org](http://www.cancerstaging.org). Part 1 is a pdf document, which includes an introduction to CS, descriptions of CS concepts, and general instructions for coders. Part 2 includes the 94 CS site-specific schemas consisting of 1,400 pages in the HTML format, and contains the site and histology specific tables for coding CS. A printed, hard copy of the *Collaborative Staging and Coding Manual* is available for free from the following standard-setting organizations: CoC, NPCR, and SEER. SEER maintains the *Collaborating Staging and Coding Manual*.

The Schema-Selection algorithm is provided as a look-up table and uses histology and site codes to choose one of the 94 CS site-specific schemas.

A CS “Train the Trainers” workshop was conducted for speakers representing the CoC. Interested individuals or groups can access the Cancer Programs page of the ACoS web site at [www.facs.org](http://www.facs.org) to schedule a CS presentation by a CoC trained speaker for local and state meetings. The objective of the presentation was to train individuals based on the CS requirements for CoC-approved cancer programs. A CS “Train the Trainers” workshop was also conducted with SEER/NPCR state cancer registry staff. The objective of this presentation is to train individuals based on the CS requirements for NPCR and SEER. The required data items for collection differ for each agency (see section 2.1). The CS training materials are maintained by the AJCC.

A CS web-based training module was developed by SEER, in conjunction with the AJCC, and is available on SEER’s training web site at [www.training.seer.cancer.gov](http://www.training.seer.cancer.gov). This self-instructional module includes a general introduction to CS, an overview of the general coding instructions and data items, and interactive coding exercises for breast, colon, lung, melanoma, and prostate cancer cases. An advanced self-instructional CS module will be made available on the SEER training web site in 2004. SEER maintains the CS modules.

Frequently Asked Questions (FAQ’s) about CS will be maintained on the AJCC web site at [www.cancerstaging.org](http://www.cancerstaging.org), and will also be included in the CoC’s Inquiry and Response (I&R) System. This System is accessible from the ACoS web site at [www.facs.org](http://www.facs.org) and allows the user to enter search criteria on the type of question they have resulting in a list of previously submitted questions and answers. CS questions should be submitted using the I&R System. AJCC and CoC maintain the FAQ’s and I&R System.

Additional training and educational resources will be made available in 2004 and include one to two videoconference training programs on CS and a CS workbook.

## 2.8 Technical Support for the Computer Algorithm Which Derives Stage Variables

The following materials to support the CS Computer Algorithm are available on the AJCC web site at [www.cancerstaging.org](http://www.cancerstaging.org):

- Computer Algorithm Program
- Application Program Interface
- Change Log and Known Issues

The CS Computer Algorithm is a dynamic link library code set that computes the respective CS derived values using the necessary recorded CS input values.

The Application Program Interface (API) is a rich text format file describing the CS API for use by programmers and software vendors. CDC maintains the API.

A Known Issues list including problems that have been identified in the site-specific schemas will be maintained by the CS Task Force and posted on the AJCC CS web site. This information is provided to keep programmers and software vendors informed about changes affecting the computer algorithm.

A CS Steering committee of representatives from the collaborating partners has been formed to review, evaluate, and incorporate modifications and/or changes made to the site-specific schema or computer notifications to the cancer registry community using the NAACCR and CoC list serves. Modifications and/or changes to the schemas will be posted on the AJCC CS web site.

An e-mail link to the CS Technical Administrator at the AJCC is available at the bottom of each field of each schema on the AJCC CS web site. The CS Technical Administrator will respond to questions regarding the site-specific schema, and can be reached at [ajcc@facs.org](mailto:ajcc@facs.org). CDC will provide technical support for the installation and execution of the computer algorithm and related programs. Questions regarding the computer algorithm and related programs can be sent to [tkr2@cdc.gov](mailto:tkr2@cdc.gov). Other CS coding inquiries can be directed to the CS Technical Administrator.

Changes and/or modifications made to the schema and/or the computer algorithm will be identified by version number items. Two separate fields for the version number have been established: one associated with the CS schema used for coding, the other for the computer algorithm used for the CS derived fields. Each field includes 6 character positions, with 3 two-digit numbers. Details appear below in section 2.15 and 2.16 of this document.

## **2.9 Software Development Support – Fall 2003 and Winter 2004**

Cancer registry software vendor support will be provided through conference calls scheduled for late October 2003, December 2003, and February 2004. CDC will provide additional support as needed. Notification will be made to known commercial software vendors and central registry software developers using the NAACCR and CoC list serves.

Two test data files have been prepared for use by cancer registry software vendors and are available from the AJCC CS web site. Both files should be used by software developers to test the performance of the CS computer algorithm, once it has been integrated into a particular software package. Both test files are in a layout consistent with NAACCR version 10.1 standards. Since there are over 2 billion combinations for each schema, the test data files are not exhaustive. One test data file includes invalid values that will have error flags/text associated with it. The other data file includes valid values of a sample of cases that will run through the computer algorithm without error.

## 2.10 Changes to the Collaborative Staging Data Set

The following tables include changes to the Derived AJCC T, Derived AJCC N, Derived AJCC M, and the Derived AJCC Stage Group allowable values. These tables take precedence over the tables published in *NAACCR Standards for Cancer Registries Volume II Data Standards and Data Dictionary Version 10.1*. The following tables must be incorporated into software programs for cases diagnosed January 1, 2004 and later.

In October 2003 two new data items, CS Version 1<sup>st</sup> and CS Version Latest, were approved by the NAACCR Uniform Data Standards and Information Technology committees with a recommendation that these new data items be stored (see section 2.15 and 2.16) for cases diagnosed January 1, 2004 and later.

## 2.11 Derived AJCC T [2940]

This table shows the allowable values for the generated CS data items. The Storage Code is the value to be stored in the field of a NAACCR record. The Storage Codes are designed for analysis. The Display String is the corresponding label that should be displayed on the screen or in a report. The meaning of these strings will be clear to the registrar or physician user.

Table 6. Allowable Values for Derived AJCC T		
Storage Code	Display String	Comments
99	TX	TX
00	T0	T0
01	Ta	Ta
05	Tis	Tis
06	Tispu	Tispu (Urethra only)
07	Tispd	Tispd (Urethra only)
10	T1	T1
11	T1mic	T1mic
19	T1NOS	T1 NOS
12	T1a	T1a
13	T1a1	T1a1
14	T1a2	T1a2
15	T1b	T1b
16	T1b1	T1b1
17	T1b2	T1b2
18	T1c	T1c
20	T2	T2

<b>Table 6. Allowable Values for Derived AJCC T</b>		
<b>Storage Code</b>	<b>Display String</b>	<b>Comments</b>
29	T2NOS	T2 NOS
21	T2a	T2a
22	T2b	T2b
23	T2c	T2c
30	T3	T3
39	T3NOS	T3 NOS
31	T3a	T3a
32	T3b	T3b
33	T3c	T3c
40	T4	T4
49	T4NOS	T4 NOS
41	T4a	T4a
42	T4b	T4b
43	T4c	T4c
44	T4d	T4d
88	NA	Not applicable

## 2.12 Derived AJCC N [2960]

This table shows the allowable values for the generated CS data items. The Storage Code is the value to be stored in the field of a NAACCR record. The Storage Codes are designed for analysis. The Display String is the corresponding label that should be displayed on the screen or in a report. The meaning of these strings will be clear to the registrar or physician user.

Table 7. Allowable Values for Derived AJCC N		
Storage Code	Display String	Comments
99	NX	NX
00	N0	N0
09	N0NOS	N0 NOS
01	N0(i-)	N0(i-)
02	N0(i+)	N0(i+)
03	N0(mol-)	N0(mol-)
04	N0(mol+)	N0(mol+)
10	N1	N1
19	N1NOS	N1 NOS
11	N1a	N1a
12	N1b	N1b
13	N1c	N1c
18	N1mi	N1mi
20	N2	N2
29	N2NOS	N2 NOS
21	N2a	N2a
22	N2b	N2b
23	N2c	N2c
30	N3	N3
39	N3NOS	N3 NOS
31	N3a	N3a
32	N3b	N3b
33	N3c	N3c
88	NA	Not applicable



### 2.13 Derived AJCC M [2980]

This table shows the allowable values for the generated CS data items. The Storage Code is the value to be stored in the field of a NAACCR record. The Storage Codes are designed for analysis. The Display String is the corresponding label that should be displayed on the screen or in a report. The meaning of these strings will be clear to the registrar or physician user.

Table 8. Allowable Values for Derived AJCC M		
Storage Code	Display String	Comments
99	MX	MX
00	M0	M0
10	M1	M1
11	M1a	M1a
12	M1b	M1b
13	M1c	M1c
19	M1NOS	M1 NOS
88	NA	Not applicable

## 2.14 Derived AJCC Stage Group [3000]

This table shows the allowable values for the generated CS data items. The Storage Code is the value to be stored in the field of a NAACCR record. The Storage Codes are designed for analysis. The Display String is the corresponding label that should be displayed on the screen or in a report. The meaning of these strings will be clear to the registrar or physician user.

<b>Table 9. Allowable Values for Derived AJCC Stage Group</b>		
<b>Storage Code</b>	<b>Display String</b>	<b>Comments</b>
00	0	Stage 0
01	0a	Stage 0a
02	0is	Stage 0is
10	I	Stage I
11	INOS	Stage I NOS
12	IA	Stage IA
13	IA1	Stage IA1
14	IA2	Stage IA2
15	IB	Stage IB
16	IB1	Stage IB1
17	IB2	Stage IB2
18	IC	Stage IC
19	IS	Stage IS
23	ISA	Stage ISA (lvmphoma only)
24	ISB	Stage ISB (lvmphoma only)
20	IEA	Stage IEA (lvmphoma only)
21	IEB	Stage IEB (lvmphoma only)
22	IE	Stage IE (lvmphoma only)
30	II	Stage II
31	IINOS	Stage II NOS
32	IIA	Stage IIA
33	IIB	Stage IIB
34	IIC	Stage IIC
35	IIEA	Stage IIEA (lvmphoma only)
36	IIEB	Stage IIEB (lvmphoma only)
37	IIE	Stage IIE (lvmphoma only)
38	IISA	Stage IISA (lvmphoma only)
39	IISB	Stage IISB (lvmphoma only)

<b>Table 9. Allowable Values for Derived AJCC Stage Group</b>		
<b>Storage Code</b>	<b>Display String</b>	<b>Comments</b>
40	IIS	Stage IIS (lvmphoma only)
41	IIESA	Stage IIESA (lvmphoma only)
42	IIESB	Stage IIESB (lvmphoma only)
43	IIES	Stage IIES (lvmphoma only)
50	III	Stage III
51	IIINOS	Stage III NOS
52	IIIA	Stage IIIA
53	IIIB	Stage IIIB
54	IIIC	Stage IIIC
55	IIIEA	Stage IIIEA (lvmphoma only)
56	IIIEB	Stage IIIEB (lvmphoma only)
57	IIIE	Stage IIIE (lvmphoma only)
58	IIISA	Stage IIISA (lvmphoma only)
59	IIISB	Stage IIISB (lvmphoma only)
60	IIIS	Stage IIIS (lvmphoma only)
61	IIIESA	Stage IIIESA (lvmphoma only)
62	IIIESB	Stage IIIESB (lvmphoma only)
63	IIIES	Stage IIIES (lvmphoma only)
70	IV	Stage IV
71	IVNOS	Stage IV NOS
72	IVA	Stage IVA
73	IVB	Stage IVB
74	IVC	Stage IVC
88	NA	Not applicable
90	OCCULT	Stage Occult
99	UNK	Stage Unknown

### **2.15 CS Version 1st [item #2935]**

This item indicates the number of the version used to initially code CS fields. The CS version number is returned as part of the output of the CS algorithm. As long as the CS algorithm is run and the output values stored at the time of initial abstracting, the returned values from the program should be automatically stored as CS Version First. This item may be blank if the CS algorithm has not been run or if this field has not been implemented. When it is implemented, this data item should be entered at the time the CS fields are first coded and the algorithm first applied. If the calculation algorithm is not called at the time of the initial abstracting, the CS Version First could also be entered manually by the abstractor. CS Version First is a 6-digit code. The first two digits represent the major version number; the second two digits represent minor version changes; and, the last two digits represent even less significant changes, such as corrections of typographical errors that do not affect coding or derivation of results.

It is not expected that this field would be updated every time a coded value is changed. However, the field should be available for future updating if, for example, the CS fields for certain records were to be systematically recoded for a special study using a later version, the CS Version First could be appropriately updated with the new version. The meaning and interpretation of CS Version First will be dependent on vendor implementation and local practices. This field should be interpreted with caution in a dataset where the actual coding procedures are unknown.

COC, NPCR, and SEER will require reporting of CS Version 1<sup>st</sup>.

The item CS Version First should be recorded in column 705-710 (the first six positions of the data item “Reserved 05” [1180]) of the NAACCR version 10.1 data transmission record layout.

### **2.16 CS Version Latest [item #2936]**

This item indicates the number of the version of the CS used most recently to derive the CS output fields. This data item is recorded the first time the CS output fields are derived and should be updated each time the CS Derived items are re-computed. The CS version number is returned as part of the output of the CS algorithm. The returned value from the program should be automatically stored as CS Version Latest. This item should not be updated manually. CS Version Latest is a 6-digit code. The first two digits represent the major version number; the second two digits represent minor version changes; and, the last two digits represent even less significant changes, such as corrections of typographical errors that do not affect coding or derivation of results.

This item should not be blank if the CS Derived items contain stored values. This item should be blank if the CS Derived items are empty or the CS algorithm has not been applied.

COC, NPCR, and SEER will require reporting of CS Version Latest.

The item CS Version Latest should be recorded in column 711-716 (starting in the seventh position of the data item “Reserved 05” [1180]) of the NAACCR version 10.1 data transmission record layout.

### **3 Benign/Borderline Intracranial and CNS Tumor Implementation**

The Benign Brain Tumor Cancer Registries Amendment Act (Appendix A) passed both the Senate and the House and was signed by the President in October 2002. Public law 107-260 requires the collection of benign and borderline intracranial and CNS tumors by NPCR, CoC and SEER added benign and borderline intracranial and CNS tumors to their case definition. Reporting begins with cases diagnosed January 1, 2004 and later.

NAACCR convened a subcommittee of the Registry Operations committee to identify changes needed in central registry operations to collect benign and borderline intracranial and CNS tumors. The Registry Operations Benign Brain Tumor Subcommittee developed general reporting rules, *Accessioning Primary Intracranial and Central Nervous System Tumors General Reporting Rules* (Appendix B), approved by the Uniform Data Standards committee in July 2003. The Benign Brain Tumor Implementation work group was convened to address the implementation issues for the reporting of benign and borderline intracranial and CNS tumors.

#### **3.1 Standard Setting Organization Requirements for Benign/Borderline Intracranial and CNS Tumor Reporting**

##### **3.1.1 COC, NPCR, and SEER Reporting Requirements**

Any tumor diagnosed on January 1, 2004 or later with a behavior code of '0' or '1' will be collected for the following site codes based on *The International Classification of Disease for Oncology, Third Edition* (ICD-O-3): meninges (C70.0 – C70.9); brain (C71.0 – C71.9); spinal cord, cranial nerves, and other parts of central nervous system (C72.0 – C72.9); pituitary gland (C75.1); craniopharyngeal duct (C75.2); and pineal gland (C75.3). Histology codes would also be based on ICD-O-3. Juvenile astrocytomas should continue to be reported as 9421/3.

Inquiries about the collection of benign and borderline intracranial and CNS tumors should be directed to Ask NAACCR (<http://www.naacccr.org/Standards/AskNAACCR.html>). A panel, including representatives from each standard setting organization, will review each question and provide an answer.

##### **3.1.2 Canadian Council of Cancer Registries**

Collection of benign and borderline intracranial and CNS tumors is not mandatory in Canada. Some provinces/territories currently collect C70.0 – C72.9 but not C75.1 – C75.3. Implementation of benign and borderline intracranial and CNS tumor reporting would affect case ascertainment practices, case completeness, policies and procedures (nationally and provincially), workload, training, edits, software upgrades, etc. Canada is not adopting these guidelines at this time. The Canadian Council of Cancer Registries will discuss this further.

### 3.2 Benign/Borderline Intracranial and CNS Tumor Implementation Issues and Recommendations for Central Cancer Registries, Reporting Facilities and Software Vendors

#### 3.2.1 Central Cancer Registries

<b>Table 10. Central Cancer Registry Implementation Needs for Benign/Borderline Intracranial and CNS Tumors</b>		
<b>Implementation Needs</b>	<b>Availability</b>	<b>Supplier</b>
Legislative/Regulatory revision	Variable*	Central cancer registry
BBT Reportable List (Included in Appendix B)	September 2003	NAACCR
BBT ICD-9-CM and ICD-10 Casefinding List (Included in Appendix C)	September 2003	NAACCR
ICD-O-3 Brain and CNS Site/Histology list (Included in Appendix D)	September 2003	SEER
BBT Multiple Primary Determination Guidelines (Included in Appendix B)	September 2003	NAACCR
Training materials	September 2003	COC, NPCR, SEER, NAACCR
Policy and Procedure Manual Updates	Variable*	Central cancer registry
Increased Workload Assessment	Variable*	Central cancer registry
Local training	January 2004	Central cancer registry & state/local associations
NAACCR Version 10 EDITS metafile	November 2003	NAACCR
Software modifications	April 2004	Vendor & Central cancer registry
BBT data analysis guidance	TBD	TBD

\*Assessment of needed changes should be in progress.

##### 3.2.1.1 Legislative Authority

Central cancer registries must evaluate the need for legislative and/or regulatory modifications to expand reporting requirements to include benign and borderline intracranial and CNS tumors. The central cancer registry needs to evaluate whether the Benign Brain Tumor Cancer Registries Amendment Act, P.L. 107-260, applies to the central cancer registry. If so, the central cancer registry must evaluate whether the change affects legislation or regulations. Legislative changes require passage of a bill through the state legislature; regulatory changes require adherence to an (usually detailed) administrative process involving the publication of notices in the state register, administrative and legal review and approval, and possibly a public hearing. Regulatory changes are usually more under the control of the central cancer registry than a change in the legislation; however, either process can be very lengthy and may not be completed by January 1, 2004. When benign and borderline intracranial and CNS tumor reporting requirements are not included in the central cancer registry's authorizing legislation or regulations, and regulatory changes will not be in place by January 1, 2004, the central cancer registry should look at provisions within other pertinent legislation to implement reporting of benign and borderline intracranial and CNS tumors on January 1, 2004 and to initiate the steps required to modify the cancer registry legislation to include authority for mandated reporting of benign and borderline intracranial and CNS tumors.

##### 3.2.1.2 Increased Workload Assessment

Benign and borderline intracranial and CNS tumor incidence has been estimated as equivalent to that of malignant CNS tumors, approximately 1% of the central cancer registry caseload. Evaluation of the impact on workload must go beyond estimation of increased case processing to include time and staffing impacts on quality control

and training activities. Due to the complexity of reporting sources and abstracting rules for these tumors, quality control and training are expected to take a disproportionate amount of time, relative to their incidence.

### **3.2.1.3 Software Systems**

#### **3.2.1.3.1 Modifications to valid data item values must be evaluated including:**

Laterality – Beginning with malignant and benign/borderline tumors diagnosed in 2004, the following sites require a laterality code of 1-4, or 9 (The NAACCR Uniform Data Standards Committee has approved this coding change.):

- C70.0 Cerebral meninges, NOS
- C71.0 Cerebrum
- C71.1 Frontal lobe
- C71.2 Temporal lobe
- C71.3 Parietal lobe
- C71.4 Occipital lobe
- C72.2 Olfactory nerve
- C72.3 Optic nerve
- C72.4 Acoustic nerve
- C72.5 Cranial nerve, NOS

The research community has indicated that the location and laterality for primary CNS tumors is of significant interest in determining causation and assessing the impact on quality of life. With respect to CNS tumors diagnosed prior to 2004: Primary brain and CNS tumors were traditionally reported with a laterality code 0, although some registries recorded laterality codes “by agreement” for these sites. Therefore, EDITS will allow CNS tumors diagnosed prior to 2004 to have laterality codes of 0, 1-4, or 9.

#### **3.2.1.3.2 World Health Organization (WHO) Grade – The WHO grade should be recorded in Site Specific Factor 1 of the CS system. Attention must be paid to the preservation of histologic grade, which will continue to be collected as the morphology sixth digit ‘Grade’.**

#### **3.2.1.3.3 Sequence Number – Primary non-malignant tumors diagnosed on or after January 1, 2004 are to be sequenced in the range of 60 - 87. If not previously done, central cancer registries with pre-existing regional or state reporting requirements for non-malignant tumors will need to convert alphabetic sequence codes. Edits comparing sequence number to Behavior ICD-O-3 are recommended to ensure the correct counting of malignant versus non-malignant primaries.**

#### **3.2.1.3.4 Site/Histology Validation List – ICD-O-3 Primary Brain and CNS Site/Histology list (Appendix D) indicates the site and corresponding 4-digit histology codes for malignant, benign and borderline intracranial and CNS tumors.**

#### **3.2.1.3.5 Juvenile astrocytomas should continue to be reported as 9421/3.**

#### **3.2.1.4 Edits**

A careful evaluation of computerized edits, including the NAACCR EDITS metafile standard edits, utilized by the central cancer registry must be completed. Modifications may be needed to accommodate non-malignant behavior codes and sequence numbers.

#### **3.2.1.5 Training**

Training materials were distributed at the NPCR Train-the-Trainer program in September 2003. Training programs within the region or state should be scheduled to take place prior to January 1, 2004, or shortly thereafter. This is especially important for reporting facilities without a facility-based registry, as reporting of 2004 cases from these facilities may begin as early as February 2004.

#### **3.2.1.6 Policy and Procedure Manual Updates**

At a minimum the central cancer registry should review and modify appropriate documentation including, Reportable List, ICD-9-CM/ICD-10 Casefinding List, and Multiple Primary Determination Guidelines, consistent with Rules for Benign Brain Tumor reporting approved by NAACCR (Appendix B). Other considerations include the staging and follow-up of these cases.

#### **3.2.1.7 Death Processing**

In order to identify death certificates with a benign and borderline intracranial and CNS tumor as a cause of death and to assess mortality attributable to these tumors, the central cancer registry death process must be modified to include the appropriate ICD-10 codes and/or terms (Appendix C) effective with 2004 cases.

#### **3.2.1.8 Follow-up**

SEER central registry follow-up activities will be inclusive of the benign and borderline intracranial and CNS tumors.

#### **3.2.1.9 Data Analysis**

Data query systems and analytic programs must be modified in order to produce tables and statistics for these tumors. Pilocytic astrocytomas are included in analysis for malignant brain tumors for continuity of trends.

#### **3.2.2 Reporting Facilities**

Consistent with state laws, reporting facilities will be required to collect data for benign and borderline intracranial and CNS tumors with a behavior code of /0 or /1 effective with cases diagnosed January 1, 2004.

Source materials for the reporting of benign and borderline intracranial and CNS tumors listed in Table 11 will assist in updating policy/procedure manuals, updating casefinding lists, updating reportable lists, determining multiple primaries, sequencing tumors, coding laterality, etc.

<b>Table 11. Reporting Facility Implementation Needs for Benign/Borderline Intracranial and CNS Tumors</b>		
<b>Implementation Needs</b>	<b>Availability</b>	<b>Suppliers</b>
BBT Reportable List (Included in Appendix B)	September 2003	NAACCR
BBT ICD-9-CM casefinding list (Included in Appendix C)	September 2003	NAACCR



ICD-O-3 Brain and CNS Site/Histology list (Included in Appendix D)	September 2003	SEER
BBT Multiple Primary Determination Guidelines (Included in Appendix B)	September 2003	NAACCR
Policy and Procedure Manual Updates	Variable	Reporting Facility
Increased Workload Assessment	Variable	Reporting Facility
Local training	January 2004	Central cancer registry & state/local associations
NAACCR Version 10 EDITS metafile	November 2003	NAACCR
Software modifications	April 2004	Vendor & Central cancer registry
BBT data analysis guidance	TBD	TBD

### 3.2.2.1 Increased Workload Assessment

The increase in a reporting facility caseload will be dependent on the type of reporting facility. Reporting facilities with small or no neurology service will likely experience a minimal increase in caseload. However, facilities with a large neurology service will likely experience a larger increase in their caseload. Reporting facilities could identify what their approximate workload increase for 2004 cases would be by reviewing casefinding sources used for 2003 cases. The following is a list of possible casefinding sources:

- Pathology, cytology
- Disease indices
- Surgery logs
- Diagnostic imaging
- Radiation oncology
- Neurology clinics
- Medical oncology
- Autopsy reports

### 3.2.2.2 Data Collection

- 3.2.2.2.1 Abstracting of the benign and borderline intracranial and CNS tumors diagnosed on or after January 1, 2004 should not be delayed but be held in suspense until software upgrades and updated edits are available. Contact your cancer registry software vendor regarding the availability of the software upgrades.
- 3.2.2.2.2 WHO Grade – Attention must be paid to the preservation of histologic grade, which will continue to be collected in the sixth digit Grade. The WHO grade should be recorded in Site Specific Factor 1 of the CS System.
- 3.2.2.2.3 Sequence Number – Primary non-malignant tumors diagnosed on or after January 1, 2004 are to be sequenced in the range of 60 - 87. Edits comparing sequence number to Behavior ICD-O-3 are recommended to ensure the correct counting of malignant versus non-malignant primaries.

- 3.2.2.2.4 Laterality – Beginning with malignant and benign/borderline tumors diagnosed in 2004, the following sites will require a laterality code of 1-4, or 9 (The NAACCR Uniform Data Standards Committee has approved this coding change.):

- C70.0 Cerebral meninges, NOS
- C71.0 Cerebrum
- C71.1 Frontal lobe
- C71.2 Temporal lobe
- C71.3 Parietal lobe
- C71.4 Occipital lobe
- C72.2 Olfactory nerve
- C72.3 Optic nerve
- C72.4 Acoustic nerve
- C72.5 Cranial nerve, NOS

The research community has indicated that the location and laterality for primary CNS tumors is of significant interest in determining causation and assessing the impact on quality of life. With respect to CNS tumors diagnosed prior to 2004: Primary brain and CNS tumors were traditionally reported with a laterality code 0, although some registries recorded laterality codes “by agreement” for these sites. Therefore, EDITS will allow CNS tumors diagnosed prior to 2004 to have laterality codes of 0, 1-4, or 9.

- 3.2.2.2.5 Site/Histology Validation List – ICD-O-3 Primary Brain and CNS Site/Histology list (Appendix D) indicates the site and corresponding 4-digit histology codes for malignant, benign and borderline intracranial and CNS tumors.

- 3.2.2.2.6 Juvenile astrocytomas should continue to be reported as 9421/3.

In 2003, the NAACCR Uniform Data Standards Committee approved the addition of code ‘8 – not applicable’ for SEER Summary Stage 1977 and SEER Summary Stage 2000. Code 8 will be used for benign and borderline tumors. SEER Summary Stage 2000 will be derived from the CS algorithm for cases diagnosed January 1, 2004 or later.

Systematic annual follow-up of patients is an important cancer registry function. Patients diagnosed with benign and borderline intracranial and CNS tumors January 1, 2004 or later must be followed for the lifetime of the patient. Lifetime follow-up information includes information about the cancer and the patient status. This information is recorded in the NAACCR items *Date of Last Contact* [1750], *Vital Status* [1760], *Cancer Status* [1770], *Recurrence Date – 1<sup>st</sup>* [1860], *Recurrence Type – 1<sup>st</sup>* [1880], *Following Registry* [2440], *Follow-up Source* [1790], and *Next Follow-up Source* [1800]. In addition, any planned treatment that had not been fully recorded (i.e., planned but not yet started) should be resolved at follow-up.

For patients diagnosed with benign and borderline intracranial and CNS tumors before January 1, 2004 follow-up recommendations have varied depending upon the requestor. Reporting facilities, as necessary, should review the central cancer registry follow-up requirements that require reporting of these cases. The CoC has required lifetime follow-up of these cases if they have been entered into CoC approved cancer program registries as class of case 0, 1, or 2.

### 3.2.3 Software Vendors

Important points for consideration when supporting clients’ transition to Version 10.1 standards (2004) implementation of data collection for benign and borderline intracranial and CNS tumors are listed below. NAACCR version 10.1 necessitates change in the following:

### 3.2.3.1 Timeliness

Software vendors must prepare to comply with new standards in advance of implementation dates. As a result software vendors need to revise/develop, test, distribute, and install software prior to implementation dates set by standard setting organizations and central cancer registries. If there are delays to the standards or errata that have not been identified, the software vendor programs will be at risk of delay. Software vendors should build this factor into their timelines.

### 3.2.3.2 Database Conversion

Primary non-malignant tumors diagnosed on or after January 1, 2004 are to be sequenced in the range of 60-87. If not previously done, registries with pre-existing regional or state reporting requirements for non-malignant tumors will need to convert sequence codes. Edits comparing sequence number to Behavior ICD-O-3 are recommended to ensure the correct counting of malignant versus non-malignant primaries.

### 3.2.3.3 Data Collection

3.2.3.3.1 Software vendors will benefit from reviewing the Registry Operations Benign Brain Tumor Work Group document, *Accessioning Primary Intracranial and Central Nervous System Tumors General Reporting Rules (Appendix B)*, to see how the rules apply to their data system.

3.2.3.3.2 ICD-O-3 Primary Brain and CNS Site/Histology Listing (Appendix D) are to be considered as appropriate for site/histology driven lookups for field validation.

3.2.3.3.3 ICD-9-CM Casefinding List (Appendix C) updates will be considered as a tool for systems that import casefinding cases – it's possible that software changes may or may not be required based on the ICD-9-CM casefinding list incorporation of intracranial and CNS sites regardless of the behavior.

3.2.3.3.4 Laterality – Beginning with malignant and benign/borderline tumors diagnosed in 2004, the following sites will require a laterality code of 1-4, or 9 (The NAACCR Uniform Data Standards Committee has approved this coding change.):

- C70.0 Cerebral meninges, NOS
- C71.0 Cerebrum
- C71.1 Frontal lobe
- C71.2 Temporal lobe
- C71.3 Parietal lobe
- C71.4 Occipital lobe
- C72.2 Olfactory nerve
- C72.3 Optic nerve
- C72.4 Acoustic nerve
- C72.5 Cranial nerve, NOS

The research community has indicated that the location and laterality for primary CNS tumors is of significant interest in determining causation and assessing the impact on quality of life. With respect to CNS tumors diagnosed prior to 2004: Primary brain and CNS tumors were traditionally reported with a laterality code 0, although some registries recorded laterality codes “by agreement” for these sites. Therefore, EDITS will allow CNS tumors diagnosed prior to 2004 to have laterality codes of 0, 1-4, or 9.

- 3.2.3.3.5 WHO Grade Code will be collected through Site Specific Factor 1 of the Collaborative Staging System for Brain and other CNS sites.
- 3.2.3.3.6 For those performing concurrent abstracting, it will be necessary to place any 2004 diagnosed benign and borderline intracranial and CNS tumor cases into suspense until the software is available. (This is not a software vendor issue, but a reporting facility issue, see reporting facility requirements section 3.2.2.)
- 3.2.3.3.7 A suspense system must be available for cases that cannot be staged by CS until the 2004 updates are completely incorporated into the software.
- 3.2.3.3.8 Juvenile astrocytomas should continue to be reported as 9421/3.

#### **3.2.3.4 Field Validation and Edits**

- 3.2.3.4.1 Software vendors can expect that NAACCR version 10 EDITS metafile for NAACCR version 10.1 record layout will incorporate changes for data collection rules of benign and borderline intracranial and CNS tumors. This will require additional implementation and testing time to allow for changes following the first software release.
- 3.2.3.4.2 NAACCR version 10 EDITS metafile updates must be included as appropriate where edits would otherwise keep these cases from passing through a data quality check.
- 3.2.3.4.3 This will also impact any state specific metafiles currently in use at the time of implementation. These metafiles may require replacement with updated files.
- 3.2.3.4.4 Suspense cases added prior to the NAACCR version 10 EDITS metafile should be processed through edits upon installation of the software upgrade.

#### **3.2.3.5 Reports**

- 3.2.3.5.1 Benign and borderline intracranial and CNS tumors should be added as a separate line item category in the client's Primary Site Table. This group must be added as a separate category in order to differentiate between the benign and borderline tumors now reportable vs. the malignant tumors.
- 3.2.3.5.2 Reports are to add a footnote that pilocytic astrocytomas are included in analysis for malignant brain tumors for continuity of trends.
- 3.2.3.5.3 Follow-up reports must be updated to include benign and borderline intracranial and CNS tumors diagnosed January 1, 2004 and later.
- 3.2.3.5.4 Follow-up Survey Worksheet (Lost to Follow-up Calculations Report) must be updated to appropriately account for benign and borderline intracranial and CNS tumors diagnosed January 1, 2004 and later.

### **3.2.3.6 Transmission of Records**

3.2.3.6.1 Changes will be required to the criteria used to determine which cases in a client database are to be exported/transmitted to central cancer registries. This will now include a requirement for reporting benign and borderline intracranial and CNS tumors with Behavior of /0 and /1.

3.2.3.6.2 In addition, the National Cancer Data Base Call for Data submission may need to be updated to include these cases for reportability.

### **3.2.3.7 On-Line Help Systems**

11.3.7.1. On-line Help systems are encouraged to incorporate material from these guidelines.

### **3.2.3.8 Technical Support and Education**

Software vendors will support their software changes and assist reporting facilities and central cancer registries in data collection and reporting requirements. Software vendors should provide training only on software upgrades, which should include reference to the source for information on year 2004 changes.

## **3.3 Benign/Borderline Intracranial and CNS Tumor EDITS**

The version 10 NAACCR EDITS Metafile will be updated to handle benign and borderline intracranial and CNS tumor processing for cases diagnosed January 1, 2004 and later. This includes modifications to the ICD-O-3 SEER Site/Histology Validation table and to many of the interfield edits that now edit primary site, histology, behavior, laterality, and sequence number (both hospital and central). The Metafile, when completed, will be available from the NAACCR web site. Anticipated date of availability is November 2003.

## **3.4 Benign/Borderline Intracranial and CNS Tumor Training/Educational Material**

The development of training materials has been funded by NPCR through a contract with NAACCR. A review committee with representatives of all standard setting organizations was formed to provide guidance on the content and format of the materials. The standard setting organizations have agreed to utilize these standard training materials to ensure uniformity in the training of central cancer registry and reporting facility staff.

The 2003 Cancer Registry Instructors Training course sponsored by NPCR in collaboration with AJCC, NAACCR, and SEER was held on September 3 – 4, 2003. One day of this two day session was devoted to training instructors on non-malignant central nervous system tumor data collection. Course participants were provided with presentation materials, case scenarios and answers as well as techniques to enhance adult learning. The training materials used for this program will be available through the NAACCR web site ([www.naaccr.org](http://www.naaccr.org)).

Requests for training at annual state cancer registry meetings are anticipated to be heavy and continued training and technical support will be required from central cancer registries and standard setters. Central cancer registries and standard setters are principally responsible for continuing these supporting activities.

A Benign Brain Tumor Reporting web-based training module is available on SEER's training web site at [www.training.seer.cancer.gov](http://www.training.seer.cancer.gov).

Inquiries about the collection of benign and borderline intracranial and CNS tumors should be directed to Ask NAACCR (<http://www.naaccr.org/Standards/AskNAACCR.html>). A panel including representatives from each standard setting organization will review each question and provide an answer.

## **4      Appendix A**

### **BENIGN BRAIN TUMOR CANCER REGISTRIES AMENDMENT ACT**

**The Benign Brain Tumor Cancer Registries Amendment Act, Public Law 107-260, is reproduced beginning on the next page.**

Public Law 107-260  
107<sup>th</sup> Congress

An Act

To amend the Public Health Service Act to provide for the collection of data on benign brain-related tumor through the national program of cancer registries.

Oct. 29, 2002  
[S. 2558]

*Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,*

Benign Brain  
Tumor Cancer  
Registries  
Amendment Act.  
42 USC 201 note.

SECTION 1. SHORT TITLE.

This Act may be cited as the “Benign Brain Tumor Cancer Registries Amendment Act”.

SEC. 2. NATIONAL PROGRAM OF CANCER REGISTRIES; BENIGN BRAIN-RELATED TUMORS AS ADDITIONAL CATEGORY OF DATA COLLECTED.

- (a) In GENERAL—Section 399B of the Public Health Service Act (42 U.S.C. 280e), as redesignated by section 502 (2)(A) of Public Law 106-310 (114 Stat. 1115), is amended in subsection(a)—
  - (1) by redesignating paragraphs (1) through (5) as subparagraphs (A) through (3), respectively, and indenting appropriately;
  - (2) by striking “(a) IN GENERAL—The Secretary” and inserting the following:
    - (a) IN GENERAL—
      - “(1) STATEWIDE CANCER REGISTRIES—The Secretary”;
      - (3) in the matter preceding subparagraph (A) (as so redesignated). By striking “population-based” and all that follows through “data” and inserting the following: “population-based, statewide registries to collect, for each condition specified in paragraph (2)(A), data”; and
      - (4) by adding at the end the following:
        - “(2) CANCER; BENIGN BRAIN-RELATED TUMORS—
          - “(A) IN GENERAL—For purposes of paragraph (1), the conditions referred to in this paragraph are the following:
            - “(i) Each form of in-situ and invasive cancer with the exception of basal cell and squamous cell carcinoma of the skin), including malignant brain-related tumors.
            - “(ii) Benign brain-related tumors
          - “(B) BRAIN-RELATED TUMOR—For purposes of subparagraph (A):

“(i) The term ‘brain-related tumor’ means a listed primary tumor (whether malignant or benign) occurring in any of the following sites:’

“(I) The brain, meninges, spinal cord, cauda equina, a cranial nerve or nerves, or any other part of the central nervous system.

“(II) The pituitary gland, pineal gland, or craniopharyngeal duct.

“(ii) The term ‘listed’, with respect to a primary tumor, means a primary tumor that is listed in the International Classification of Diseases for Oncology (commonly referred to as the ICD-O).

“(iii) The term ‘International Classification of Diseases for Oncology’ means a classification system that includes topography (site) information and histology (cell type information) developed by the World Health Organization, in collaboration with international centers, to promote international comparability in the collection, classification, processing, and presentation of cancer statistics. The ICD-O system is a supplement to the International Statistical Classification of Diseases and Related Health Problems (commonly known as the ICD) and is the standard coding system used by cancer registries worldwide. Such term includes any modification made to such system for purposes of the United States. Such term further includes any published classification system that is internationally recognized as a successor to the classification system referred to in the first sentence of this clause.

“(C) STATEWIDE CANCER REGISTRY—References in this section to cancer registries shall be considered to be references to registries described in this subsection.”.

- (b) APPLICABILITY—The amendments made by subsection (a) apply to grants under section 399B of the Public Health Service Act for fiscal year 2002 and subsequent fiscal years, except that, in the case of a State that received such a grant for fiscal year 2000, the Secretary of Health and Human Services may delay the applicability of such amendments to the State for not more than 12 months if the Secretary determines that compliance with such amendments requires the enactment of a statute by the State or the issuance of State regulations.

Grants.  
42 USC 280e note.

Approved October 29, 2002.

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**LEGISLATIVE HISTORY—s. 2558:**

Congressional record, Vol. 148 (2002):

Aug. 1. considered and passed Senate.

Oct 10. considered and passed House.



## **5      Appendix B**

### **Accessioning Primary Intracranial and Central Nervous System Tumors General Reporting Rules**

Prepared by the NAACCR Registry Operations Committee Benign Brain Tumor Subcommittee

Reviewed and Approved by NAACCR Uniform Data Standards Committee July 2, 2003

#### **Introduction**

In the early 1900's, the neurosurgeon Harvey Cushing made the observation that some brain tumors are malignant because of their histology, and some are malignant because of their location. By this he meant that in the early 1900's some tumors were not resectable and would result in the death of the patient because of mass effects on vital areas of the brain. In the past 100 years, with advances in microsurgery, radiation therapy, and earlier diagnosis, the maxim of Dr. Cushing still stands, although at a greatly diminished number. The tumors, whether benign or malignant, produce clinical effects by similar mechanisms of mass effect, hemorrhage, seizure activity, and edema. Long-term follow-up in these studies are generally absent. Although these tumors are individually rare, patients with benign brain tumors represent an under-appreciated financial and health burden in the United States. These cases include those tumors arising in families with an inherited tendency to develop benign and malignant brain tumors, tumors arising from developmental abnormalities, morbidity from ruptured benign brain tumors, and eventual malignant transformation in a subgroup of patients with optic nerve gliomas.

Existing coding rules for brain and CNS tumors have been guided by the behavior of these tumors. With the change to a site definition to guide their collection, the ROC Benign Brain Tumor Subcommittee reviewed coding rules applicable to both nonmalignant and malignant brain and CNS tumors. Recommendations applicable to the current rules guiding multiple primaries for malignant brain and CNS tumors are contained in a separate document and have been forwarded to the SEER Histology Coding Committee for review in 2003.

**Rules for Benign Brain Tumors**  
Effective with cases diagnosed January 2004 and after

(Note: the rules for malignant brain tumors follow the same rules for multiple primaries that have been in effect, but are presented with those for non-malignant brain tumors for ease of use.)

Beginning with tumors diagnosed on or after January 1, 2004, reportable tumors required to be abstracted include non-malignant primary intracranial and central nervous system tumors in ICD-O-3 with a behavior code of /0 or /1 (benign and borderline, or “non-malignant”) regardless of histologic type, for the following ICD-O-3 topography codes.

<b>Table 1. Topography Codes for Benign Brain Tumors</b>	
<b>Codes</b>	<b>Description</b>
C70.0 C70.1 C70.9	Meninges Cerebral meninges Spinal meninges Meninges, NOS
C71.0 C71.1 C71.2 C71.3 C71.4 C71.5 C71.6 C71.7 C71.8 C71.9	Brain Cerebrum Frontal lobe Temporal lobe Parietal lobe Occipital lobe Ventricle, NOS Cerebellum, NOS Brain stem Overlapping lesion of brain Brain, NOS
C72.0 C72.1 C72.2 C72.3 C72.4 C72.5 C72.8 C72.9	Spinal Cord, Cranial Nerves and Other Parts of the Central Nervous System Spinal cord Cauda equina Olfactory nerve Optic nerve Acoustic nerve Cranial nerve, NOS Overlapping lesion of brain and central nervous system Nervous system, NOS
C75.1 C75.2 C75.3	Other Endocrine Glands and Related Structures Pituitary gland Craniopharyngeal duct Pineal gland

- For non-malignant primary intracranial and central nervous system tumors (C70.0 – C72.9, C75.1 – C75.3), the terms “tumor” and “neoplasm” are considered diagnostic for the purpose of case reporting, in addition to the terms generally applicable to malignant tumors.

**I. Definitions:**

A. Non-malignant: behavior code of /0 or /1.

B. Malignant: behavior code of /2 or /3.

C. Same Site

1. Non-malignant: same 4-digit site

*Exception:* 4-digit NOS site code (C70.9, C71.9, C72.9) with specific 4-digit site code in same rubric

*Example:* meninges, NOS (C70.9) with spinal meninges (C70.1) or cerebral meninges (C70.0) is the same site

2. Malignant: same 3-digit site

D. Different site

1. Non-malignant: different 4 digit site code

*Exception:* 4-digit NOS site code (C70.9, C71.9, C72.9) with specific 4-digit site code in same rubric

*Example of exception:* Brain stem (C71.7) with intracranial site (C71.9) is the *same* site.

2. Malignant: different 3 digit site

E. Same histology

1. Non-malignant (in priority order):

- a. Use Table 2 listed under II.D. in this document – if both histologies are in the same histologic group, then same histology
- b. If same first 3 digits as any histology in Table 2, then same histology
- c. If same first 3 digits but neither in Table 2, then same histology

2. Malignant (current rule): same at 3-digit level

F. Different histology

1. Non-malignant:

- a. If 2 different histologic groups in Table 2
- b. If different at 3 digit level and not in same group in Table 2
- c. If different at 3 digit level and neither in Table 2, then different histology

2. Malignant (current rule): different at 3 digit level

G. Timing

1. Non-malignant: current 2-month timing rule does not apply.

2. Malignant:

- a. Within 2 months
- b. 2+ months

H. Laterality:

1. Single side (SS): involves only one side of sites listed in Section III, A.
2. Both sides (BS): involves both sides of sites listed in Section III, A.
3. Laterality unknown (LX): Site does not have laterality coded or laterality is not coded for site

**II. General Rules for Determining Multiple Primaries: The following rules apply for defining multiple primaries for non-malignant and malignant primary intracranial and central nervous system tumors (C70.0 – C72.9, C75.1 – C75.3).**

*Rationales for multiple primaries rules:*

1. The natural biology of non-malignant tumors is that of expansive, localized growth, with local recurrences common, and metastasis uncommon or unusual.
2. Non-malignant tumors of the same histology, same site, and same side will recur in the same location. If they recur, even after 20 years, they are still the same tumor.
3. The corollary to statement 2 is that multiple non-malignant tumors of the same histology identified in different locations or sides of the CNS should be considered separate primaries.

A. Multiple lesions in which all are non-malignant tumors

1. If different sites, then separate primaries
2. If different histologies, then separate primaries
3. If same site and same histology\*:
  - a. and laterality is same side, one side unknown or not applicable, then single primary
  - b. and laterality is both sides, then separate primaries

\* Note: if two histologies are in the same group in Table 2, code the more specific histology

B. Multiple tumors in which one was non-malignant and the other was a malignant lesion

1. Non-malignant tumor followed by malignant tumor: separate primaries regardless of timing
2. Malignant tumor followed by a non-malignant tumor: separate primaries regardless of timing

C. Multiple malignant tumors

1. If same histology:
  - a. < 2 months:
    - i. 1 if same site
    - ii. 2 if different site and not stated to be a recurrence or metastases
  - b. 2+ months (site does not matter):
    - i. 2 unless stated to be a recurrence or metastases
2. If different histologies:
  - a. <2 months:
    - i. 2 if same site unless one is more specific histology
    - ii. 2 if different site
  - b. 2+ months:
    - i. always 2 primaries

- D. Table 2. Histologic groupings to determine same histology for non-malignant brain tumors. (See COC FORDS and SEER Program Manual for histology coding instructions.)

Choroid plexus neoplasms	9390/0, 9390/1
Ependymomas	9383, 9394, 9444
Neuronal and neuronal-glial neoplasms	9384, 9412, 9413, 9442, 9505/1, 9506
Neurofibromas	9540/0, 9540/1, 9541, 9550, 9560/0
Neurinomatosis	9560/1
Neurothekeoma	9562
Neuroma	9570
Perineurioma, NOS	9571/0

*Rationale:* Brain tumor histologies grouped in Table 2 do not follow the standard 3-digit histology difference rule because they represent a progression, differentiation or subtype of a single histologic category.

In a review of the ICD-O histology codes, applying the current 3-digit histology rule to non-malignant tumors would combine tumors that are no longer considered to be biologically related.

### III. Collection of additional data

#### A. Laterality

Beginning with malignant and benign/borderline tumors diagnosed in 2004, the following sites require a laterality code of 1-4, or 9 (The NAACCR Uniform Data Standards Committee has approved this coding change.):

C70.0 Cerebral meninges, NOS  
C71.0 Cerebrum  
C71.1 Frontal lobe  
C71.2 Temporal lobe  
C71.3 Parietal lobe  
C71.4 Occipital lobe  
C72.2 Olfactory nerve  
C72.3 Optic nerve  
C72.4 Acoustic nerve  
C72.5 Cranial nerve, NOS

The research community has indicated that the location and laterality for primary CNS tumors is of significant interest in determining causation and assessing the impact on quality of life. With respect to CNS tumors diagnosed prior to 2004: Primary brain and CNS tumors were traditionally reported with a laterality code 0, although some registries recorded laterality codes "by agreement" for these sites. Therefore, EDITS will allow CNS tumors diagnosed prior to 2004 to have laterality codes of 0, 1-4, or 9.

- Rationale:*
- a. Laterality is needed to determine multiple primaries for benign brain tumors.
  - b. Researchers, including epidemiologists, have requested the collection of laterality (*Inskip PD, Neuroepidemiology 2003; 22;130-138*). The location of certain tumors might help in determining causation. Certain investigations such as those involving cell phone usage would benefit from having this variable routinely available.
  - c. Non-treatment-related factors such as location of tumor by hemisphere can be predictive factors for cognitive outcome. (*Brown PD, Buckner, JC, Uhm JH, and Shaw EG 2003*) The neurocognitive effects of radiation in adult low-grade glioma patients. *Neuro-Oncology 5*, 161-167, 2003.

#### B. WHO Grade Code

This item is to be coded in Site Specific Factor 1 of the Collaborative Staging System for Brain and other Central Nervous System sites.

WHO Grade I - Code 010 in Collaborative Staging System  
WHO Grade II - Code 020  
WHO Grade III - Code 030  
WHO Grade IV - Code 040  
WHO Grade unknown - Code 999

WHO grade I generally describes non-malignant or benign tumors; however, non-malignant tumors should not be coded as Grade I unless WHO grade is specifically stated in the source document.

WHO grade II generally describes a malignant tumor but it can describe a non-malignant tumor depending on histologic type.

WHO grade III and IV describe malignant tumors.

For certain types of CNS tumors, no WHO grade is assigned.

#### C. Reportability/Sequence number

1. Non-malignant: a primary non-malignant tumor of any of the sites specified diagnosed *on or after* January 1, 2004, is reportable. The sequence number for the tumor is in the range 60 – 87.

Non-malignant tumors diagnosed before January 1, 2004 should be included in the lifetime sequence of non-malignant and borderline tumors in the range 60-87.

A primary non-malignant tumor of any of the sites specified diagnosed *before* January 1, 2004, is not reportable unless there are specific preexisting regional or state reporting requirements.

*Rationale:* To clarify reporting implementation date and sequence rules for non-malignant tumors.

2. Malignant: the sequence number for the malignancy is in the range 00-35.

3. The sequencing of non-malignant tumors does not affect the sequencing of malignant tumors, and vice versa. For example, a first malignancy (sequence 00) will remain sequence 00 if followed by a non-malignant tumor (sequence 60-87)

#### **IV. Analysis/Reporting of Brain and CNS Tumors:**

The ROC Benign Brain Tumor Subcommittee **recommends** that non-malignant and malignant brain tumors be reported separately with a footnote that pilocytic astrocytomas are included in analysis for malignant brain tumors for continuity of trends.

**We recommend** reviewing the standard site and histology groupings for tabulating estimates of these tumors to allow comparability of information across registries.

**We recommend** that training for reporting and tabulating primary intracranial and CNS tumors be offered on a regular basis.

#### **Registry Operations Committee Benign Brain Tumor Subcommittee Members**

Susan Bolick-Aldrich (Chair)	SC Central Cancer Registry, Registry Operations Committee Co-Chair
Trista Aarnes-Leong	St. Vincent Medical Center, Los Angeles
Gayle Clutter	National Program of Cancer Registries, CDC
April Fritz	SEER Program, NCI
Susan Gershman, PhD	Massachusetts Cancer Registry, Registry Operations Committee Co-Chair
Bette Smith	Ohio Cancer Incidence Surveillance System
Carol Kruchko	Central Brain Tumor Registry of the US
Bridget McCarthy, PhD	Central Brain Tumor Registry of the US
Roger McLendon, MD	Neuropathologist, Duke University Medical Center, Durham, NC
Fran Michaud	National Program of Cancer Registries, CDC
Eileen Morgan	Duke University Medical Center Cancer Registry, Durham, NC
Donna Morrell	USC School of Medicine Cancer Surveillance Program, Los Angeles
Jerri Linn Phillips	American College of Surgeons, Commission on Cancer
Katheryne Vance	California Cancer Registry
Shannon Vann	Independent contractor, NAACCR
Claudia Feight	Oregon State Cancer Registry
James Gurney, PhD	University of Minnesota Division of Pediatric Epidemiology
Elaine Hamlyn	Canadian Cancer Registry, Statistics Canada
Linda Mulvihill	North Carolina Central Cancer Registry
James Smirniotopoulos, MD	Dept of Radiology & Radiological Sciences, Uniform Services University of the Health Sciences
Valerie Vesich	American College of Surgeons, Commission on Cancer

## 6 Appendix C

### Additions to Cancer Registry ICD-9-CM and ICD-10 Casefinding List

Cases are sorted in the hospital diagnosis indices by ICD-9-CM diagnosis code. Each cancer registry, central or hospital, uses a list of ICD-9-CM cancer codes to identify potential cases. With the implementation of collection of benign and borderline intracranial and CNS tumors, ICD-9-CM codes for these diseases need to be added to the cancer registry casefinding list. The additional codes follow:

ICD-9-CM Casefinding Codes for Benign and Borderline Intracranial and CNS Tumors	
ICD-9-CM Code	Description of Neoplasm
225.0	Benign neoplasm of brain
225.1	Benign neoplasm of cranial nerves
225.2	Benign neoplasm of cerebral meninges; cerebral meningioma
225.3	Benign neoplasm of spinal cord, cauda equina
225.4	Benign neoplasm of spinal meninges; spinal meningioma
225.8	Benign neoplasm of other specified sites of nervous system
225.9	Benign neoplasm of nervous system, part unspecified
227.3	Benign neoplasm of pituitary, craniopharyngeal duct, craniobuccal pouch, hypophysis, Rathke's pouch, sella turcica
227.4	Benign neoplasm of pineal gland, pineal body
237.0	Neoplasm of uncertain behavior of pituitary gland and craniopharyngeal duct
237.1	Neoplasm of uncertain behavior of pineal gland
237.5	Neoplasm of uncertain behavior of brain and spinal cord
237.6	Neoplasm of uncertain behavior of meninges: NOS, cerebral, spinal
237.70	Neurofibromatosis, Unspecified von Recklinghausen's Disease
237.71*	Neurofibromatosis, Type One von Recklinghausen's Disease
237.72	Neurofibromatosis, Type Two von Recklinghausen's Disease
237.9	Neoplasm of uncertain behavior of other and unspecified parts of nervous system; cranial nerves

\*Code 237.71 may not be reportable, however, these diagnosis may indicate a reportable condition and should be reviewed.



Central cancer registries use ICD-10 codes and/or terms to identify “death certificate found” tumors. The central cancer registry death process must be modified to include the following benign and borderline intracranial and CNS codes:

<b>ICD-10 Casefinding Codes for Benign and Borderline Intracranial and CNS Tumors</b>	
<b>ICD-10 Code</b>	<b>Description of Neoplasm</b>
D32	Benign neoplasm of meninges
D32.0	Cerebral meninges
D32.1	Spinal meninges
D32.9	Meninges, unspecified
D33	Benign neoplasm of brain and other parts of the central nervous system
D33.0	Brain, supratentorial
D33.1	Brain, infratentorial
D33.2	Brain, unspecified
D33.3	Cranial nerves
D33.4	Spinal cord
D33.7	Other specified parts of central nervous system
D33.9	Central nervous system, part unspecified
D35	Benign neoplasm of other and unspecified endocrine glands
D35.2	Pituitary gland
D35.3	Craniopharyngeal duct
D35.4	Pineal gland
D42	Neoplasm of uncertain or unknown behavior of meninges
D42.0	Cerebral meninges
D42.1	Spinal meninges
D42.9	Meninges, unspecified
D43	Neoplasm of uncertain or unknown behavior of brain and central nervous system
D43.0	Brain, supratentorial
D43.1	Brain, infratentorial
D43.2	Brain, unspecified
D43.3	Cranial nerves
D43.4	Spinal cord
D43.7	Other parts of central nervous system
D43.9	Central nervous system, unspecified
D44	Neoplasm of uncertain or unknown behavior of endocrine glands
D44.3	Pituitary gland
D44.4	Craniopharyngeal duct
D44.5	Pineal gland
Q85.1*	Neurofibromatosis (non-malignant); Von Recklinghausen disease

\*Code Q85.1 may not be reportable, however, these diagnosis may indicate a reportable condition and should be reviewed.

## 7 Appendix D

### ICD-O-3 Primary Brain and CNS Site/Histology Listing

Based on ICD-O-3 SEER Site/Histology Validation list

Reviewed by Neuropathologists: Drs. Roger McLendon, Janet Bruner, Steven Moore

SEER: Lynn Ries

CBTRUS: Dr. Bridget McCarthy, Carol Kruchko

Underlined bold type indicates histology codes with a benign or uncertain behavior code that have been added by CBTRUS and not contained in the ICD-O-3 SEER Site/Histology Validation List.

**Bold type** indicates histology codes with a malignant behavior code that have been added by CBTRUS and not contained in the ICD-O-3 SEER Site/Histology Validation List.

Red color indicates histology codes new to the ICD-O-3 SEER Site/Histology Validation List.

#### MENINGES (CEREBRAL,SPINAL) C700-C709

NEOPLASM

800

##### 8000/0 Neoplasm, benign

8000/1 Neoplasm, uncertain whether benign or malignant

8000/3 Neoplasm, malignant

##### 8001/0 Tumor cells, benign

8001/1 Tumor cells, uncertain whether benign or malignant

8001/3 Tumor cells, malignant

8005/3 Malignant tumor, clear cell type

NEVI & MELANOMAS

872

8720/3 Malignant melanoma, NOS

##### 8728/0 Diffuse melanocytosis

##### 8728/1 Meningeal melanocytoma

8728/3 Meningeal melanomatosis

SARCOMA, NOS

880

##### 8800/0 Soft tissue tumor, benign

8800/3 Sarcoma, NOS

8801/3 Spindle cell sarcoma

8805/3 Undifferentiated sarcoma

8806/3 Desmoplastic small round cell tumor

FIBROMATOUS NEOPLASMS	881	<u>8810/0 Fibroma, NOS</u> <u>8810/3 Fibrosarcoma, NOS</u> <u>8815/0 Solitary fibrous tumor</u>
LIPOMATOUS NEOPLASMS	885	<u>8850/0 Lipoma, NOS</u> <u>8851/0 Fibrolipoma</u>
ANGIOLIPOMA	886	<u>8861/0 Angiolipoma, NOS</u>
MYOMATOUS NEOPLASMS	889	8890/3 Leiomyosarcoma, NOS
EMBRYONAL RHABDOMYOSARCOMA	891	8910/3 Embryonal rhabdomyosarcoma, NOS
TERATOMA	908	<u>9080/0 Teratoma, benign</u> <u>9080/1 Teratoma, NOS</u> <u>9080/3 Teratoma, malignant, NOS</u> <u>9084/0 Dermoid cyst, NOS</u> 9084/3 Teratoma with malig. transformation
BLOOD VESSEL TUMORS	912	<u>9120/0 Hemangioma, NOS</u> <u>9121/0 Cavernous hemangioma</u>
HEMANGIOPERICYTOMA	915	<u>9150/0 Hemangiopericytoma, benign</u> <u>9150/1 Hemangiopericytoma, NOS</u> 9150/3 Hemangiopericytoma, malignant
HEMANGIOBLASTOMA	916	<u>9161/1 Hemangioblastoma</u>
OSSEOUS & CHONDROMATOUS NEOPLASMS	924	9240/3 Mesenchymal chondrosarcoma

MENINGIOMA	953	<u>9530/0 Meningioma, NOS</u> <u>9530/1 Meningiomatosis, NOS</u> 9530/3 Meningioma, malignant <u>9531/0 Meningothelial meningioma</u> <u>9532/0 Fibrous meningioma</u> <u>9533/0 Psammomatous meningioma</u> <u>9534/0 Angiomatous meningioma</u>  <u>9537/0 Transitional meningioma</u> <u>9538/1 Clear cell meningioma</u> 9538/3 Papillary meningioma <u>9539/1 Atypical meningioma</u> 9539/3 Meningeal sarcomatosis
MALIGNANT LYMPHOMA, NOS	959	9590/3 Malignant lymphoma, NOS 9591/3 Malignant lymphoma, non-Hodgkin 9596/3 Composite Hodgkin and non-Hodgkin lymphoma
HODGKIN LYMPHOMA	965	9650/3 Hodgkin lymphoma, NOS 9651/3 Hodgkin lymphoma, lymphocyte-rich 9652/3 Hodgkin lymphoma, mixed cellularity, NOS 9653/3 Hodgkin lymphoma, lymphocytic deplet., NOS 9654/3 Hodgkin lymphoma, lymphocyt. deplet., diffuse fibrosis 9655/3 Hodgkin lymphoma, lymphocyt. deplet., reticular 9659/3 Hodgkin lymphoma, nodular lymphocyte predom.
HODGKIN LYMPHOMA, NOD. SCLER.	966	9661/3 Hodgkin granuloma 9662/3 Hodgkin sarcoma 9663/3 Hodgkin lymphoma, nodular sclerosis, NOS 9664/3 Hodgkin lymphoma, nod. scler., cellular phase 9665/3 Hodgkin lymphoma, nod. scler., grade 1 9667/3 Hodgkin lymphoma, nod. scler., grade 2
ML, SMALL B-CELL LYMPHOCYTIC	967	9670/3 ML, small B lymphocytic, NOS

		9671/3 ML, lymphoplasmacytic
		9673/3 Mantle cell lymphoma
		9675/3 ML, mixed sm. and lg. cell, diffuse
ML, LARGE B-CELL, DIFFUSE	968	
		9680/3 ML, large B-cell, diffuse
		9684/3 ML, large B-cell, diffuse, immunoblastic, NOS
		9687/3 Burkitt lymphoma, NOS
FOLLIC. & MARGINAL LYMPH, NOS	969	
		9690/3 Follicular lymphoma, NOS
		9691/3 Follicular lymphoma, grade 2
		9695/3 Follicular lymphoma, grade 1
		9698/3 Follicular lymphoma, grade 3
		9699/3 Marginal zone B-cell lymphoma, NOS
T-CELL LYMPHOMAS	970	
		9701/3 Sezary syndrome
		9702/3 Mature T-cell lymphoma, NOS
		9705/3 Angioimmunoblastic T-cell lymphoma
OTHER SPEC. NON-HODGKIN LYMPHOMA	971	
		9714/3 Anaplastic large cell lymphoma, T-cell and Null cell type
		9719/3 NK/T-cell lymphoma, nasal and nasal-type
PRECURS. CELL LYMPHOBLASTIC LYMPH.	972	
		9727/3 Precursor cell lymphoblastic lymphoma, NOS
		9728/3 Precursor B-cell lymphoblastic lymphoma
		9729/3 Precursor T-cell lymphoblastic lymphoma
PLASMA CELL TUMORS	973	
		9731/3 Plasmacytoma, NOS
		9734/3 Plasmacytoma, extramedullary
MAST CELL TUMORS	974	
		9740/3 Mast cell sarcoma
		9741/3 Malignant mastocytosis

NEOPLASMS OF HISTIOCYTES AND  
ACCESSORY LYMPHOID CELLS

975

- 9750/3 Malignant histiocytosis
- 9754/3 Langerhans cell histiocytosis, disseminated
- 9755/3 Histiocytic sarcoma
- 9756/3 Langerhans cell sarcoma
- 9757/3 Interdigitating dendritic cell sarcoma
- 9758/3 Follicular dendritic cell sarcoma

**BRAIN, C710-C714 & C717-C719, (EXCL. VENTRICLE, CEREBELLUM)**  
**SPINAL CORD C720, CAUDA EQUINA C721 & CRANIAL NERVES, C722-C725**

NEOPLASM	800	<b><u>8000/0 Neoplasm, benign</u></b> <b><u>8000/1 Neoplasm, uncertain whether benign or malignant</u></b> 8000/3 Neoplasm, malignant <b><u>8001/0 Tumor cells, benign</u></b> <b><u>8001/1 Tumor cells, uncertain whether benign or malignant</u></b> 8001/3 Tumor cells, malignant 8002/3 Malignant tumor, small cell type 8003/3 Malignant tumor, giant cell type 8004/3 Malignant tumor, spindle cell type 8005/3 Malignant tumor, clear cell type
PARAGANGLIOMA	868	<b><u>8680/1 Paraganglioma, NOS</u></b>
NEVI & MELANOMAS	872	<b>8720/3 Malignant melanoma</b>
SARCOMA, NOS	880	<b><u>8800/0 Soft tissue tumor, benign</u></b> 8800/3 Sarcoma, NOS 8801/3 Spindle cell sarcoma 8805/3 Undifferentiated sarcoma 8806/3 Desmoplastic small round cell tumor
LIPOMATOUS NEOPLASMS	885	<b><u>8850/0 Lipoma, NOS</u></b> <b><u>8851/0 Fibrolipoma</u></b> <b>8851/3 Liposarcoma</b>
GERM CELL TUMORS	906	<b>9060/3 Dysgerminoma</b> <b>9064/3 Germinoma</b>

EMBRYONAL CARCINOMA	907	9070/3 Embryonal carcinoma, NOS 9071/3 Yolk Sac Tumor
TERATOMA	908	<u>9080/0 Teratoma, benign</u> <u>9080/1 Teratoma, NOS</u> 9080/3 Teratoma, malignant, NOS 9081/3 Teratocarcinoma 9085/3 Mixed germ cell tumor
TROPHOBLASTIC NEOPLASMS	910	9100/3 Choriocarcinoma, NOS
BLOOD VESSEL TUMORS	912	<u>9120/0 Hemangioma, NOS</u> <u>9121/0 Cavernous hemangioma</u> <u>9122/0 Venous hemangioma</u>
HEMANGIOENDOTHELIOMA	913	<u>9131/0 Capillary hemangioma</u>
HEMANGIOPERICYTOMA	915	<u>9150/1 Hemangiopericytoma, NOS</u>
HEMANGIOBLASTOMA	916	<u>9161/1 Hemangioblastoma</u>
CHORDOMA	937	9370/3 Chordoma, 9371/3 Chondroid chordoma 9372/3 Dedifferentiated chordoma
GLIOMA	938	9380/3 Glioma, malignant 9381/3 Gliomatosis cerebri 9382/3 Mixed glioma <u>9383/1 Subependymoma</u> <u>9384/1 Subependymal giant cell astrocytoma</u>





EPENDYMOMA, NOS	939	9391/3 Ependymoma, NOS 9392/3 Ependymoma, anaplastic 9393/3 <b>Papillary Ependymoma</b> <u>9394/1 Myxopapillary ependymoma</u>
ASTROCYTOMA, NOS	940	9400/3 Astrocytoma, NOS 9401/3 Astrocytoma, anaplastic
PROTOPLASMIC ASTROCYTOMA	941	9410/3 Protoplasmic astrocytoma 9411/3 Gemistocytic astrocytoma <u>9412/1 Desmoplastic infantile astrocytoma</u> <u>9413/0 Dysembryoplastic neuroepithelial tumor</u>
FIBRILLARY ASTROCYTOMA	942	9420/3 Fibrillary astrocytoma <u>9421/1 Pilocytic astrocytoma</u> 9423/3 Polar spongioblastoma 9424/3 Pleomorphic xanthoastrocytoma
ASTROBLASTOMA	943	9430/3 Astroblastoma
GLIOBLASTOMA, NOS	944	9440/3 Glioblastoma, NOS 9441/3 Giant cell glioblastoma <u>9442/1 Gliofibroma</u> 9442/3 Gliosarcoma <u>9444/1 Chordoid glioma</u>
OLIGODENDROGLIOMA, NOS	945	9450/3 Oligodendroglioma, NOS 9451/3 Oligodendroglioma, anaplastic
OLIGODENDROBLASTOMA	946	9460/3 Oligodendroblastoma

PRIMITIVE NEUROECTODERMAL	947	9473/3 Primitive neuroectodermal tumor, NOS
GANGLIONEUROBLASTOMA	949	<b><u>9490/0 Ganglioneuroma</u></b> 9490/3 Ganglioneuroblastoma <b><u>9492/0 Gangliocytoma</u></b>
NEUROBLASTOMA, NOS	950	9500/3 Neuroblastoma, NOS 9501/3 Medulloepithelioma, NOS 9502/3 Teratoid medulloepithelioma 9503/3 Neuroepithelioma, NOS <b><u>9505/1 Ganglioglioma, NOS</u></b> 9505/3 Ganglioglioma, anaplastic 9508/3 Atypical teratoid/rhabdoid tumor
MENINGIOMA	953	<b><u>9530/0 Meningioma, NOS</u></b> <b><u>9530/1 Meningiomas, NOS</u></b> 9530/3 Meningioma, malignant <b><u>9531/0 Meningotheliomatous meningioma</u></b> <b><u>9532/0 Fibrous meningioma</u></b> <b><u>9533/0 Psammomatous meningioma</u></b> <b><u>9534/0 Angiomatous meningioma</u></b> <b><u>9537/0 Transitional meningioma</u></b> <b><u>9538/1 Clear cell meningioma</u></b> 9538/3 Papillary meningioma <b><u>9539/1 Atypical meningioma</u></b> 9539/3 Meningeal sarcomatosis
NEUROFIBROSARCOMA	954	<b><u>9540/0 Neurofibroma, NOS</u></b> <b><u>9540/1 Neurofibromatosis, NOS</u></b> 9540/3 Malignant peripheral nerve sheath tumor <b><u>9541/0 Melanotic neurofibroma</u></b>
PLEXIFORM NEUROFIBROMA	955	<b><u>9550/0 Plexiform neurofibroma</u></b>

NEURILEMOMA	956	<u>9560/0 Neurilemoma, NOS</u> <u>9560/1 Neurinomatosis</u> 9560/3 Neurilemoma, malignant 9561/3 Triton tumor, malignant <u>9562/0 Neurothekeoma</u>
NEUROMA	957	<u>9570/0 Neuroma, NOS</u> <u>9571/0 Perineurioma, NOS</u> 9571/3 Perineurioma, malignant
MALIGNANT LYMPHOMA, NOS	959	9590/3 Malignant lymphoma, NOS 9591/3 Malignant lymphoma, non-Hodgkin 9596/3 Composite Hodgkin and non-Hodgkin lymphoma
ML, SMALL B-CELL LYMPHOCYTIC	967	9670/3 ML, small B lymphocytic, NOS 9671/3 ML, lymphoplasmacytic 9673/3 Mantle cell lymphoma 9675/3 ML, mixed sm. and lg. cell, diffuse
ML, LARGE B-CELL, DIFFUSE	968	9680/3 ML, large B-cell, diffuse 9684/3 ML, large B-cell, diffuse, immunoblastic, NOS 9687/3 Burkitt lymphoma, NOS
FOLLIC. & MARGINAL LYMPH, NOS	969	9690/3 Follicular lymphoma, NOS 9691/3 Follicular lymphoma, grade 2 9695/3 Follicular lymphoma, grade 1 9698/3 Follicular lymphoma, grade 3 9699/3 Marginal zone B-cell lymphoma, NOS
T-CELL LYMPHOMAS	970	9701/3 Sezary syndrome 9702/3 Mature T-cell lymphoma, NOS

OTHER SPEC. NON-HODGKIN LYMPHOMA	971	9705/3 Angioimmunoblastic T-cell lymphoma
		9714/3 Large cell lymphoma
		9719/3 NK/T-cell lymphoma, nasal and nasal-type
PRECURS. CELL LYMPHOBLASTIC LYMPH.	972	9727/3 Precursor cell lymphoblastic lymphoma, NOS
		9728/3 Precursor B-cell lymphoblastic lymphoma
		9729/3 Precursor T-cell lymphoblastic lymphoma
PLASMA CELL TUMORS	973	9731/3 Plasmacytoma, NOS
		9734/3 Plasmacytoma, extramedullary
NEOPLASMS OF HISTIOCYTES AND ACCESSORY LYMPHOID CELLS	975	9750/3 Malignant histiocytosis
		9754/3 Langerhans cell histiocytosis, disseminated
		9755/3 Histiocytic sarcoma
		9756/3 Langerhans cell sarcoma
		9757/3 Interdigitating dendritic cell sarcoma
		9758/3 Follicular dendritic cell sarcoma
LEUKEMIA	993	9930/3 Myeloid sarcoma

## VENTRICLE C715

NEOPLASM	800	<u>8000/0 Neoplasm, benign</u> <u>8000/1 Neoplasm, uncertain whether benign or malignant</u> 8000/3 Neoplasm, malignant <u>8001/0 Tumor cells, benign</u> <u>8001/1 Tumor cells, uncertain whether benign or malignant</u> 8001/3 Tumor cells, malignant 8005/3 Malignant tumor, clear cell type
TERATOMA	908	9085/3 Mixed germ cell tumor
MISCELLANEOUS TUMORS	937	9370/3 Chordoma, NOS 9371/3 Chondroid chordoma 9372/3 Dedifferentiated chordoma
GLIOMA	938	9380/3 Glioma, malignant 9381/3 Gliomatosis cerebri 9382/3 Mixed glioma <u>9383/1 Gliomatosis cerebri</u> <u>9384/1 Subependymal giant cell astrocytoma</u>
EPENDYMOMA, NOS	939	<u>9390/0 Choroid plexus papilloma, NOS</u> <u>9390/1 Atypical choroid plexus papilloma</u> 9390/3 Choroid plexus papilloma, malignant 9391/3 Ependymoma, NOS 9392/3 Ependymoma, anaplastic 9393/3 Papillary ependymoma
ASTROCYTOMA, NOS	940	9400/3 Astrocytoma, NOS 9401/3 Astrocytoma, anaplastic

PROTOPLASMIC ASTROCYTOMA	941	9410/3 Protoplasmic astrocytoma 9411/3 Gemistocytic astrocytoma
FIBRILLARY ASTROCYTOMA	942	9420/3 Fibrillary astrocytoma <b><u>9421/1 Pilocytic astrocytoma</u></b> 9423/3 Polar spongioblastoma 9424/3 Pleomorphic xanthoastrocytoma
ASTROBLASTOMA	943	9430/3 Astroblastoma
GLIOBLASTOMA, NOS	944	9440/3 Glioblastoma, NOS 9441/3 Giant cell glioblastoma 9442/3 Gliosarcoma <b><u>9444/1 Chordoid glioma</u></b>
OLIGODENDROGLIOMA, NOS	945	9450/3 Oligodendroglioma, NOS 9451/3 Oligodendroglioma, anaplastic
PRIMITIVE NEUROECTODERMAL	947	9473/3 Primitive neuroectodermal tumor (PNET)
GANGLIONEUROBLASTOMA	949	<b><u>9490/0 Ganglioneuroma</u></b> 9490/3 Ganglioneuroblastoma <b><u>9492/0 Gangliocytoma</u></b>
NEUROBLASTOMA, NOS	950	9500/3 Neuroblastoma, NOS 9501/3 Medulloepithelioma, NOS 9502/3 Teratoid medulloepithelioma 9503/3 Neuroepithelioma, NOS <b><u>9505/1 Ganglioglioma, NOS</u></b> 9505/3 Ganglioglioma, anaplastic <b><u>9506/1 Central neurocytoma</u></b>

9508/3 Atypical teratoid/rhabdoid tumor

MENINGIOMAS 953

9530/0 Meningioma, NOS  
9530/1 Meningiomatosis, NOS  
 9530/3 Meningioma, malignant  
9531/0 Meningotheliomatous meningioma  
9532/0 Fibrous meningioma  
9533/0 Psammomatosis meningioma  
9534/0 Angiomatous meningioma  
9537/0 Transitional meningioma  
9538/1 Clear cell meningioma  
 9538/3 Papillary meningioma

MALIGNANT LYMPHOMA, NOS 959

9590/3 Malignant lymphoma, NOS  
 9591/3 Malignant lymphoma, non-Hodgkin  
 9596/3 Composite Hodgkin and non-Hodgkin lymphoma

ML, SMALL B-CELL LYMPHOCYTIC 967

9670/3 ML, small B lymphocytic, NOS  
 9671/3 ML, lymphoplasmacytic  
 9673/3 Mantle cell lymphoma  
 9675/3 ML, mixed sm. and lg. cell, diffuse

ML, LARGE B-CELL, DIFFUSE 968

9680/3 ML, large B-cell, diffuse  
 9684/3 ML, large B-cell, diffuse, immunoblastic, NOS  
 9687/3 Burkitt lymphoma, NOS

FOLLIC. & MARGINAL LYMPH, NOS 969

9690/3 Follicular lymphoma, NOS  
 9691/3 Follicular lymphoma, grade 2  
 9695/3 Follicular lymphoma, grade 1  
 9698/3 Follicular lymphoma, grade 3  
 9699/3 Marginal zone B-cell lymphoma, NOS

T-CELL LYMPHOMAS 970

9701/3 Sezary syndrome



		9702/3 Mature T-cell lymphoma, NOS
		9705/3 Angioimmunoblastic T-cell lymphoma
OTHER SPEC. NON-HODGKIN LYMPHOMA	971	
		9714/3 Anaplastic large cell lymphoma, T-cell and Null cell type
		9719/3 NK/T-cell lymphoma, nasal and nasal-type
PRECURS. CELL LYMPHOBLASTIC LYMPH.	972	
		9727/3 Precursor cell lymphoblastic lymphoma, NOS
		9728/3 Precursor B-cell lymphoblastic lymphoma
		9729/3 Precursor T-cell lymphoblastic lymphoma
PLASMA CELL TUMORS	973	
		9731/3 Plasmacytoma, NOS
		9734/3 Plasmacytoma, extramedullary
NEOPLASMS OF HISTIOCYTES AND ACCESSORY LYMPHOID CELLS	975	
		9750/3 Malignant histiocytosis
		9754/3 Langerhans cell histiocytosis, disseminated
		9755/3 Histiocytic sarcoma
		9756/3 Langerhans cell sarcoma
		9757/3 Interdigitating dendritic cell sarcoma
		9758/3 Follicular dendritic cell sarcoma

**CEREBELLUM C716**

NEOPLASM	800	<b><u>8000/0 Neoplasm, benign</u></b> <b><u>8000/1 Neoplasm, uncertain whether benign or malignant</u></b> 8000/3 Neoplasm, malignant <b><u>8001/0 Tumor cells, benign</u></b> <b><u>8001/1 Tumor cells, uncertain whether benign or malignant</u></b> 8001/3 Tumor cells, malignant 8005/3 Malignant tumor, clear cell type
SARCOMA, NOS	880	<b><u>8800/0 Soft tissue tumor, benign</u></b> 8800/3 Sarcoma, NOS 8805/3 Undifferentiated sarcoma 8806/3 Desmoplastic small round cell tumor
FIBROMATOUS NEOPLASMS	881	<b><u>8810/3 Fibrosarcoma, NOS</u></b> <b><u>8815/0 Solitary fibrous tumor</u></b>
LIPOMATOUS NEOPLASMS	885	<b><u>8850/0 Lipoma, NOS</u></b>
GERM CELL NEOPLASMS	908	<b><u>9080/0 Teratoma, benign</u></b> <b><u>9080/1 Teratoma, NOS</u></b> <b><u>9080/3 Teratoma, malignant, NOS</u></b> <b><u>9084/0 Dermoid cyst, NOS</u></b>
BLOOD VESSEL TUMORS	912	<b><u>9120/0 Hemangioma, NOS</u></b>
HEMANGIOENDOTHELIOMA	913	<b><u>9131/0 Capillary hemangioma</u></b>

HEMANGIOPERICYTOMA	915	<b><u>9150/1 Hemangiopericytoma, NOS</u></b>
HEMANGIOBLASTOMA	916	<b><u>9161/1 Hemangioblastoma</u></b>
CHORDOMA	937	9370/3 Chordoma, NOS 9371/3 Chondroid chordoma 9372/3 Dedifferentiated chordoma
GLIOMA	938	9380/3 Glioma, malignant 9381/3 Gliomatosis cerebri 9382/3 Mixed glioma <b><u>9383/1 Subependymoma</u></b>
EPENDYMOMA, NOS	939	9391/3 Ependymoma, NOS 9392/3 Ependymoma, anaplastic 9393/3 Papillary ependymoma
ASTROCYTOMA, NOS	940	9400/3 Astrocytoma, NOS 9401/3 Astrocytoma, anaplastic
PROTOPLASMIC ASTROCYTOMA	941	9410/3 Protoplasmic astrocytoma 9411/3 Gemistocytic astrocytoma
FIBRILLARY ASTROCYTOMA	942	9420/3 Fibrillary astrocytoma <b><u>9421/1 Pilocytic astrocytoma</u></b> 9424/3 Pleomorphic xanthoastrocytoma
ASTROBLASTOMA	943	9430/3 Astroblastoma

GLIOBLASTOMA, NOS	944	9440/3 Glioblastoma, NOS 9441/3 Giant cell glioblastoma 9442/3 <b>Gliosarcoma</b>
OLIGODENDROGLIOMA, NOS	945	9450/3 Oligodendroglioma, NOS 9451/3 Oligodendroglioma, anaplastic
MEDULLOBLASTOMA, NOS	947	9470/3 Medulloblastoma, NOS 9471/3 Desmoplastic medulloblastoma 9472/3 Medullomyoblastoma 9473/3 Primitive neuroectodermal tumor 9474/3 <b>Large cell medulloblastoma</b>
CEREBELLAR SARCOMA, NOS	948	9480/3 Cerebellar sarcoma, NOS
GANGLIONEUROBLASTOMA	949	<u><b>9490/0 Ganglioneuroma</b></u> 9490/3 Ganglioneuroblastoma <u><b>9492/0 Gangliocytoma</b></u> <u><b>9493/0 Dysplastic gangliocytoma of cerebellum (Lhermitte-Duclos)</b></u>
NEUROBLASTOMA, NOS	950	9500/3 Neuroblastoma, NOS 9501/3 Medulloepithelioma, NOS 9502/3 Teratoid medulloepithelioma 9503/3 Neuroepithelioma, NOS <u><b>9505/1 Ganglioglioma, NOS</b></u> <u><b>9506/1 Central neurocytoma</b></u> 9508/3 <b>Atypical teratoid/rhabdoid tumor</b>
MENINGIOMAS	953	<u><b>9530/0 Meningioma, NOS</b></u> <u><b>9530/1 Meningiomatosis, NOS</b></u> 9530/3 Meningioma, malignant <u><b>9531/0 Meningotheliomatous meningioma</b></u>

		<u>9532/0 Fibrous meningioma</u> <u>9533/0 Psammomatous meningioma</u> <u>9534/0 Angiomatous meningioma</u> <u>9537/0 Transitional meningioma</u> <u>9538/1 Clear cell meningioma</u> <b>9538/3 Papillary meningioma</b>
MALIGNANT LYMPHOMA, NOS	959	9590/3 Malignant lymphoma, NOS 9591/3 Malignant lymphoma, non-Hodgkin <b>9596/3 Composite Hodgkin and non-Hodgkin lymphoma</b>
ML, SMALL B-CELL LYMPHOCYTIC	967	9670/3 ML, small B lymphocytic, NOS 9671/3 ML, lymphoplasmacytic 9673/3 Mantle cell lymphoma 9675/3 ML, mixed sm. and lg. cell, diffuse
ML, LARGE B-CELL, DIFFUSE	968	9680/3 ML, large B-cell, diffuse 9684/3 ML, large B-cell, diffuse, immunoblastic, NOS 9687/3 Burkitt lymphoma, NOS
FOLLIC. & MARGINAL LYMPH, NOS	969	9690/3 Follicular lymphoma, NOS 9691/3 Follicular lymphoma, grade 2 9695/3 Follicular lymphoma, grade 1 9698/3 Follicular lymphoma, grade 3 <b>9699/3 Marginal zone B-cell lymphoma, NOS</b>
T-CELL LYMPHOMAS	970	<b>9701/3 Sezary syndrome</b> <b>9702/3 Peripheral T-cell lymphoma, NOS</b> <b>9705/3 Angioimmunoblastic T-cell lymphoma</b>
OTHER SPEC. NON-HODGKIN LYMPHOMA	971	<b>9714/3 Anaplastic large cell lymphoma, T-cell and Null cell type</b> <b>9719/3 NK/T-cell lymphoma, nasal and nasal-type</b>

PRECURS. CELL LYMPHOBLASTIC LYMPH.	972	9727/3 Precursor cell lymphoblastic lymphoma, NOS 9728/3 Precursor B-cell lymphoblastic lymphoma 9729/3 Precursor T-cell lymphoblastic lymphoma
PLASMA CELL TUMORS	973	9731/3 Plasmacytoma, NOS 9734/3 Plasmacytoma, extramedullary
NEOPLASMS OF HISTIOCYTES AND ACCESSORY LYMPHOID CELLS	975	9750/3 Malignant histiocytosis 9754/3 Langerhans cell histiocytosis, disseminated 9755/3 Histiocytic sarcoma 9756/3 Langerhans cell sarcoma 9757/3 Interdigitating dendritic cell sarcoma 9758/3 Follicular dendritic cell sarcoma

**OTHER NERVOUS SYSTEM C728-C729**

NEOPLASM

800

**8000/0 Neoplasm, benign**

**8000/1 Neoplasm, uncertain whether benign or malignant**

8000/3 Neoplasm, malignant

**8001/0 Tumor cells, benign**

**8001/1 Tumor cells, uncertain whether benign or malignant**

8001/3 Tumor cells, malignant

8002/3 Malignant tumor, small cell type

8003/3 Malignant tumor, giant cell type

8004/3 Malignant tumor, spindle cell type

8005/3 Malignant tumor, clear cell type

SARCOMA, NOS

880

**8800/0 Soft tissue tumor, benign**

8800/3 Sarcoma, NOS

8801/3 Spindle cell sarcoma

8802/3 Giant cell sarcoma

8803/3 Small cell sarcoma

8804/3 Epithelioid sarcoma

8805/3 Undifferentiated sarcoma

8806/3 Desmoplastic small round cell tumor

LIPOMATOUS NEOPLASMS

885

**8850/0 Lipoma, NOS**

**8850/1 Atypical lipoma**

**8850/3 Liposarcoma, NOS**

ANGIOLIPOMA

886

**8861/0 Angiolipoma**

MYOMATOUS NEOPLASMS

889

**8890/0 Leiomyoma, NOS**

**8890/1 Leiomyomatosis, NOS**

**8890/3 Leiomyosarcoma, NOS**

**8897/1 Smooth muscle tumor, NOS**

RHABDOMYOSARCOMA	890	<u>8900/0 Rhabdomyoma, NOS</u> 8900/3 Rhabdomyosarcoma, NOS
EMBRYONAL RHABDOMYOSARCOMA	891	8910/3 Embryonal rhabdomyosarcoma, NOS
ALVEOLAR RHABDOMYOSARCOMA	892	8920/3 Alveolar rhabdomyosarcoma
GERM CELL TUMORS	906	9064/3 Germinoma
TERATOMA	908	<u>9080/1 Teratoma, NOS</u> 9080/3 Teratoma, malignant, NOS 9082/3 Malignant teratoma, undiff. <u>9084/0 Dermoid cyst, NOS</u> 9084/3 Teratoma with malig. transformation
BLOOD VESSEL TUMORS	912	<u>9120/0 Hemangioma, NOS</u> 9120/3 Hemangiosarcoma <u>9121/0 Cavernous hemangioma</u>
HEMANGIOENDOTHELIOMA	913	<u>9130/0 Hemangioendothelioma, benign</u> <u>9130/1 Hemangioendothelioma, NOS</u> 9130/3 Hemangioendothelioma, malignant
KAPOSI SARCOMA	914	9140/3 Kaposi sarcoma
HEMANGIOPERICYTOMA	915	<u>9150/0 Hemangiopericytoma, benign</u>



		<b><u>9150/1 Hemangiopericytoma, NOS</u></b> <b>9150/3 Hemangiopericytoma, malignant</b>
HEMANGIOBLASTOMA	916	<b><u>9161/1 Hemangioblastoma</u></b>
MISCELLANEOUS BONE TUMORS	926	<b>9260/3 Ewing sarcoma</b>
CHORDOMA	937	9370/3 Chordoma, NOS 9371/3 Chondroid chordoma 9372/3 Dedifferentiated chordoma
NEUROBLASTOMA, NOS	950	9500/3 Neuroblastoma, NOS 9501/3 Medulloepithelioma, NOS 9502/3 Teratoid medulloepithelioma 9503/3 Neuroepithelioma, NOS 9508/3 Atypical teratoid/rhabdoid tumor
MENINGIOMA	953	<b><u>9530/0 Meningioma, NOS</u></b> <b><u>9530/1 Meningiomatosis, NOS</u></b> <b>9530/3 Meningioma, malignant</b> <b><u>9531/0 Meningotheliomatous meningioma</u></b> <b><u>9532/0 Fibrous meningioma</u></b> <b><u>9533/0 Psammomatous meningioma</u></b> <b><u>9534/0 Angiomatous meningioma</u></b> <b><u>9537/0 Transitional meningioma</u></b> <b><u>9538/1 Clear cell meningioma</u></b> <b>9538/3 Papillary meningioma</b>
NEUROFIBROSARCOMA	954	<b><u>9540/0 Neurofibroma, NOS</u></b> <b><u>9540/1 Neurofibromatosis, NOS</u></b> 9540/3 Malignant peripheral nerve sheath tumor <b><u>9541/0 Melanotic neurofibroma</u></b>

PLEXIFORM NEUROFIBROMA	955	<b><u>9550/0 Plexiform neurofibroma</u></b>
NEURILEMOMA	956	<b><u>9560/0 Neurilemmoma, NOS</u></b> 9560/3 Neurilemmoma, malignant 9561/3 Triton tumor, malignant <b><u>9562/0 Neurothekeoma</u></b>
NEUROMA	957	<b><u>9570/0 Neuroma, NOS</u></b> <b><u>9571/0 Perineurioma, NOS</u></b> 9571/3 Perineurioma, malignant
MALIGNANT LYMPHOMA, NOS	959	9590/3 Malignant lymphoma, NOS 9591/3 Malignant lymphoma, non-Hodgkin 9596/3 Composite Hodgkin and non-Hodgkin lymphoma
HODGKIN LYMPHOMA	965	9650/3 Hodgkin lymphoma, NOS 9651/3 Hodgkin lymphoma, lymphocyte-rich 9652/3 Hodgkin lymphoma, mixed cellularity, NOS 9653/3 Hodgkin lymphoma, lymphocytic deplet., NOS 9654/3 Hodgkin lymphoma, lymphocyt. deplet., diffuse fibrosis 9655/3 Hodgkin lymphoma, lymphocyt. deplet., reticular 9659/3 Hodgkin lymphoma, nodular lymphocyte predom.
HODGKIN LYMPHOMA, NOD. SCLER.	966	9661/3 Hodgkin granuloma 9662/3 Hodgkin sarcoma 9663/3 Hodgkin lymphoma, nodular sclerosis, NOS 9664/3 Hodgkin lymphoma, nod. scler., cellular phase 9665/3 Hodgkin lymphoma, nod. scler., grade 1 9667/3 Hodgkin lymphoma, nod. scler., grade 2
ML, SMALL B-CELL LYMPHOCYTIC	967	9670/3 ML, small B lymphocytic, NOS 9671/3 ML, lymphoplasmacytic

		9673/3 Mantle cell lymphoma
		9675/3 ML, mixed sm. and lg. cell, diffuse
ML, LARGE B-CELL, DIFFUSE	968	
		9680/3 ML, large B-cell, diffuse
		9684/3 ML, large B-cell, diffuse, immunoblastic, NOS
		9687/3 Burkitt lymphoma, NOS
FOLLIC. & MARGINAL LYMPH, NOS	969	
		9690/3 Follicular lymphoma, NOS
		9691/3 Follicular lymphoma, grade 2
		9695/3 Follicular lymphoma, grade 1
		9698/3 Follicular lymphoma, grade 3
		9699/3 Marginal zone B-cell lymphoma, NOS
T-CELL LYMPHOMAS	970	
		9701/3 Sezary syndrome
		9702/3 Mature T-cell lymphoma, NOS
		9705/3 Angioimmunoblastic T-cell lymphoma
OTHER SPEC. NON-HODGKIN LYMPHOMA	971	
		9714/3 Anaplastic large cell lymphoma, T-cell and Null cell type
		9719/3 NK/T-cell lymphoma, nasal and nasal-type
PRECURS. CELL LYMPHOBLASTIC LYMPH.	972	
		9727/3 Precursor cell lymphoblastic lymphoma, NOS
		9728/3 Precursor B-cell lymphoblastic lymphoma
		9729/3 Precursor T-cell lymphoblastic lymphoma
PLASMA CELL TUMORS	973	
		9731/3 Plasmacytoma, NOS
		9734/3 Plasmacytoma, extramedullary
MAST CELL TUMORS	974	
		9740/3 Mast cell sarcoma
		9741/3 Malignant mastocytosis

NEOPLASMS OF HISTIOCYTES AND  
ACCESSORY LYMPHOID CELLS

975

9750/3 Malignant histiocytosis  
9754/3 Langerhans cell histiocytosis, disseminated  
9755/3 Histiocytic sarcoma  
9756/3 Langerhans cell sarcoma  
9757/3 Interdigitating dendritic cell sarcoma  
9758/3 Follicular dendritic cell sarcoma

LYMPHOID LEUKEMIAS

982

**9827/3 Adult T-cell leukemia/lymphoma (HTLV-1 positive)**

MYELOID LEUKEMIAS

986

**9861/3 Acute myeloid leukemia, NOS**

OTHER LEUKEMIAS

993

**9930/3 Myeloid sarcoma**

**PITUITARY GLAND and CRANIOPHARYNGEAL DUCT C751-C752**

NEOPLASM

800

**8000/0 Neoplasm, benign**

**8000/1 Neoplasm, uncertain whether benign or malignant**

8000/3 Neoplasm, malignant

**8001/0 Tumor cells, benign**

**8001/1 Tumor cells, uncertain whether benign or malignant**

8001/3 Tumor cells, malignant

**8005/0 Clear cell tumor, NOS**

8005/3 Malignant tumor, clear cell type

CARCINOMA, NOS

801

**8010/0 Epithelial tumor, benign**

8010/2 Carcinoma in situ, NOS

8010/3 Carcinoma, NOS

ADENOCARCINOMA, NOS

814

**8140/0 Adenoma, NOS**

8140/2 Adenocarcinoma in situ

8140/3 Adenocarcinoma, NOS

**8146/0 Monomorphic adenoma**

PAPILLARY ADENOMA, NOS

826

**8260/0 Papillary adenoma, NOS**

CHROMOPHOBE CARCINOMA

827

**8270/0 Chromophobe adenoma**

8270/3 Chromophobe carcinoma

**8271/0 Prolactinoma**

**8272/0 Pituitary adenoma, NOS**

8272/3 Pituitary carcinoma, NOS

ACIDOPHIL CARCINOMA

828

**8280/0 Acidophil adenoma**

8280/3 Acidophil carcinoma

**8281/0 Mixed acidophil-basophil adenoma**

8281/3 Mixed acidophil-basophil carcinoma

OXYPHILIC ADENOCARCINOMA	829	<b><u>8290/0 Oxyphilic adenoma</u></b> 8290/3 Oxyphilic adenocarcinoma
BASOPHIL CARCINOMA	830	<b><u>8300/0 Basophil adenoma</u></b> 8300/3 Basophil carcinoma
CLEAR CELL ADENOC., NOS	831	<b><u>8310/0 Clear cell adenoma</u></b>
GRANULAR CELL CARCINOMA	832	8320/3 Granular cell carcinoma <b><u>8323/0 Mixed cell adenoma</u></b> 8323/3 Mixed cell adenocarcinoma
SOFT TISSUE TUMORS	880	<b><u>8800/0 Soft tissue tumor, benign</u></b> <b>8800/3 Sarcoma, NOS</b>
LIPOMATOUS NEOPLASMS	885	<b><u>8850/0 Lipoma, NOS</u></b>
DYSGERMINOMA	906	9060/3 Dysgerminoma 9064/3 Germinoma 9065/3 Germ cell tumor, nonseminomatous
EMBRYONAL CARCINOMA, NOS	907	9070/3 Embryonal carcinoma, NOS 9071/3 Yolk sac tumor 9072/3 Polyembryoma
TERATOMA, NOS	908	<b><u>9080/0 Teratoma, benign</u></b> <b><u>9080/1 Teratoma, NOS</u></b> 9080/3 Teratoma, malignant, NOS 9081/3 Teratocarcinoma 9082/3 Malignant teratoma, undiff.

		9083/3 Malignant teratoma, intermediate
		9084/3 Teratoma with malig. transformation
		9085/3 Mixed germ cell tumor
CRANIOPHARYNGIOMA	935	<u><b>9350/1 Craniopharyngioma</b></u> <u><b>9351/1 Adamantinomatous craniopharyngioma</b></u> <u><b>9352/1 Papillary craniopharyngioma</b></u>
CHORDOMA	937	9370/3 Chordoma 9371/3 Chondroid chordoma 9372/3 Dedifferentiated chordoma
NEUROBLASTOMA, NOS	950	9500/3 Neuroblastoma, NOS 9501/3 Medulloepithelioma, NOS 9502/3 Teratoid medulloepithelioma 9503/3 Neuroepithelioma, NOS 9505/3 Ganglioglioma, anaplastic
GRANULAR CELL TUMORS	958	<u><b>9580/0 Granular cell tumor, NOS</b></u>
FOLLIC. & MARGINAL LYMPH, NOS	969	9699/3 Marginal zone B-cell lymphoma, NOS

**PINEAL GLAND C753**

NEOPLASM	800	<b><u>8000/0 Neoplasm, benign</u></b> <b><u>8000/1 Neoplasm, uncertain whether benign or malignant</u></b> 8000/3 Neoplasm, malignant <b><u>8001/0 Tumor cells, benign</u></b> <b><u>8001/1 Tumor cells, uncertain whether benign or malignant</u></b> 8001/3 Tumor cells, malignant
CARCINOMA, NOS	801	<b><u>8010/0 Epithelial tumor, benign</u></b>
DYSGERMINOMA	906	9060/3 Dysgerminoma 9064/3 Germinoma 9065/3 Germ cell tumor, nonseminomatous
EMBRYONAL CARCINOMA, NOS	907	9070/3 Embryonal carcinoma, NOS 9071/3 Yolk sac tumor 9072/3 Polyembryoma
TERATOMA, NOS	908	<b><u>9080/0 Teratoma, NOS</u></b> 9080/3 Teratoma, malignant, NOS 9081/3 Teratocarcinoma 9082/3 Malignant teratoma, undiff. 9083/3 Malignant teratoma, intermediate <b><u>9084/0 Dermoid cyst, NOS</u></b> 9084/3 Teratoma with malig. transformation 9085/3 Mixed germ cell tumor
PINEALOMA, MALIGNANT	936	<b><u>9360/1 Pinealoma, NOS</u></b> <b><u>9361/1 Pineocytoma</u></b> 9362/3 Pineoblastoma



CHORDOMA	937	9370/3 Chordoma, NOS 9371/3 Chondroid chordoma 9372/3 Dedifferentiated chordoma
PRIMITIVE NEUROECTODERMAL	947	<b>9473/3 Primitive neuroectodermal tumor, NOS</b>
GANGLIONEUROBLASTOMA	949	9490/3 Ganglioneuroblastoma <b><u>9492/0 Gangliocytoma</u></b>
NEUROBLASTOMA, NOS	950	9500/3 Neuroblastoma, NOS 9501/3 Medulloepithelioma, NOS 9502/3 Teratoid medulloepithelioma 9503/3 Neuroepithelioma, NOS <b><u>9505/1 Ganglioglioma, NOS</u></b> 9505/3 Ganglioglioma, anaplastic
ML, LARGE B-CELL, DIFFUSE	968	<b>9680/3 ML, large B-cell, diffuse</b>
FOLLIC. & MARGINAL LYMPH, NOS	969	9699/3 Marginal zone B-cell lymphoma, NOS