

Collaborative Stage Transition Newsletter

March 13, 2015

Introduction

This is the latest issue in a series of newsletters providing communication updates from organizations within the cancer surveillance community to share with their members and other constituents. It addresses the processes and ongoing efforts to coordinate and effectively transition from the Collaborative Staging v2 system to the AJCC TNM staging standard, beginning with the 2016 incidence data. This includes continued collection of information regarding related biomarkers and prognostic factors. Shortly after the decision was made to transition from Collaborative Stage, a CS Transition Group was formed as an information sharing and planning forum. This group brings together the four data collection agencies/organizations (Statistics Canada/Canadian Council of Cancer Registries, CDC/NPCR, NCI/SEER, and American College of Surgeons CoC), the agency responsible for staging rules (AJCC), the cancer surveillance umbrella organization (NAACCR), the organization representing cancer registry professionals (NCRA), and the American Cancer Society. The CS Transition Group provides a collaborative opportunity to identify issues involved in the transition and to share the tasks involved in developing best practices for both the overall surveillance community and the individual agencies/organizations to address this change.

The agencies and organizations participating in this communication recognize that the transition away from CS is a major change and are committed to working with stakeholders to develop appropriate implementation plans and processes. This transition continues to be a work in progress and the partners are working hard to answer the many questions that have yet to be fully addressed. As answers become available, they will be shared and communicated to the surveillance community through the updates provided in subsequent sections. In addition, all of the partners continue to provide opportunities for members to identify issues and concerns. If you have ideas that you think are important for the partners and/or the CS Transition Group to consider, please email them to Patricia Murphy (Murphy, Patricia (NIH/NCI)), who will collate and disseminate them.

As a reminder, the initial change in 2016 for CDC and NCI registries will be focused on the transition to directly assigned TNM stage, but will not eliminate all of the variables collected under CS. In particular, most Site Specific Factors (SSFs) will continue to be required as they are either: a) a critical component of stage assignment; or b) essential to understanding the cancer (predictive or prognostic factors). Thus the initial transition will focus on assignment of T, N, M, and the AJCC TNM stage group. As the coordinating bodies, we will clarify which additional variables and which SSFs will continue to be required based on their importance and feasibility to be collected by registrars. The methods, studies, and processes that will be used to make

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these determinations are described below. It is worth noting Item 4 in the NCI project list (NCI coordinating with NPCR and NAACCR to assess needs for changes in algorithms, and other IT needs related to the transition). One important aspect of the move to AJCC TNM stage and the maintenance of the SSFs is that the data warehouse and the Application Program Interface (API) that is being developed will eliminate obsolete variables and values, simplifying what registrars must consider in their abstraction.

Each participating entity continues to perform specific and coordinated tasks focused on assessing needs for the transition, projecting its impact, and coordinating the logistical components to implement the changes. Updates to these activities are described below along with the organization and task leader responsible for that activity.

Recently it has come to our attention that there is still some confusion about the continued collection of site specific factors (SSFs). All of the standard setting organizations have agreed to continue to collect biomarkers and prognostic factors through the SSFs as they are currently collected for the foreseeable future. Our previous newsletters have stated (emphasis added):

On June 17, 2014 the CS Transition Group agreed to continue collecting Site Specific Factors using the current NAACCR data layout and definitions **at least through 2016**.

It is anticipated that we will continue to use the data and variable definitions for SSFs used in Collaborative Stage until there has been a thorough review of the biomarkers and prognostic factors to determine which are clinically relevant, available to be collected by cancer registrars, and the best NAACCR data structure for collection of the SSFs has been established.

The 8th Edition of the AJCC staging manual is scheduled to be released in 2016, and will take effect for cases diagnosed as of January 1, 2017. We anticipate that there will be changes in the collection of SSFs at that time (effective date of AJCC 8th edition) to accommodate any changes in the modified staging system, as well as any changes in requirements that may be proposed by others (CDC, NCI, Canada).

Given the inherent uncertainties and the complexity of the issues involved with coordinating various agencies and priorities, and the evolution of scientific knowledge, it is difficult to pinpoint the timing of any changes. However, for the foreseeable future, central cancer registries should continue to collect SSFs as they have in the past and in compliance with program guidelines. We will continue to work together to ensure that central cancer registries will have adequate time to prepare for any changes.

Agency Updates

Following are summaries, written by the respective agency/organization, that report on the status of each activity being undertaken by the organization. We intend to continue providing

regular updates on these activities. In some cases you will note that agencies are working independently on specific issues, while in other cases shared project work is underway.

We have identified several common questions and provided responses from NCI/SEER, CDC/NPCR, and the CoC. These are available in previous newsletters and on the web at <http://seer.cancer.gov/registrars/cs-tnm/>.

Current and planned activities by the partner organization in relation to the CS Transition:

A. American Cancer Society

No new updates

B. AJCC

AJCC's newly developed education product, "[AJCC Curriculum for Registrars](#)," for cancer registrars and the surveillance community through the support of the CDC, has been met with much success. This education will assist registrars with the transition to directly assigning AJCC TNM stage.

Over 1,000 people registered for the live Module I Webinar. This is in addition to the webinar for 94 CDC staff and state Education Training Coordinators. The recorded webinar will be available along with the quiz for those who were unable to attend the live broadcast, providing them the same opportunities to measure their self-learning and understanding of the six Module I Lessons.

This webinar is available on the [AJCC website home page](#) and through [Cancer Staging Education – Registrar](#). Currently Module I is available. The next Modules will be posted according to the published schedule.

Module II will be available by March 15, 2015, allowing over 5 weeks to take the pre-education quiz, and then self-study the Module II Beginning, along with Lessons 8 through 13. This will prepare you for Quiz and recap of the lessons in the live webinar Lesson 14 on April 21, 2015 from 1:00pm – 3:00pm CDT and earn 2.0 CE hours.

Module and Lesson Approach

Why this format?

- Adult education principles
- Self-guided learning
- Build knowledge instead of everything at once
- Enables quick identification of specific topics or rules for future reference

How to use this curriculum

- 1st through 5th lessons
 - Review content

- Study principles described in the lessons
- Be prepared for live webinar
- 6th lesson
 - Link to additional material
 - Reinforces information taught in this module
- 7th lesson
 - Live webinar to recap the self-study lessons
 - Quiz given as a live poll to assess learning
 - Quiz questions will be taken from the NCRA-AJCC Education Needs Assessment

Module Content

Module I Introduction

- Overview of staging
- High level explanation of why and how
- For staff that do not assign stage (many central registry staff, statisticians, researchers)
 - Basic principles of stage
 - Understand terminology used
 - Only lesson they will need
- For staff assigning stage
 - Foundation of why AJCC staging is different from CS and summary stage
 - How it is used

Module II Beginning

- Learn basic rules

Module III Intermediate

- Move on to the nuances and exceptions for complex cases

Module IV Advanced

- Move on to the nuances and exceptions for complex cases

Schedule

Module	Self-Study Activity – to be completed before webinar	Live Webinar with Quiz – recap of self-study material
Module I	Lessons posted January 15, 2015	February 24, 2015, 1:00pm CST
Module II	Lessons posted March 15, 2015	April 21, 2015, 1:00-3:00pm CDT
Module III	Lessons posted May 15, 2015	June – last week
Module IV	Lessons posted July 15, 2015	August – last week

Summary

Questions may be submitted to the [CAnswer Forum](#). New subforums have been added to the AJCC forum explicitly for these modules.

The intent is to provide accurate detailed information to guide the registrars in learning or refreshing their knowledge of AJCC TNM staging. AJCC, as the authoritative source for our staging system, is seeking to meet the needs of cancer registrars and the surveillance community in using AJCC TNM staging.

Visit the [AJCC Cancer Staging Education - Registrar page](#) to view all of the educational opportunities, including two presentations that were posted in September 2014 on the AJCC Chapter 1 cancer staging rules and Explaining Blanks and X, and other issues.

C. Statistics Canada and the Canadian Council of Cancer Registries

Definition of TNM Data Variables for Canada: Draft 3 – February 13, 2015

In mid January, the Canadian Council of Cancer Registries held a special teleconference to review the proposed data variables for supporting TNM data collection in Canada, which will begin for cases diagnosed January 1, 2017. Council did not have any significant concerns with the draft dataset. The Staging Committee will now carry out further consultation with other key stakeholders and make any remaining modifications/updates in the coming months. This will include a review of final decisions on proposed new staging related data variables currently under review for inclusion in the NAACCR Volume II Data Standards and Data Dictionary (e.g. best/composite stage). A final proposal will be then returned to Council for formal approval, planned for this spring.

Readiness Assessment:

The Canadian Cancer Staging Working Group has initiated a discussion on carrying out a readiness assessment for provincial/territorial cancer registries (PTCRs). This assessment will start the process for understanding the technical and operational challenges that will be faced by PTCRs when implementing the new TNM data collection standards. Work will continue on scoping out the assessment over the next several weeks. When more information is available, it will be shared with PTCRs.

Training Plan:

The need for a coordinated, national level approach for training has been identified. Several groups, including Statistics Canada and the Public Health Agency of Canada, have provided leadership and support in stage training over the past number of years. The Staging Work Group has agreed that will be a key focus in the coming months in terms of ensuring a complete plan is put in place. The group will be working with stakeholders to determine who is best positioned to provide leadership on this issue and to understand PTCR requirements and expectations. It is recognized that a number of resources are already

available from other agencies that can help support this work, and it will be important to leverage these in developing a Canadian approach.

Dialogue with AJCC:

A teleconference was held with AJCC leadership in January to address key questions related to Canadian adoption of TNM. This was a very productive meeting, and there will be follow up on several issues in the coming months. For example, we are looking forward to receiving additional details this spring on the licensing model for access to AJCC TNM content/tools, which will help inform our overall adoption strategies in Canada.

D. Centers for Disease Control and Prevention

No new updates

E. Commission on Cancer

No new updates

F. NAACCR

No new updates

G. NCI

1. Evaluation of the frequency of pTNM in the surgical pathology report

The pTNM study continues to make progress in its development of rules for auto-identifying the pTNM components from unstructured pathology reports. Phase I, consisting of the validation of a test set of pathology reports and selection criteria for capturing pTNM, is expected to be finished by April. At that point, the system will be tested with a large set of pathology reports from the five participating registries.

Estimated completion date: Phase I- April 2015

Contact person: Carol Kosary/Annie Noone

2. Comparison of cases restaged with AJCC TNM

The first manuscript is under review at the Journal of Registry Management. We are planning a new study that we hope will open this spring. The new study will use the same study cases and will evaluate components of stage that will continue to be collected after the transition to TNM, such as tumor size and nodes removed/examined. The motivation for this study is that we will need to verify that these key components are being correctly assigned and determine whether additional training is needed for these critical elements. Because the AJCC TNM staging system is primarily designed for clinical decision making, and not cancer

surveillance reporting, it will be important to understand the impact of the change from CS to TNM staging over time on cancer trends by stage. Therefore, to provide information on the impact of the transition, the second study will also provide a direct comparison of both CS best stage and TNM stage in the same cases. This new study will allow us to understand more clearly where those differences are and the potential impact on staging over time as we move to TNM.

Because we are using the same study cases, we will not release the preferred answers or rationales until this second study is complete.

Contact person: Carol Kosary/Annie Noone/Kevin Ward

3. Evaluation of Site Specific Factors (SSFs)

The SSFs evaluation is continuing on schedule. At this time, approximately 90% of the CS schemas have been reviewed. As part of the evaluation, possibilities for automated collection of Site Specific Factors (SSFs) were assessed. A number of pilot projects are in the planning stages to evaluate automated collection of selected SSFs, with a particular emphasis on tissue-based biomarkers and pTNM, as reported above.

The work being done at NCI is being coordinated with the Data Standards Committee for the AJCC 8th edition as well as the work being done by NAACCR.

Timeline for completion: March 2015

Contact person: Valentina Petkov

4. NCI coordinating with NPCR and NAACCR to assess needs for changes in algorithms and other IT needs related to the transition

TNM Transition Challenges

Population-based cancer registries, and the public health surveillance systems they support, provide the necessary information to describe the burden of cancer in their respective underlying populations and also offer users of these data the ability to calculate patient end results through population-based cancer survival measures. The assessment of end results, however, relies on the ability to accurately capture important prognostic information that can affect patient outcomes.

Cancer stage at diagnosis is one of the strongest prognostic indicators of patient survival. While stage is measured by clinicians following clinical examination before definitive therapy and then again after surgery, the most accurate data for estimating patient prognosis and calculating end results comes from a combination of the two. While the pathologic stage assigned by the clinician uses evidence acquired before treatment in conjunction with additional information from surgery, not all patients undergo surgery. Additionally, not all patients undergoing surgery

have the same level of evaluation and not all cancers are staged using the AJCC system most commonly utilized by the clinical community. It is for these primary reasons that population-based cancer registries in the United States have consistently, since their inception, used combined clinical and pathologic information collected through a series of individual data elements. These are relevant for describing tumor involvement and measuring the extent of disease in the cancer patient.

As the cancer surveillance community begins the transition to collecting both clinical and pathologic AJCC stage separately, it is imperative for the mission of population-based cancer registries that we continue to collect the information necessary to produce an extent of disease measure that: 1) combines clinical and pathologic information; and 2) facilitates the ability to stage all cancers. In that regard, work is underway to develop algorithms that can combine clinical and pathologic AJCC data, as available, to create a combined measure of stage that can be used for prognostic purposes, as in the past. In addition, consideration is being given to additional variables that can support the derivation of a stage measure for those cancers not supported by the existing AJCC system. While the continued collection of SEER Summary Stage meets this need to some degree, it has long been acknowledged by the cancer surveillance community that this summary measure is often too simplistic for the needs of many data users.

TNM Informatics

NCI and IMS continue work to release the first version of the Subject Matter Expert data entry tool. This tool will be used to edit all TNM metadata (TNM data items with their lists of permissible values, coding instructions for each data item, agency requirements, schema matching, as well as TNM staging) for release of version 1.0 of this TNM metadata. The first version of the Subject Matter Expert data entry tool is expected to be released in early April of 2015. This will enable those experts to continue the work of preparing the TNM metadata for release to the public. NCI and IMS continue to work on the public-facing Staging and Predictive and Prognostic (S&PP) Factors website. This website will present users with access to the metadata that Subject Matter Experts will be working on, once those metadata have been finalized and released. This website will allow users to view the TNM data items with their lists of permissible values and coding instructions, will have links to NAACCR documentation, will present visual representations of each staging algorithm for each schema, and will have a staging tool as well. The website will allow users to view the documentation for CS 02.05.50 and to switch between CS and TNM and all future versions of TNM metadata. The website will also provide links to documentation in the use of the S&PP Representational State Transfer (REST) API, and to download any available TNM and CS libraries.

Work continues on the S&PP Factors REST API. This S&PP API is used by the Subject Matter Expert data entry tool as well as the public facing S&PP website. This same

REST API can be used to access a copy of the CS 02.05.50 data, once the release takes place in March.

Work continues to make the CS 02.05.50 data available via the S&PP REST API and to develop a Java library to access this same data. In March, NCI/IMS will release the first version of the new staging API. It will be released as an open source Java library and also made available via the S&PP REST API. The initial release will only support the legacy CS version 02.05.50 data. TNM support will be added to this library when the TNM metadata are released. The setup used to access the CS data from the Java library or from the S&PP API is the same basic setup that will be used to access the TNM data.

5. Development of training aids to help registrars assign TNM

No new updates

6. Develop and lead focus groups consisting of hospital and central registrars (who perform abstraction)

TNM Transition Focus Groups: Summary of Groups I, II, and III

The three focus groups have been completed. Participants' experience in the registry profession ranged from 3 years to over 30 years. The majority of the participants are Certified Tumor Registrars (CTR), with several from Focus Group I having just received this credential or preparing to take the exam. Participants are currently employed in hospital registries or central registries. It is important to note that Focus Group I participants have not gone through a major change in coding systems. They have only used collaborative staging.

All three focus groups were in consensus on the following issues and suggestions:

- Switch to TNM should be done after AJCC 8th Edition: While AJCC may feel that the differences between 7th and 8th Editions are minimal; the impact on the registrars may be more complex and require updated education (training modules and manuals), revisions to software and edits.
- Switch to coding Summary Stage should be made after the SS2000 is updated to SS2016.
- Extensive training will be needed: The training needs to be provided by experts and must be consistent. All registrars and medical abstractors must have access to the same education and be allowed time and support by their registries and/or hospital administrations to attend training (such as webinars, on-line training, workshops) during work hours.
- Long-term educational support must be available, for example Ask a SEER Registrar type resource. They need a resource to submit questions to and get timely, correct answers with clear rationales.

- Impact on workload and timeliness during transition: This issue will affect registry responsibilities from abstracting to consolidation and editing and finally quality review.
- Need a TNM coding manual for registrars.
- Coding materials need to be provided to registries/registrars free of charge.
- ***Focus Group I and II request that the TNM Transition Leadership provide registrars with a letter they can give to administrators, supervisors and Cancer Committee chairs, explaining the impact the transition from CS to TNM will have on the cancer registrar workload, timeliness, and most importantly staffing. Hospital administrators and Cancer Center managers are under the impression that the transition will decrease the workload enough to justify downsizing the registry staff. Do not assume the administrators and managers receive or read the Transition newsletters. A letter given to them by the registrars will have far more influence when discussing their requests for education, coding materials, etc.***

Status: Complete

Contact person: Lois Dickie

7. Development of Summary Stage 2016

No new updates- continued development and testing underway.

H. NCRA

1. Education

Special TNM and Summary Stage Section on NCRA's Center for Cancer Registry Education

NCRA continues to populate the special TNM and Summary Stage section of its Center for Cancer Registry Education (CCRE). The section serves as a hub for all NCRA training on the transition to AJCC TNM Stage and NCI Summary Stage. NCRA will archive its current webinar series and add these learning modules to the site soon, including: NCI Summary Stage: Lung Cancer; NCI Summary Stage: Melanoma; NCI Summary Stage: Endometrial Cancer; AJCC TNM Stage: Lung Cancer; AJCC TNM Stage: Prostate Cancer; AJCC TNM Stage: Thyroid Cancer; and AJCC TNM Stage: Lymphoma.

The hub also includes free training, such as the transition-related sessions from NCRA's 2014 Annual Conference. NCRA will also post, free of charge, related sessions from its 2015 conference scheduled for May 20-23, 2015, in San Antonio.

To learn more, go to www.CancerRegistryEducation.org/tnm-ss-transition.

NCRA Added a New LIVE Webinar: The Transition from Collaborative Stage to AJCC TNM Stage: You Know More than You Think You Do

The webinar, *The Transition from Collaborative Stage to AJCC TNM Stage: You Know More than You Think You Do!*, occurred took place on February 19 and is designed to showcase the differences and similarities between Collaborative Stage and AJCC TNM Stage. The presenter demonstrated how stage is obtained for both systems, highlighting the relationships between the two. Several case studies were reviewed.

Special AJCC TNM Stage and NCI Summary Stage Training Subscription to the CCRE: May 1

NCRA will offer a special member subscription to its Center for Cancer Registry Education (CCRE) that will include all of NCRA's AJCC TNM Stage and NCI Summary Stage training from fall 2014 and winter/spring 2015, including the two webinars on general rules and all of the webinars focused on specific sites. In the summer, NCRA will add the relevant sessions from the 2015 annual conference to this subscription.

Case Studies

NCRA is developing a booklet of case studies and creating an online case study product to help registrars practice for the transition. The booklet will be available at the 2015 Annual Conference in San Antonio; the online product will launch August 1. It will be available through the CCRE.

Contact person: Peggy Meehan (pmeehan@ncra-usa.org)

2. Credentialing

The Council on Certification is actively monitoring the transition efforts and will post any CTR examination changes related to new content on its website:

www.ctrexam.org

Contact person: Michael Hechter (mhechter@ncra-usa.org)

3. Social Media

A web page has been created on the NCRA website dedicated to "all things transition" with the purpose of being a one-stop shop for NCRA members as the transition moves forward:

<http://www.ncrausa.org/i4a/pages/index.cfm?pageid=4132>

Contact person: Janice Ford (jford@ncra-usa.org)