North American Association of Central Cancer Registries

GUIDELINES FOR IMPLEMENTATION OF SEER SUMMARY STAGE 2000

Prepared by the

**NAACCR SEER Summary Stage 2000
Implementation Work Group**

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1 INTRODUCTION

These consensus guidelines, developed by the North American Association of Central Cancer Registries (NAACCR) SEER Summary Stage 2000 (SSS2000) Work Group and approved by the NAACCR Board of Directors, address implementation of SSS2000 for cases diagnosed on or after January 1, 2001. The guidelines are patterned after those of the ICD-O-3 Work Group, which were released on November 27, 2000 and address another coding change that is also effective for cancers diagnosed on or after January 1, 2001. Members of the SSS2000 work group are listed below and they include standard setting organizations, central registries, and cancer registry software vendors.

Implementation of new standards is never 100 percent problem-free. The concept of SSS2000 was first presented to the Uniform Data Standards Committee in November 1999. The need for a revised manual to provide more specific staging instructions, for all primary sites, was recognized. At that time, the new manual was projected to be available in the fall of 2000.

The SSS2000 changes affect hospital registrars in the United States, most U.S. central registries, the National Program of Cancer Registries, and software vendors. Although the staging scheme is called "SEER Summary Stage," the NCI SEER program does not require its submission; NCI-SEER derives Summary Stage from Extent of Disease (EOD) codes by means of a computer algorithm. Canadian registries do not collect or derive SEER Summary Stage.

SSS2000 WORK GROUP MEMBERS

Toshi Abe, MSW, CTR
New Jersey State Cancer Registry

Sally Bushhouse, DVM, PhD
Minnesota Cancer Surveillance System

April Fritz, RHIT, CTR
National Cancer Institute
Surveillance Epidemiology & End Results
Program

Ken Gerlach, MPH, CTR
Centers for Disease Control and Prevention
National Program of Cancer Registries

Dianne Hultstrom, RHIT, CTR
Medical Registry Services, Inc.

Annette Hurlbut, RHIT, CTR
IMPAC Medical Systems, Inc.

Betsy A. Kohler, MPH, CTR
New Jersey State Cancer Registry

Robin Otto, RHIA, CTR
Pennsylvania Cancer Registry

Lynn Ries, MS
National Cancer Institute
Surveillance Epidemiology & End Results
Program

Steven Roffers, PA, CTR
Emory University

Jan Snodgrass, CTR
Illinois State Cancer Registry

Patricia Tary, CTR
American College of Surgeons

Thomas Tucker, MPH
Kentucky Cancer Registry

John L. Young, Jr., DrPH, CTR
Atlanta SEER Program
Emory University

2   BACKGROUND AND IMPLEMENTATION ISSUES

2.1   Why SEER SUMMARY STAGE 2000?

Development of SSS2000, an international coding scheme, has been underway for several years. The new manual (called the SEER Summary Staging Manual 2000 – SSS Manual 2000) replaces the Summary Staging Guide (1977). Unlike the previous document, the SSS2000 document is intended as a coding manual rather than a staging guide. It has more detailed instructions, complete with drawings, for staging. It has coding instructions for each anatomic site in the International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3). Also, certain undocumented rules commonly applied to summary staging have now been documented and some existing rules have been clarified. It is hoped that the new, more specific coding rules will result in the collection of more accurate staging information.

2.2   How sweeping is the change?

The change from the Summary Staging Guide (SSS1977) to the SSS Manual 2000 consists primarily of clarification. However, because no translation between the old and new coding systems is possible, it is important that abstractors use the correct scheme – based on diagnosis date (not accession date).

- The codes themselves do not change, although some tumors that were "regional" under SSS1977 may be "distant" under SSS2000, and vice versa (varies by site). The number of tumors this will affect is unknown.
- It is impossible to map codes from SSS1977 to SSS2000 or vice versa.
- Each anatomic site/histology grouping in the ICD-O-3 has a corresponding SSS2000 staging scheme.
- Certain specific histologic types (e.g., mycosis fungoides, Kaposi sarcoma, retinoblastoma, leukemia, and lymphoma) also have specific staging schemes.
- Some sites, which previously had separate staging guides (e.g., segments of the colon), now have a single, common staging scheme.
- Some sites, which previously had a single guide (e.g., larynx), now have separate schemes for each subsite.
- Some lymph nodes have been redefined as indicating "Regional" instead of "Distant" spread; some others have been redefined as "Distant" instead of "Regional" (varies by site).
- The timing rule for inclusion of information[*] now extends to four months in the absence of progression, instead of two months.

2.3   When will the SSS Manual 2000 be available?

An electronic (PDF) version of the draft SSS Manual 2000 (without drawings) will be available by December 31, 2000 on the SEER web site: www.seer.cancer.gov/publications. The hard copy has not yet been sent to the printer but is expected to be available from SEER in April 2001. As for all SEER publications, orders of up to 20 copies will be available at no cost. To order in the U.S., go to the SEER web site, or if you don't have web access, write to:

> National Cancer Institute
> SEER Program, SRP, DCCPS
> Executive Plaza North (EPN)
> Room 343
> 6130 Executive Blvd. MSC 7350
> Bethesda, Maryland 20892-7350

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[*] Timing is not the only criterion for inclusion of staging information. The entire rule is, "Summary stage should include all information available through completion of surgery(ies) in the first course of treatment or within four months of diagnosis in the absence of disease progression, whichever is longer."

2.4   What about training for data collectors?

The editors of the new SSS Manual 2000 have provided several in-person training sessions. A web-based training module will be available on the SEER web site in mid-January (www.training.seer.cancer.gov).

2.5   What impact does the delayed release of the SSS Manual 2000 have on cancer registry software development and release?

None. Because no new codes are being used and it is not possible to translate SSS1977 to or from SSS2000, vendors do not need to develop translation software. However, because it is expected that vendors will not release version 9-compatible software until July 2001, SSS2000 will have to be stored in the existing summary stage field [item 760] for cases that are diagnosed in 2001 and abstracted prior to the release of new software.

The issues for vendors are: (1) New abstracting software should provide guidance to registrars about which coding scheme to use, based on diagnosis year; (2) The software should store the information properly; and (3) Data submission software must place the SSS2000 information in a separate field from the SSS1977 information when writing records in NAACCR record versions 9 and forward.

2.6   What are the conversion issues?

No conversion of codes is possible. It will have to be assumed that tumors diagnosed prior to January 1, 2001 were coded according to the Summary Staging Guide (1977), and that tumors diagnosed on or after January 1, 2001, were coded according to the SSS Manual 2000. It is very important that all data coders observe this coding standard.

2.7   How should reporting facilities and central/state registries abstract and report cases diagnosed in 2001, until abstracting and reporting software handles this field correctly?

SSS2000 should be abstracted, stored, and reported in the SSS1977 data field until software has the ability to handle the new field. During this period of transition, text documentation should indicate which set of rules was used. The burden for coding cases correctly falls on the hospital registrars, who will need to have both manuals available for a period of time. Cases diagnosed prior to January 1, 2001 (regardless of date abstracted) should be coded according to the Summary Staging Guide (1977). Cases diagnosed on or after January 1, 2001 should be coded according to the SSS Manual 2000.

2.8   What is the relationship between the implementation of SSS2000 and NAACCR's data exchange record layout, version 9?

Version 9 of the NAACCR layout is the first version to contain a data item for the new SSS2000 field. Because SSS2000 uses a different set of rules, NAACCR's Uniform Data Standards Committee decided to implement SSS2000 by setting up a new data field [item 759] for the SSS2000 codes, designating the old General Summary Stage field [item 760] to be used for SSS1977 codes only. Technically, all cases diagnosed in 2001 and later should have SSS2000 codes, but not have SSS1977 codes. Likewise, pre-2001 cases should have SSS1977 codes, but not SSS2000 codes. However, state cancer registry systems that cannot use version 9 of the NAACCR data exchange record to send or receive abstracts should use data item 760 (the field for SSS1977) to transmit SSS2000 codes. When the registry is able to implement Version 9 of the NAACCR layout, the SSS1977 codes for cases diagnosed on or after January 1, 2001 would be moved to the SSS2000 field.

3 STATEMENTS FROM STANDARD-SETTING ORGANIZATIONS ABOUT SSS2000 IMPLEMENTATION

3.1 The American College of Surgeons Commission on Cancer (CoC) Approved Cancer Programs

CoC-approved cancer programs will be required to use SSS2000 codes for cases diagnosed on or after January 1, 2001. Because the SSS Manual 2000 is available electronically, there should be no delay in abstracting 2001 diagnoses, unless the histology is changed or new in ICD-O-3 (see NAACCR's ICD-O-3 Implementation Guidelines for more details). The SSS2000 code should be abstracted into the field for SSS1977 until software can handle SSS2000 directly. During this period of transition, the text documentation for staging should indicate which set of coding rules was used.

3.2 Centers for Disease Control and Prevention, National Program of Cancer Registries (NPCR)

NPCR funded programs are expected to implement SSS2000 with cancers diagnosed on or after January 1, 2001. Since the SSS Manual 2000 is available on the SEER Web site in PDF format, a copy can be downloaded and reproduced by any facility with internet access. NPCR registries need to plan for the distribution of the new staging manuals either from the PDF file or the printed version to all data reporters who code summary stage. If registry software is not yet able to handle SSS2000 directly, the SSS2000 code should be abstracted using the SSS Manual 2000, but stored and reported in the SSS1977 field. During this period of transition, the text documentation for staging in the NPCR required data item "Text—Staging" [2600], should indicate which set of coding rules was used (other text fields could be used for this purpose).

From the perspective of summary stage, there should be no delay in abstracting 2001 cancers. Delays, however, could occur if the histology is affected by ICD-O-3 (see NAACCR's Guidelines For ICD-O-3 Implementation).

Since SSS2000 is not the same entity as SSS1977 and since the time rules changed dramatically, the major challenge for NPCR registries (as well as other central cancer registries) will be in deciding how to analyze and present summary stage data correctly over the time period of the transition. For example, can breast cancer incidence rates by summary stage from 1999 to 2002 be meaningfully compared and presented in an annual report? To ascertain the sites that will be comparable over the time period, the data from re-abstracting and re-coding studies will need to be analyzed and site-specific guidance will need to be developed.

3.3 National Cancer Institute, SEER Registries

SEER registries code summary stage directly, but the NCI SEER Program does not require it. NCI-SEER derives Summary Stage from EOD by means of a computer algorithm. Similar to NPCR funded registries, local SEER registries will need to modify their databases and data processing software to handle SSS2000. NCI is coordinating the development of SSS2000 to enhance the accuracy of deriving SSS2000 from EOD using a computer algorithm. Differences between SSS1977 and SSS2000 are indicated in the SSS Manual 2000, as well as in the new Comparative Staging Guide (which will be released in the spring of 2001). The new Comparative Staging Guide will contain algorithms for converting EOD codes to SSS1977, SSS2000, as well as historic stage and AJCC stage.

4 NAACCR CONSENSUS RECOMMENDATIONS

The work group has identified key components that need to be in place to facilitate coordinated implementation by reporting facilities, registry software vendors, and central registries. They are shown in

a table format when possible. Consensus recommendations are then reported in a table format or narrative form.

4.1   Reporting facilities (includes CoC approved cancer programs)

Table 1: Hospital Level Implementation Needs and Availability

Implementation Need	Availability
SSS Manual 2000 (draft PDF version)	December 31, 2000
NAACCR Version 9 EDITS metafiles	January 1, 2001
SSS Manual 2000 (final PDF version)	January 2001
SSS Manual 2000 (hard copy)	April 2001
Software upgrade delivered for ICD-O-3 & SSS2000	July 2001
State-specific Version 9 Edits metafiles	Varies by state.

Table 2: Implementation for Reporting Facilities (Includes CoC Approved Hospitals)

Recommended Implementation:

Download SSS Manual 2000 from SEER web site and use it for coding cases diagnosed on or after January 1, 2001. Obtain printed manual when it becomes available. Enter the SSS2000 code in the old, Summary Stage, field. Use the associated text field to indicate the staging scheme used.

Issues:

No software reminders/checks will be available to ensure that the correct summary staging manual is used. Data from the SSS1977 field will be moved to the SSS2000 field for 2001 diagnoses based solely on diagnosis date, when NAACCR version 9-compatible software is available.

Problem:

EDITS applied to data after conversion to version 9 may find errors that current EDITS did not find (e.g., codes 2, 3, & 4 specifically excluded for lymphomas in SSS2000; code 9 not allowed for leukemias). See Appendix II of the SSS Manual 2000 for a list of recommended edits.

4.2   Vendors

Table 3: Vendor Implementation Needs and Availability

Implementation Need	Availability
NAACCR Version 9 EDITS metafile	January 1, 2001
SSS Manual 2000 (final PDF version)	January 2001 on SEER web site
NAACCR data exchange record* conversion (Version 9 to 8, 7, or 6)	March 2001
NAACCR data exchange record* conversion (Version 6, 7, or 8 to 9)	March 2001
Program to convert EOD codes to SSS2000**	April 2001
Software upgrade delivered for ICD-O-3 & SSS2000	July 2001

* required only if submitting and receiving registries are not compatible
**not needed if data set does not include EOD codes

4.2.1 Recommendations for Vendors

For vendors, this upgrade to SEER Summary Stage 2000 comes at the same time as ICD-O-3 and the Commission on Cancer (CoC) 2001 Patient Care Evaluation studies (PCEs). Vendors will need to provide software upgrades so that the new data fields can be collected. Until the upgrades are available, facilities

will continue to report cases to their state registries using their existing software. The record conversion programs scheduled for release in March 2001 will handle SSS2000 information appropriately during this period of transition, so that reporting from facilities to central registries should continue without interruption, even when vendors and central registries are using different record versions.

All cancer data collection systems must be able to import or export a NAACCR Version 9 record in order to properly handle SSS2000. The Uniform Data Standards Committee approved a new data item in the NAACCR Record Layout Version 9 for the SSS2000 code (Data Item 759). Pre-2001 summary stage codes should be stored in a separate field (Data Item 760) in a registry database. However, because summary stage codes themselves are not changing (e.g., "0" will still mean "in situ," etc.); because the coding system will be assumed, based on diagnosis date; and because SSS1977 codes will <u>not</u> be translated into SSS2000 – a vendor might choose NOT to create a new internal variable to hold SSS2000. Table 4 outlines the options and impact of the two possible decisions for internal storage of SSS2000.

Table 4: Implementation Options for Vendors and Central Registries (related to whether to use one or two fields for internal storage of Summary Stage)

Recommended Option: **Create a new field to hold SSS2000**.	**Alternative Option:** **Use the existing Summary Stage field to hold SSS2000.**

Issues:
1. Reports displaying summary staging data over several years will need to take into account how the data are stored.
2. NAACCR record version 9 requires that SSS2000 be reported in a different field than SSS1977.
3. The metafiles from NAACCR, CoC, and individual states will assume that SSS1977 and SSS2000 are in separate fields.

Advantages:	**Advantages:**
1. It may be appropriate that deliberate action will be required to group SSS1977 with SSS2000, since the rules for assigning codes have changed. 2. No special logic will be required to read or write a NAACCR version 9 record. 3. No special logic will be required to utilize standard EDITS metafiles on stored data.	1. It will be simple to develop multi-year reports describing summary stage.
Disadvantages:	**Disadvantages:**
1. If combining summary stage data over several years <u>is</u> appropriate, more programming will be required than if the data were stored in a single field.	1. Unsophisticated data users might prepare inappropriate multi-year reports describing summary stage, if it is <u>not</u> appropriate to combine SSS1977 and SSS2000. 2. When reading or writing a NAACCR version 9 record, diagnosis date will have to be queried for each record in order to correctly read/write the summary stage field (do I read/write item 759 or item 760?). 3. If EDITS will be run on stored data (before it is written to a flat file), the holder of the data will have to modify the EDITS logic for summary stage so that it checks pre-2001 cases according to the rules for SSS1977 and 2001+ cases according to the rules for SSS2000.

Registrars will be recording SSS2000 information in the current Summary Stage field (Data Item 760) until NAACCR version 9-compatible software is available from their vendor. When a facility's database is upgraded to be compatible with NAACCR version 9, codes from Data Item 760 should be moved to the SSS2000 field (Data Item 759) for all cases with diagnosed on or after January 1, 2001. The SSS1977 field should be blank for 2001+ diagnoses after the conversion to NAACCR version 9.

4.3   Population-Based Central/State Registries

Table 5: Population-based Registry Implementation Needs and Availability

Implementation Need	Availability
SSS Manual 2000 (draft PDF version)	December 31, 2000
NAACCR Version 9 EDITS metafiles	January 1, 2001
SSS Manual 2000 (final PDF version)	January 2001
NAACCR data exchange record conversion (Version 6, 7, or 8 to 9)	March 2001
NAACCR data exchange record conversion (Version 9 to 8, 7, or 6)	March 2001
SSS Manual 2000 (hard copy)	April 2001
Program to convert EOD to SSS2000*	April 2001
Software upgrade to Version 9	July 2001
Updated manual report forms	Varies by registry

* needed only by registries that collect EOD

4.3.1 Recommendations for Population-Based State/Central Registries

All cancer data collection systems must be able to import or export a NAACCR Version 9 record in order to properly handle SSS2000. The Uniform Data Standards Committee approved a new data item in the NAACCR Record Layout Version 9 for the SSS2000 code (Data Item 759). Pre-2001 summary stage codes should be stored in a separate field (Data Item 760) in a registry database. However, because summary stage codes themselves are not changing (e.g., "0" will still mean "in situ," etc.); because the coding system will be assumed, based on diagnosis date; and because SSS1977 codes will <u>not</u> be translated into SSS2000 – a central registry might choose NOT to create a new internal variable to hold SSS2000. Table 4 outlines the options and impact of the two possible decisions for internal storage of SSS2000.

Registrars will be recording SSS2000 information in the current Summary Stage field (Data Item 760) until NAACCR version 9-compatible software is available from their vendor. Until the upgrades are available, facilities will continue to report cases to their state registries using their existing software. Central registries will simply need to convert the incoming data records to the format that their software can handle (using one of the record conversion programs to be released in March 2001) and load the data. When the central registry's database is fully NAACCR version 9-compatible, codes from SSS1977 (Data Item 760) should be moved to the SSS2000 field (Data Item 759) for all cases with diagnosed on or after January 1, 2001. The SSS1977 field should be blank for 2001+ diagnoses after the conversion to NAACCR version 9.

4.4   Recommendations for EDITS Software Users

The NAACCR EDITS Subcommittee will review and revise the edits for two summary stage fields. Most of the edits using these fields will allow the fields to be blank, but there will be new edits to check that the fields are filled in appropriately by diagnosis year. SSS1977 will be required if the year portion of the date of diagnosis is prior to 2001, and SSS2000 will be required if the year of date of diagnosis is 2001 or later. SEER, NPCR, and CoC Edits will also need to be reviewed for possible revisions. See Appendix II

of the SSS Manual 2000 for a list of recommended edits. Examples of new edits are that 7 is the only allowed SSS2000 code for leukemias, and that SSS2000 codes 2, 3, and 4 will be specifically excluded for lymphomas.

5 QUESTIONS AND ANSWERS

Question 1: *For cases diagnosed before January 1, 2001 that are accessioned after January 1, 2001 what summary stage scheme should be used?*

  Answer: The Summary Staging Guide (1977) coding scheme should be used for any case diagnosed before January 1, 2001.

Question 2: *Will SEER, CoC, NAACCR and NPCR expect old records to be converted to SSS2000 codes, or can old records remain in SSS1977?*

  Answer: SSS1977 codes cannot be converted to SSS2000. Old records must remain coded in SSS1977.

Question 3: *Under what circumstances will it be appropriate to combine SSS1977 with SSS2000 for multi-year reports?*

  Answer: The answer to this question will not be known for several years. Studies will be required to compare the impact of the new coding rules on each site. Studies might consist of comparisons of the results from mapping EOD codes, or of abstracting the same cases according to the two coding systems. The results of this work will be distributed as soon as it is available.