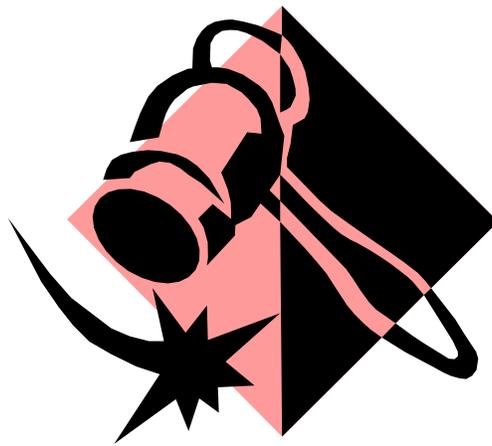


# **NAACCR Standards Implementation Guidelines**



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**January 2003**

**North American Association of Central Cancer Registries, Inc.**

Suggested Citation:

Hultstrom D, Gershman S, Havener L (eds). *NAACCR Standards Implementation Guidelines*.  
Springfield (IL): North American Association of Central Cancer Registries, January 2003. 9 pp.

The printing of this publication was made possible by Cooperative Agreement  
#U75/CCU515998-05 from the Centers for Disease Control and Prevention (CDC). Its contents  
are solely the responsibility of the authors and do not necessarily represent the official views of  
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# North American Association of Central Cancer Registries Standards Implementation Guidelines

## Background and Mission

A fundamental necessity of cancer surveillance is that case definitions and coding practices be standardized. This enables the compilation of consistent case-specific information from which meaningful interpretations can be made. It also enables meaningful comparisons of data across different registries.

Established in 1987, the North American Association of Central Cancer Registries (NAACCR) is a collaborative umbrella organization for cancer registries, governmental agencies, professional associations, and private groups in North America interested in enhancing the quality and use of cancer registry data. In 2002, all central cancer registries in the United States and Canada are members. When NAACCR was first organized, it focused its efforts on achieving consensus in cancer registration standards among the many standard setters in the United States. Today all registries throughout the United States have adopted the NAACCR consensus standards and Canada registries are moving toward adopting NAACCR standards. As these standards are updated to incorporate changing medical practices, the maintenance of current standards to meet the needs of the NAACCR community is an ongoing and major activity.

On October 15, 1997, the NAACCR Board of Directors approved a policy on the timing of all revisions. “All suggested revisions that are completed by the annual meeting will be released in the standards volume and the data exchange layout to be effective in January of the subsequent year. Revisions will occur no more frequently than once a year.” Although the policy was passed in a year when the annual meeting was held in April, plans had already been implemented to change the annual meeting to June. This policy reflected this change; that vendors and registries would have at least six months for implementation, conversions, and training for proposed changes. This policy was written to institute a schedule for making changes and to invoke an annual cycle for changes that all standard setters would follow.

Over the past three years, there have been some major changes in cancer registration and data collection. In 2000, WHO produced the 3rd Edition of the ICD-O, which added new morphology terms and synonyms, and recommended deletion of selected morphology terms. In addition, several terms had a change in the behavior code. SEER published updates to the SEER Summary Staging Manual in 2001 (SSS2000) changing staging schemes for most sites and adding staging schemes so that all sites and histologies are now represented in the SSS2000. In 2002, the Commission on Cancer of the American College of Surgeons (COC) introduced a new standards manual, *Facility Oncology Registry Data Standards (FORDS)*. COC added new data items, removed data items from their previous required and recommended lists, and revised items with modified code sets, definitions, or fields lengths. In addition, new auto-coded or derived items (that do not have to be abstracted) were added.

It has become apparent in the last three years, with the addition of the above mentioned manuals, that the timeline for making and implementing changes and additions to data standards cannot be completed annually. Many central registries lack the resources to implement annual changes to the data exchange layout leaving them no option but to delay or even skip implementation of new versions of the data exchange layout (e.g., many central registries went from version 6 to version 9, skipping versions 7 and 8). It has been increasingly difficult for central registries, reporting facilities, and vendors to implement the changes in a timely manner because manuals, training materials, conversion programs, and EDITS have been often published later than expected dates allowing inadequate time for testing, training, conversions, and other implementation steps.

An overarching priority identified at the NAACCR Strategic Planning meeting in July 2000 was to revisit the process and timing for revising standards. The NAACCR Board of Directors established a Standards Implementation Task Force to review the current timeline for changes to data standards and to recommend guidelines for a new timeline that will meet the needs of the standard setting organizations, central cancer registries, vendors and reporting facilities.

## Guidelines

The Standards Implementation Task Force developed guidelines for all future data standard revisions. These guidelines are listed below.

1. All changes will be labeled as **major** or **minor** related to their different impact on implementation.
  - a. **Major** changes would be implemented on a three-year cycle (see table 2 for timeline). All standard setters would adhere to the same three-year cycle, with immediate implementation of the process (January 2003) with the next implementation date for major changes occurring on January 1, 2006 (i.e., then 2009, 2012, 2015, etc.). These changes would require the publication of a new Version of the NAACCR Volume II Data Dictionary and Data Standards, e.g., from Version 10.x to Version 11.0. Examples of **major** changes include:
    - Addition of new data items
    - Changes to the format, the record layout, and/or conversions
    - Publication of a new abstracting, staging or coding manual requiring revisions to data collection and data exchange fields.
  - b. **Minor** changes would be implemented on an annual cycle. The schedule will be similar to the one followed now (see table 3 for timeline). These changes would be published in an update of the current Version of the NAACCR Volume II Data Dictionary and Data Standards, e.g., Version 10.1 (*Exception: An updated Version will not be published the year a new Version is published, minor changes will be included in the new Version*). The intent is that one has the ability to fix errors and clarify codes or add new codes should they be necessary during the interval between the scheduled major revisions and updates. Examples of **minor** changes include:

- Addition of a new code to an existing field
- Clarification of a current code
- Issuing an erratum from previously published material.

2. The Uniform Data Standards (UDS) Committee will make the final determination as to whether a change is to be considered **major** or **minor** based upon documentation submitted by the requestor. For example, changes to the data exchange record, even if a new data item is required, may not have a large impact on the data dictionary and record layout and could be added within a one-year time frame. An example is the recent addition of the Rural-Urban Continuum code (Beale Code) data item used in the data exchange record only.

3. All **major** and/or **minor** change requests MUST be proposed to UDS using the forms, *Request for Addition of a New Data Item* and/or *Request for Change to an Existing Data Item*, provided on the NAACCR website [www.naacr.org](http://www.naacr.org) (Registration Standards).

4. Request forms must be completed for new data items or changes to existing data items. Request forms MUST include:

- a. Date of Request
- b. Requestor and contact information for requestor
- c. Checked as to whether the request is Preliminary or Final
- d. Category of change – **Major** or **Minor** [N.B. UDS will make the final determination]
- e. Proposed effective date for new item or change
- f. Proposed data item name; proposed length of field; proposed format with allowable values, codes and defaults
- g. Description of the data item
- h. Rationale for the addition or change of the data item
- i. Proposed Organizational Source of Standard
- j. Proposed Required Status for organizational requestor (NPCR, COC, SEER, NAACCR Exchange, Incidence and Full)
- k. Timeline for Educational plan and notification
- l. If conversions are necessary for this field, conversion specifications should be included as well as a timeline for the conversion.
- m. Proposed edits for the new field or change

5. UDS will determine whether changes to the record layout will be sent to the Information and Technology (IT) Committee at the time of preliminary or final request. **Major** changes to the record layout should be sent to IT no later than 20 months before the change is to take effect to allow IT sufficient time to address concerns before final approval by UDS.

6. UDS will review all conversion specifications and the anticipated timeline for the conversion.

7. A proposed **major** change will require the formation of an Implementation Task Force that will be designated by either the standard setting organization requesting the change or the NAACCR Board. When a NAACCR designated Implementation Task Force is formed, the NAACCR President will appoint the Task Force chair. The NAACCR Board, standard setting organization, and appointed Task Force chair will determine the composition of the Task Force. All affected parties (COC, SEER, NPCR, NAACCR, Statistics Canada, and software vendors) should have representation on the Task Force. The Task Force should be formed as early as 24 months and no later than 18 months prior to the implementation, and the final document should be produced at least 9 months prior to the implementation.

8. All educational material, documentation, conversion routines, updated edits and anything else the standard setter may need to implement a **major** change as determined by UDS and the standard setter **MUST** be in final format and distributed no later than July 1 of the year prior to implementation in order to ensure that the change not be postponed. While NAACCR has no authority over standard setters implementation schedules, NAACCR requires all changes to be published in Volume II to take place only once per year.

If the July 1 deadline cannot be met, the NAACCR Board following consultation with UDS, IT, Registry Operations, standard setters and an existing Implementation group will determine whether to postpone the date of implementation for the change.

9. The final draft of NAACCR *Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary* including a **major** change must be completed no later than 15 months prior to implementation. The final draft will be distributed to the NAACCR Board of Directors at least 2 weeks prior to the Board meeting.

10. The final draft of NAACCR *Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary* including a **minor** change must be completed no later than May 1 of the year prior to implementation. The final draft will be distributed to the NAACCR Board of Directors at least 2 weeks prior to the May Board meeting.

11. The final version of Volume II for **major** changes must be completed and sent to the professional editors in ample time to be printed by January 1 of the year prior to implementation and after Board approval.

12. The final version of Volume II for **minor** changes must be completed and sent to the professional editors in ample time to be printed by July 1 of the year prior to implementation and after Board approval.

13. These guidelines will go into effect immediately in January 2003. The next **major** change implementation will be January 2006, allowing requests for **major** changes to be proposed from January 2003 through June 2004. Thus, the first 18 months in each 3-year cycle is the time when revisions can be proposed and approved.

## Implementation Issues for a Major Change

The following list summarizes the various activities when implementing a **major** change and the length of time needed for each that must be completed before implementation of major revisions to standards.

Table 1. Implementation Issues for a Major Change

<b>ISSUES – STANDARD SETTING ORGANIZATIONS</b>	<b>TIME REQUIRED TO COMPLETE</b>
Propose changes: UDS approval and IT review of changes/additions to current standards	12 months
Provide and test conversion tables, programs and instructions	9-12 months
Prepare Volume II draft	9 months
Update EDITS metafile	6-9 months
Develop Implementation Work Group (as necessary)	6-9 months
Receive NAACCR Board approval on Volume II	1 month
Publish and distribute Volume II (NAACCR)	2-3 months
Provide educational workshops and training material (national, state, regional, and local level)	6-9 months
Perform analysis of impact of change (e.g., SSS2000)	6-9 months
<b>ISSUES: CENTRAL REGISTRIES</b>	<b>TIME REQUIRED TO COMPLETE</b>
Modify database systems (includes facility software provided by central registries).	12 months
Test EDITS metafile(s) for new standards.	9 months
Test conversion programs (includes manual editing when there are automated conversion problems).	9 months
Notify reporting facilities and vendors of the implementation date and central registry changes for new standards.	9 months
Provide educational workshops and materials for central registry staff and reporting facilities' staff at the state, regional and local levels.	9 months

<b>ISSUES: CENTRAL REGISTRIES</b>	<b>TIME REQUIRED TO COMPLETE</b>
Test phase among vendors, reporting facilities and central registries to review submissions of new standards.	6-9 months
Update manuals for reporting facilities.	6 months
Update policy and procedure manuals for implementation of new standards.	6 months

<b>ISSUES: VENDORS</b>	<b>TIME REQUIRED TO COMPLETE</b>
Modify database systems (vendor software provided to facilities).	12 months
Test EDITS metafile(s) for new standards (must be included in the modification of the database system).	12 months
Test conversion programs (includes manual editing when there are automated conversion problems).	9 months
Notify facilities and central registries of proposed release of software to accommodate changes.	6-9 months
Test phase among vendors, reporting facilities and central registries to review submissions of new standards.	6-9 months
Update software and labeling documentation i.e., release notes and user manuals (online help systems, where applicable) for reporting facilities.	6 months

**Table 2. Timeline for Implementation of Major Changes.**

Activity	yr mo	y1 08	y1 09	y1 10	y1 11	y1 12	y2 01	y2 02	y2 03	y2 04	y2 05	y2 06	y2 07	y2 08	y2 09	y2 10	y2 11	y2 12	y3 01	y3 02	y3 03	y3 04	y3 05	y3 06	y3 07	y3 08	y3 09	y3 10	y3 11	y3 12	Implementation	
1. Propose request to change/add standards	SS																															
	CR																															
	V																															
	RF																															
2. UDS approval & IT review of request to changes/additions to standards	SS																															
	CR																															
	V																															
	RF																															
3. Provide and test conversion tables, programs and instructions for UDS approval	SS																															
	CR																															
	V																															
	RF																															
4. Prepare Volume II draft (Volume II work group)	SS																															
	CR																															
	V																															
	RF																															
5. Update EDITS metafile	SS																															
	CR																															
	V																															
	RF																															
6. Develop Implementation work group (as necessary)	SS																															
	CR																															
	V																															
	RF																															
7. Receive NAACCR Board approval on Volume II	SS																															
	CR																															
	V																															
	RF																															
8. Publish and distribute Volume II	SS																															
	CR																															
	V																															
	RF																															
9. Update software, modify database systems & V documentation (V software provided to RF)	SS																															
	CR																															
	V																															
	RF																															
10. Update CR reporting manuals & modify database systems (RF software provided by CR)	SS																															
	CR																															
	V																															
	RF																															
11. Test EDITS metafile(s) for new standards	SS																															
	CR																															
	V																															
	RF																															
12. Test conversion programs (includes manual editing when there are automated conversion problems)	SS																															
	CR																															
	V																															
	RF																															
13. Notify facilities and central registries of upcoming changes &/or proposed release of software	SS																															
	CR																															
	V																															
	RF																															
14. Provide educational workshops & training material (national, state, regional, and local)	SS																															
	CR																															
	V																															
	RF																															
15. Test phase among Vs, RFs, and CRs to review submissions of new standards	SS																															
	CR																															
	V																															
	RF																															
16. Update policy & procedure manuals for implementation of new standards	SS																															
	CR																															
	V																															
	RF																															
17. CR update reporting manuals for RFs	SS																															
	CR																															
	V																															
	RF																															
18. Perform analysis of impact of change (e.g., SS2000)	SS																														After implementation	
	CR																														After implementation	
	V																															
	RF																														After implementation	
SS - Standard Setters		CR - Central Registries		V - Vendors		RF - Reporting Facilities																										

**Table 3. Timeline for Implementation of Minor Changes.**

Activity	yr mo	y1 01	y1 02	y1 03	y1 04	y1 05	y1 06	y1 07	y1 08	y1 09	y1 10	y1 11	y1 12	Implementation
1. Propose minor change request	SS													
	CR													
	V													
	RF													
2. UDS approval & IT review of request to changes/additions to standards	SS													
	CR													
	V													
	RF													
3. Prepare Volume II draft (Volume II work group)	SS													
	CR													
	V													
	RF													
4. Update EDITS metafile	SS													
	CR													
	V													
	RF													
5. Receive NAACCR Board approval on Volume II	SS													
	CR													
	V													
	RF													
6. Publish and distribute Volume II	SS													
	CR													
	V													
	RF													
7. Revise software, modify database systems & V documentation (V software provided to RF)	SS													
	CR													
	V													
	RF													
8. Revise CR reporting manuals & modify database systems (RF software provided by CR)	SS													
	CR													
	V													
	RF													
9. Notify facilities and central registries of revisions	SS													
	CR													
	V													
	RF													
10. Provide educational workshops & training material (national, state, regional, and local)	SS													
	CR													
	V													
	RF													
11. Prepare revisions of CR manuals for RFs	SS													
	CR													
	V													
	RF													
<b>SS - Standard Setter    CR - Central Registry    V - Vendor    RF - Reporting Facility</b>														