

The Future of the Collaborative Stage Data Collection System

Many of you may be wondering about the title of this article and are asking yourselves, with implementation of Collaborative Stage (CS) Version 2 still underway, why would I be interested in learning about the future of the CS System? As a representative of the CS Project Management Team, I share your concerns relative to the magnitude of the changes implemented this year and appreciate your commitment to implementation of these changes in an effective and efficient fashion. These are challenging times and delays and obstacles that impacted the release of CS Version 2 led to action on the part of the CS Project Management Team to undertake a detailed assessment to determine the best way to manage, maintain, and in fact, enhance overtime, the CS System to keep pace with the needs of the clinical and surveillance communities. Therefore, it is appropriate to take some time to tell you how the CS Project Management Team intends to accomplish these things moving forward.

The CS Project Management Team realized early on in the development of CS Version 2 that future maintenance, including annual updates, and eventually new version releases, will require some major re-engineering. The CS Project Management Team, comprised of leadership from all of the standard-setting and surveillance agencies and organizations, is committed to building a more efficient and timely system. To kick-start the re-engineering process, a two-day Process Review Session was held in March with the CS Project Management Team members, individual team leaders, and key individuals involved in the development of CS Version 2. The objectives of the meeting were to review and analyze the CS Version 2 development process, discuss how best to maintain, update, and revise the CS System, the long term plan for creating a sustainable program to support major and minor releases, the roles and responsibilities of the program management team, and the development of project plans and timelines. In addition, the session addressed recommendations for ongoing funding and support for CS and staffing expertise required to manage the program. It was important to gain consensus and commitment from the participating organizations on the decisions made about the future trajectory of the CS System.

The session included a dissection of the CS Version 2 development process around several different themes – communication, training, organization of the project, and individual involvement. The following table summarizes the opinions and perspectives of all of the individuals (team leaders, team members, contractors, and others.) who were involved in the CS Version 2 development, and is separated by what worked well in the development process versus what didn't work well. As you can see, there was variability in the levels of opinion.

Themes	What Worked Well	What Didn't Work Well
Communication	Broad input from various stakeholders. Communication among and between CS Version 2 teams and the management team. Opportunities to share ideas and information through open communication. Use of technology (Share point) sites to enhance communication. Relationships with vendors.	Not enough communication with cancer registry and surveillance community, vendors about progress.
Training	Recruitment of cadre of trainers. Use of web-based training. Dedicated web site for trainer support. High-quality educational materials on major sites.	Training and materials were developed too early.

[More on page 13 >](#)

Collaborative Stage Data Collection System (cont.)

Continued from Page 12

Themes	What Worked Well	What Didn't Work Well
Project Organization	Structure worked well with project leader, team leaders, reporting to Project Management Team. Team member expertise resulting in contributions of new ideas, concepts, and perspectives. Strong informatics structure for programming/testing.	Project was bigger than most imagined—huge workloads. Repeatedly missed deadlines. Unrealistic schedule—lack of adequate time for all the steps in the process. Prep of AJCC chapters missed expected deadlines. Lack of input from cancer registrars. Needed early triggers to help make decisions about how to move forward or delay. Teams needed process to manage change requests to determine “in-scope” or “out of scope”. Style manual “how to” for mapping team. Ineffective team management/leadership. Lack of defined authority structure.
Individuals Involved	Many dedicated individuals with subject matter expertise. AJCC staff support. Willingness of team members to work together. Talented and experienced technical leadership. Major players in cancer registry field involved.	Too much reliance on volunteers. Extensive resources spent on contractors. Duplicate work conducted.

So where do we go from here?

Major outcomes from the meeting to address and improve upon what “did not work well” and “what we need to do differently” involve a variety of initiatives being spearheaded by the CS Project Management Team. These include spending time thinking about and defining processes that will:

- Increase the involvement of the cancer registry community in the CS development process
- Ensure responsiveness from AJCC authors and clinical experts in CS schema development
- Define the level of CS involvement in AJCC chapter development
- Analyze what can be collected and how it can be collected prior to starting the development process
- Determine balance between being up-to-date clinically and burdening the cancer registries
- Assess who is using registry data and for what purposes
- Evaluate the cost benefit of adding new data items

Currently, the CS Project Management Team is engaged in the following activities:

- Recruitment of a full-time CS Program Manager housed at the AJCC offices
- An external contractor is currently dissecting the processes used in the CS Version 2 development to determine where improvements and enhancements can be made
- Development of an annual update project plan and timeline that incorporates the NAACCR Implementation Guidelines and timelines. This plan and related timelines will be broadly communicated in January 2011 so that registries can anticipate the annual update cycle

More on page 14 >

NAACCR Process Improvement Program

Are you planning your state or province association annual workshop?

Then add the Process Improvement Program to your workshop agenda. The Process Improvement half-day workshop is designed to enhance data quality through improved collaboration, more effective communication, and strengthening the relations between central cancer registry staff and local cancer registrars/reporters. Visit the NAACCR website to complete an application.

Closing Dates

January 1, April 1, July 1, October 1

Go to www.naacr.org for more information and application forms or contact Jim Hofferkamp at jhofferkamp@naacr.org or (217)698-0800 ext. 5.



This project has been funded by the National Cancer Institute, National Institutes of Health, Department of Health and Human Services, under Contract No. HHSN261200900015C and ADB No. N02PC-2009-0015 to NAACCR. Subject to the availability of federal funds.

Collaborative Stage Data Collection System (cont.)

Continued from Page 13

- Enhanced communication with the user community to include regular articles and updates in registry-related communication vehicles
- Planning a Surveillance Summit (for first quarter 2011) to define the needs of the clinical versus surveillance communities for staging data, facilitate closer collaboration with the AJCC on the staging system revision process, define the feasibility and criteria to evaluate the scope of proposed changes and build a vetting, feasibility, and pilot testing process for new concepts and major changes
- Preparations are underway for a version release which will take place before the end of this year. This release will incorporate all changes from data validation which was a review of site-specific schemas and tables for consistency, completeness and accuracy. This will result in some code changes and new codes, and the conversion will be designed to handle the majority of the changes
- Education and Training will continue in 2011 with new presentations developed and delivered by the trainers and through NCRA and NAACCR on Part 1, Section 1 Coding Instructions, Part 1, Section 2 Site-Specific Factors, and additional topics currently being defined by the Education and Training Team
- A field test is in development and is planned for implementation in the fall of 2011

Given the challenges with implementing CS Version 2, the CS Project Management met recently and determined that integration and implementation of Pre- and Post-Treatment Staging into the CS System, has been put on hold. The Team concluded that more research needs to be conducted on how to best capture these data, what needs to be collected, and under what circumstances. In addition, careful consideration needs to be given to minimizing the burden and maximizing the utility for such data collection if and when these data elements are defined and required.

Finally, I'd like to conclude with a reminder of the tools available to support use of CS Version 2:

- Printed manual available from NCRA
- Access to downloadable pdf versions of the CS site-specific schemas grouped by anatomic site (head and neck) or individually from the CS Web site at <http://www.cancerstaging.org/cstage/index.html>
- Coding questions and answers can be submitted to the new CAnswer Forum located on the CoC Web site at <http://www.facs.org/cancer>. CS questions are answered by a team of knowledge-based experts
- Software and informatics-type questions and comments can be submitted to Joe Rogers at CDC at JRogers@cdc.gov

- Connie Bura
Administrative Director, Cancer Programs
American College of Surgeons