

**SEER*DMS Change Control Advisory Board (CCAB) Users Group
Workshop 5
April 3, 2023
2:00 p.m. to 4:00 p.m. EST**

Representatives from the NCI, IMS, the Scientific Consulting Group, Inc. (SCG), and 25 cancer registries participated in the SEER*DMS Webinar on April 3, 2023. Participants included:

REGISTRIES:

Alaska
Arkansas
California Cancer Registry
Cherokee Nation
Connecticut
Detroit
Georgia
Greater Bay Area
Greater California
Hawaii
Idaho
Illinois
Iowa
Kentucky
Los Angeles
Louisiana
Massachusetts
Minnesota
New Jersey
New Mexico
New York
Seattle
Texas
Utah

NCI: Peggy Adamo, Lois Dickie,
Marina Matatova, Serban Negoita,

IMS: Suzanne Adams, David Angelaszek, David
Annett, Linda Coyle, Scott Depuy

SCG: Kathy Brown-Huamani, Carolyn Fisher,
rapporteurs

Action Items

- NCI and IMS will consider SEER real-time reporting as a future workshop topic.

Introduction and Background

Linda Coyle, Marina Matatova

The SEER*DMS Workshops are the CCAB User Group's mechanism for discussing topics in greater detail. Each 2-hour webinar covers a single topic and replaces the in-person conferences hosted at the NCI prior to the COVID-19 pandemic. The first series of workshops were held in 2022. Workshop 5 focused on the annual North American Association of Central Cancer Registries (NAACCR) updates in SEER*DMS and the optimal timing for these updates. The agenda also included status reports from the 2022 SEER*DMS Workshops; SEER*DMS updates, 2023 meeting schedule, and a brief update on Social Security Administration (SSA) linkages. The webinar was recorded and will be made available, along

with meeting materials, in the [CCAB SEER*DMS portal](#). Members are welcome to email Linda with topics to discuss during quarterly CCAB workshops.

NAACCR Versions

Linda Coyle

Linda reminded the group that the NAACCR version 18 (v18) was a major update and specifications were released in SEER*DMS in May 2018, which was quite earlier than other vendors. Earlier deployment was not possible due to delay in receiving specifications. There were no updates in 2019 or 2020. Versions 21 and 22 were released in February 2021 and March 2022, respectively. Version 23 is scheduled for release on April 14, 2023, to allow time for programming needed to change the date flags across all modules. IMS anticipates releasing v24 in March 2024.

Historically, all SEER registries use the same NAACCR version for the February submission to the NCI, either by creating an extract from their updated DMS or by running an extract in the old version and using the conversion tool. Recognizing that it would be difficult for non-SEER*DMS registries (e.g., California registries) to send their submission using the latest NAACCR version prior to the February deadline, IMS decided to implement the next NAACCR update after the February submission deadline, with the update tentatively scheduled for March. The plan is for all SEER registries to be using SEER*DMS by early 2025.

Discussion

Participants discussed whether to implement NAACCR updates in January, February, or March beginning in 2025. Linda noted some considerations:

- Resubmission of the previous year's November or December data.
- Compatibility with abstracting software.
- Time for Certified Tumor Registrars (CTRs) to adapt to new coding standards.
- The National Program of Cancer Registries (NPCR) requirements.
- SEER requirements for the February submission.
- Timing for the final release of NAACCR specifications, which would need to be finalized between August to early October.

Serban Negoita co-chairs the NAACCR Mid-Level Tactical Group that develops detailed implementation plans each January for the next NAACCR version. Serban commented that the many actors involved in developing the NAACCR standards have expressed a preference to move the deadlines to January. The NCI is interested in hearing recommendations from the registries and, subsequently, from the wider cancer surveillance community.

The Seattle registry representative pointed out that significant NAACCR changes have resulted in a lot of downstream problems in the past (e.g., in 2018). Registries might be able to prepare to avoid some of these problems. As the pressure to rapidly build CTCs from pathology (path) reports increases, the need for earlier SEER*DMS updates increases. The representative expressed a strong preference for implementing the NAACCR v23 update after February 2024 because the Seattle registry has created more than 6000 CTCs in 2023 to date, which would need to be revised if v23 was implemented before the February NCI submission.

The Georgia, Louisiana and Texas registries indicated that they would prefer March updates, and the Arkansas and Alaska registries have no preference, but March has worked.

Mona Highsmith (Minnesota registry) asked when the NAACCR Edits Metafile is released. Jennifer Stevens noted that the first release of the v23 Edits Metafile was in September 2022 and the second one at the end of March 2023. Serban confirmed this time frame.

The New York registry (Colleen Sherman) did not have a preference for the schedule but noted that the NAACCR Standardization and Registry Development Steering Committee (of which she is a member) discussed that subsequent Edits Metafile updates could be delayed to provide registries adequate time to use the metafile and find issues.

The majority of participants favored NAACCR updates in March for future years. Serban asked participants how this timeline might affect hospital registries and their update schedules.

- The New York registry has a 4-month delay and will not begin accepting v23 cases from hospitals until May to ensure that the appropriate treatment and staging information is being abstracted.
- For the Detroit registry, the state hospitals typically receive updates from their vendor in June, July, or August. METRIQ is the primary vendor, but some hospitals are now using CRStar.
- Brent Mumphrey of the Louisiana registry explained that in the past few years, the local hospitals have performed updates in May or June. Serban inquired if there was a reason the hospitals update later. Registries agreed that it was because the vendors are not ready to update until May or June.

Serban moved the discussion to what would be the optimal time for the updates, given the schedules of the vendors and the hospitals.

The Seattle registry has been receiving inquiries from their area hospitals about when the v23 updates would be implemented. Although most of these hospitals rely on the vendors, some hospitals can upgrade their systems as soon as SEER*DMS is upgraded. This registry has not enforced a date for the updates, nor have registry staff observed any issues with hospitals upgrading to the latest NAACCR version while still continuing to work on a prior diagnosis year, with 2018 being the exception.

The Louisiana registry upgrades to the newest NAACCR version each year but the hospitals are always 1 year behind. Registry staff, however, do not view the hospital registry upgrade delays as a problem.

When asked how frequently hospitals will update their systems prior to SEER*DMS updates, Desiree Montgomery (Kentucky registry) noted that updating software before SEER*DMS updates caused problems with importing records. Kentucky (KCR) is different because KCR is the vendor for their hospitals.

Nancy Lozon noted that the Detroit registry has informed its local registries that NAACCR v23 cannot be implemented until SEER*DMS has been updated. This registry has a large facility that performs concurrent abstracting and has already started 2023 cases. Nancy explained that concurrent abstracting is a concept from the American College of Surgeons (ACoS) and relies on monthly National Cancer Database (NCDB) reporting. The process entails immediately uploading cases as soon as a diagnosis has been made. Within 4 weeks, cases are reviewed and information on procedures (e.g., surgery, X-rays, computed tomography scans) are captured and reports modified.

Serban clarified that in concurrent abstracting, cases are generated with the expectation that the abstracting will be completed 6 or 9 months after diagnosis. He asked for input from the registries on this process.

The Seattle registry has Commission on Cancer (CoC) facilities that use a process similar to the ACoS process. Cases are not marked as complete until all the information has been uploaded, which can be up to 4 months after a diagnosis.

Registries agreed that the modified NAACCR abstracts can be cumbersome and would rather wait until the cases are completed to receive the abstract.

Assuming that SEER*DMS would be updated annually in March, Serban asked whether any registries would take exception and report cases in January or February.

- Because the Detroit registry does not accept updates from hospital registries until SEER*DMS and SEER*Abs have been upgraded, the only cases the registry would receive would be those from the July or August with new primaries diagnosed in January or February.
- The Greater California registry does not accept files until they have been certified for the diagnosis. If the software vendor approves files before SEER*DMS is ready, that file is put on hold.
- The Seattle registry accepts any cases abstracted using any NAACCR version from the Department of Defense (DoD) and the Department of Veterans Affairs (VA). Currently, the VA is using v21 and will be upgrading to v22 in June 2023. The DoD's and VA's 2022 and 2023 cases are being accepted without the latest NAACCR updates.

Linda asked participants if they preferred to implement SEER*Abs or SEER*DMS first.

- The Alaska, Detroit, New York, and Seattle registry representatives preferred to implement SEER*DMS upgrades before SEER*Abs upgrades.
- The New Mexico registry typically implements the metafile later and would not be ready for a January submission. Linda explained that SEER*Abs and SEER*DMS can be updated simultaneously.
- The Illinois registry representative noted that METRIQ software will not be ready until May or June 2023. Updates to SEER*Abs are preferred to SEER*DMS to accommodate new data items that are implemented for that version. CoC reporting facilities prefer to abstract after the full treatment plan is made available, which is typically 4 to 6 months post diagnosis.

Marina asked Alaska, Detroit, New York, and Seattle registries about the feasibility of abstracting using SEER*Abs and then pausing until SEER*DMS is ready. This approach likely would not be feasible for the New York registry because the registry's system is structured to autoloading from SEER*Abs to SEER*DMS nightly. The Seattle registry representative added that this approach would create additional work because registry staff would need to track what cases in SEER*DMS still needed to be completed.

Linda noted that the core fields (e.g., histology, behavior) in the abstracts are unchanged from year to year, regarding the real-time reporting. She proposed implementing a process to load the NAACCR

updated version before it is fully supported in order to capture just the minimum elements; and reprocess those files when SEER*DMS is fully updated.

Linda asked whether registries could implement v23 in January. Jennifer Hafterson (Seattle registry) explained that if SEER*DMS implements v23 in January, registry staff would begin building the CTCs from path reports using this version, and cases failing edits would need to be revisited when metafiles are updated. Colleen Sherman (New York registry) highlighted the registry's rule to not accept abstracts from a given year until May when abstracts are complete.

Randi Rycroft (Idaho registry) observes that standards setters, including ACoS, are promoting real-time data collection. She noted the need to change thinking about cancer abstracting and to have software updates in place by January 1 of each year if the goal is real-time data collection. New systems, operations, and procedures for processing records will be necessary as well as reliable alert flags. Marina suggested discussing necessary changes to technology and procedures to facilitate real-time data collection at a future CCAB meeting. Serban agreed with this suggestion for the topic of an upcoming CCAB workshop and noted the need to clearly define real-time. From the NCDB's perspective, real-time refers to collection within days of diagnosis whereas for SEER this timeframe is approximately 2 months. NAACCR is having discussions to define the minimum dataset that should be submitted to satisfy the real-time criteria, which would not include treatment data. The CCAB also should discuss the minimum dataset for SEER real-time reporting.

Mona (Minnesota) mentioned that path-only edit sets have been discussed at NPCR. She proposed creating a field or record type for this type of record, with the understanding that an abstract with additional information will be received later. Mariana suggested making this proposal a topic of a future CCAB meeting.

Status Reports

Linda Coyle

Recap: 2022 SEER*DMS Workshops

Linda provided a recap of the 2022 workshops, highlighting the outcomes. The March 2022 Workshop titled "Preparing a CTC for Submission" allowed the Surveillance Research Program (SRP) staff to better understand registry operations related to data collection, editing, acquiring missing data items, and verification. SRP's Rocky Feuer and others involved in the Real-Time Reporting project participated in that workshop to better understand the feasibility of a 2-month submission. Since that workshop was held, several registries joined a pilot project to build CTCs from path reports. Discussion of this topic will continue at future workshops.

The August 2022 workshop titled "Follow-back Processes" focused on requirements gathering for follow-back and approaches for supporting follow-back activities. Since the 2018 in-person meetings, increased support for follow-back tasks has been on the SEER*DMS road map. However, other development efforts took precedence. During the August 2022 workshop, registries described mechanisms for secure transfer of data to physicians and hospitals, the types of data sent to hospital abstractors, and requests for missing data items, particularly those related to treatment.

The November 2022 workshop titled "Consolidation" focused on how consolidation works, the differences among registries, and approaches for improvements, including changes in the consolidation task, algorithms to reduce manual tasks, and dashboards.

Projects and Outcomes

In terms of real-time reporting, IMS worked with pilot registries to build CTCs from path reports. IMS will resume efforts related to this project in late April 2023, after NAACCR v23 is released. Regarding follow-back, requirements gathering will resume later in 2023. The new project will involve changes in SEER*DMS and in the new SEER*Transfer system. For support of consolidation, IMS released two new features: the Consolidation Task Dashboard and the ability to add and view “rejected” values in View Source Data. Next steps will include additional dashboard of changes to show auto-consolidations and differences between current values and auto-consolidation logic, new auto-consolidation rules, and conversion of the old rules to the new format.

SEER Updates

Linda Coyle and IMS, Marina Matatova

SEER*Transfer System

Marina explained that the SEER*Transfer system (former Data Receiver System) was first discussed in the fall of 2022. The goal is to support the transmission of cancer surveillance data to central cancer registries securely and efficiently.

Linda noted some imports that SEER*DMS accepts, including claims, NAACCR XML, pharmacy data, and death certificate data. SEER*Transfer will support existing imports of Unlimited, CVS, and Walgreen data. The previous set up has limitations in scalability, long-term maintenance, and functionality. SEER*Transfer will support data transfer and parsing mechanisms more efficiently and will reduce IMS efforts to onboard a new provider while reducing work for the data providers. Although it is a single application, SEER*Transfer will be deployed in multiple environments. National and multi-regional data will use a shared island, whereas registry-specific data will use the island dedicated to that registry. Currently, local cancer surveillance data are sent from the laboratories, hospitals, and vendors to the central registry system and then transferred from each registry's system into SEER*DMS. SEER*Transfer standardizes this process.

The project goals and objectives are to—

- Improve the management of current data streams.
- Reduce effort to onboard a new data stream.
- Reduce delays in transmission of cancer data to the registry.
- Provide a platform to support deployment of algorithms developed by NCI–U.S. Department of Energy initiatives, such as the Reportability API.

SEER*Transfer components include user authentication and account management; secure data transfer mechanisms; data validation, filtering (based on reportability algorithms), and parsing mechanisms; transfer of data to the registry systems using a REST (representational state transfer) API endpoint; and generation of reports, feedback, and follow-back information for the data providers and registry managers. Additionally, this system could support data abstraction and/or path screening activities at a later time and can be used to apply data retention and destruction policies.

SEER*Transfer was designed to meet security requirements. Organizations submitting data to registries will not have to log in to SEER*DMS, thus protecting the data and reducing liabilities to a tolerable level. This new system allows login access via the open internet and alleviates the need for VPN accounts, which reduces IMS technical support. SEER*Transfer will take over some of the SEER*DMS modules and offers another mechanism for communication between the registries and reporting facilities.

Phase 1 functionalities of SEER*Transfer include a web-based interface for manual data transfers, a web-based API for automatic data transfer, support for standard SEER*DMS imports, and the file validation parsing, transfer, reporting, tracking, and data destruction. Phase 2 functionalities will include integrating the Reportability API, matching data to the SEER*DMS database to determine if it should be sent, follow-back, and integrating standards setter edits.

The project was approved in December 2022. The goals are to implement Phase 1 by the end of 2023 or early 2024, continue requirements analysis for Phase 2 in 2023, define the technical specifications and a tentative timeline for deploying Phase 2 in 2023, and release some Phase 2 components in 2024 and others in 2025. Chuck May and his team are leading these efforts.

Marina explained that this project has multiple phases, and that the NCI anticipates that this separate transfer system will accomplish multiple program and registry objectives. SEER*Transfer will leverage several follow-back mechanisms that have been important to the functioning of registries over the past few years. Scott Deputy added that efforts IMS is aligning the development of SEER*Transfer with the testing, production, and deployment of SEER*DMS. SEER*Transfer will undergo the same annual, independent audits.

Discussion

The Greater California registry representative, Scott Riddell, wanted to be able to disable an account if activity has been minimal. Chuck clarified that accounts will be disabled for inactivity, which is also the current procedure in SEER*DMS.

Linda confirmed that SEER*Transfer will be able to send out reports in the later phase of the project.

Mariana asked whether registry managers would be able to review the facility-level accounts before becoming trusted users. Chuck noted that external users sign up for accounts through a registration process. The registry managers will receive a notification to either accept or reject that request. Registry managers can log in and review the users who have accounts on SEER*Transfer. Registry managers also will have the ability to manage users, including deactivating and reactivating accounts.

In response to a question from Scott Riddell on file segregation, Chuck explained that the SEER registries send an invitation to external users to register. Registry managers will have the ability to view all files (i.e., imports) across users/vendors, but vendors (standard users) will be restricted to the files they upload themselves. IMS can consider adding a feature that allows users to see all files from their facilities, not merely the files they uploaded.

This new system replaces logging into SEER*DMS and uploading a file (SEER*DMS import interface) or setting up a transfer mechanism to the Autoloader. SEER*Transfer does not need to replace other systems registries use to receive data, but it will replace the SEER*DMS import interface. SEER*Transfer will allow transfer of CVS and Walgreens data for follow-back. Registries can choose whether or not they want this and other optional new features. Registry representatives were encouraged to provide feedback on SEER*Transfer.

Overview of Consolidation Changes

IMS released a dashboard that shows counts for different categories of manual tasks. One of the uses for the dashboard is for the IMS team to evaluate how to effectively reduce the burden of manual tasks.

IMS also released a strike-through feature for rejected values. The auto-consolidation rule would not fail if a record was received with a discrepancy and the value had already been rejected. Feedback on this feature is being collected via Squish from registries that have opted to use this feature.

Social Security Administration (SSA) Linkages

Linda Coyle

SSA Epidemiologic Linkage (Vital Status)

IMS sent Batch 1 of the SSA linkage data was sent to seven registries (Detroit, Georgia, Idaho, Kentucky, Louisiana, New York, Utah) on March 21, 2023. Batch 2 was sent on April 3, 2023 for 10 registries (Alaska, Cherokee Nation, Connecticut, Greater Bay, Iowa, Illinois, Maine, New Jersey, New Mexico, Seattle). Batch 3 was scheduled to be sent to the Arkansas, Hawaii, and greater California registries by April 18. Data from the Los Angeles, Michigan, Missouri, Texas, and Wisconsin registries were in process.

SSA Birthplace Linkage

IMS will request birthplace linkage files after the vital status linkage is completed. Linda asked if any registries had experience with a Social Security Death Index (SSDI) linkage.

Discussion

The Minnesota registry representative agreed to investigate the ways his registry uses the SSDI linkage.

The Idaho registry performs the SSDI linkage once a year, prior to preparing files for the National Death Index.

The Louisiana registry used the SSDI linkage until limitations were placed on the amount of data being released. The registry has since switched to an SSA linkage, which provides more detailed information. The Georgia registry discontinued using SSDI linkage for the similar reason.

2023 Meeting Dates

Linda Coyle

CCAB meetings have been scheduled on:

- July 18, 2023
- September 12, 2023
- December 4, 2023

The discussion topics will be based on earlier requests, including real-time reporting, follow-back, consolidation, and SEER*Transfer.

Linda reminded the participants to request the ability to set the CCAB or workgroup flag in their SEER*DMS user accounts to join a workgroup or receive CCAB notifications. Non-SEER*DMS registries can email to Suzanne Adams (adamss@imsweb.com).