SEER*DMS Change Control Advisory Board (CCAB) Users Group
Webinar Summary
August 30, 2022
11:00 a.m. to 1:00 p.m. EDT

Representatives from the NCI, IMS, the Scientific Consulting Group, Inc. (SCG), and 23 cancer registries participated in the SEER*DMS Webinar on August 30, 2022. Participants included:

REGISTRIES:

Alaska
California Cancer Registry
Central California
Cherokee Nation
Connecticut
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, Sylkk Anash, Kathy Cronin, Eric "Rocky" Feuer, Johanna Goderre, Betsy Hsu, Marina Matatova, Serban Negoita, Radu Robotin, Valentina Petkov

IMS: Suzanne Adams, David Angelaszek, Linda Coyle, Chuck May, Jennifer Stevens, Nicki Schussler, David Annett

SCG: Kathy Brown-Huamani, rapporteur

Action Items

- The Greater California registry staff will share information on the procedures for using METRIQ® and/or C-NExT software packages to automatically process follow-up updates.
- IMS staff will contact the Seattle registry information technology (IT) staff to discuss the process used by the registry to extract facility-specific data from SEER*DMS to send to hospital registrars.
- Linda agreed to review the process for using NAACCR XML files to generate hospital-specific identifiers for matching records at a future meeting.

Recap: Registry Workshop Ideas from February 2022 Workshop

Linda reminded participants that the SEER*DMS Workshops are the CCAB User Group's approach to addressing topics in a more detailed manner. Each 2-hour webinar will address a single topic and will be held in lieu of in-person conferences hosted at the NCI prior to the COVID-19 pandemic. During the March 21, 2022, CCAB webinar, participants discussed processes to make data submissions Cancer/Tumor/Case (CTC) ready. During that webinar, participants requested meetings to discuss follow back, review different SEER*DMS modules, overhaul of the SEER*DMS Help system, and new data sources. This webinar focused on SEER*DMS follow back. The agenda included a summary of the results of a follow back survey of registries and their plans to support follow back and a summary of a discussion on suggested approaches for supporting follow-back processes. The next workshop on November 7, 2022, will focus on review of a single, consolidated SEER*DMS Module.

Marina noted that the webinar is being recorded and will be made available on the CCAB SEER*DMS portal after the meeting.

SEER*DMS Follow-Back Procedures and Processes

Introduction

The registries can submit a request for follow-back in the Patient Set Editor by selecting "Add Follow-Back" from the actions menu. Users can track follow-back requests in the SEER*DMS Follow-Back Manager. During the September 2018 face-to-face meeting, registry participants suggested adding more comprehensive follow-back tools to SEER*DMS. In 2020, IMS began gathering information on the follow-back tools needed by the registries via Squish #8254. IMS and the NCI reviewed and categorized feedback from registries and aligned their requirements with the project roadmap and priorities. The project was designed based on the size of SEER*DMS in 2020. Follow-back priorities have changed since 2020 and might need to be revisited for 2022–2023.

Linda summarized SEER*DMS achievements from 2020–2022, which included: (1) an update from Apache Struts 1 to Struts 2, (2) auto-consolidation improvements, (3) integration of the Extraction API, (4) usability testing and updates to the user interface based on usability study results, (5) new registry onboarding, (6) real time reporting capabilities, (7) security improvements, (8) enhancements to the dashboard, (9) support for new data sources, and (10) annual updates. For the registry onboarding, Texas went live with SEER*DMS in August 2022 and Illinois in June; Arkansas will go live in October 2022 and Michigan by 2023. IMS plans are to begin working with California in 2022 for a 2023 launch. Regarding real-time reporting, IMS updated the SEER*DMS workflow to build CTCs from pathology reports to reduce reporting delay. These updates and improvements will facilitate follow-back improvements.

Registry Survey

Linda reviewed definitions of common terms:

- Abstract Facility Lead (AFL) is metadata auto-created when a reportable pathology report, casefinding record, death certificate (DC), or other source record indicates that an abstract is expected from a facility. An open AFL indicates that an abstract is needed; the AFL is closed when an abstract is received or if the registry determines that it is no longer needed. Registry-defined rules can be implemented to auto-create and auto-close AFLs.

- AFL Manager is a SEER*DMS module designed to assist registry staff in managing AFLs generated by pathology reports and other records, with the exception of DCs. This module allows staff to view and open AFLs by year, facility, and other attributes and to generate reports.

- DC Manager has the same functionality as the AFL manager, but only displays AFLs derived from DCs. This module generates reports for death clearance.

- Follow-back Need (FBN) and FB Manager enable registry staff to submit questions or comments to abstractors. To date, two registries have used this tool to generate requests for follow back. The majority follow back requests still are created manually.

After a demonstration of the use of the SEER*DMS modules and managers just described, Linda summarized the responses to the survey questions.

Responses to the question "**How do you define follow back?"** fell into the following three categories:

- **Casefinding**, which involves a request for an abstract based on pathology, radiology, or DC data or other sources indicating that a patient has a history of cancer. Casefinding also can involve requests for hospital reports to determine completeness of reporting, such as the Idaho Year End Hospital Processing File.

- **Quality improvement activities**, which may include discrepancy reports, requests for missing data items, and feedback to the abstractors. For example, Bobby Matt recently performed an abstractor review at the Iowa registry.

- **Providing data to hospitals**, such as information about treatment that patients received at a different facility and/or follow up information.

Responses to the question "**What are your follow-back processes?"** included the following:

- **Casefinding processes**, including generating lists of SEER*DMS AFLs, automatically pulling AFLs into SEER*Abs, use third party software, commercial tools, and systems outside of SEER*DMS maintained by the registry for creating casefinding files.

- **Quality improvement processes** such as sending queries to physicians and hospitals via traditional methods (mail, fax, email) and using the FB Manager to create a list of data to review.

- **Providing data back to abstractors and hospitals** via a secure email system.

Discussion

Linda asked participants to share other follow-back processes being used.

The New York registry has been receiving more pathology reports directly from hospitals over the past few years, which has increased the need to retrieve additional information from the hospital when an abstract is not provided. The registry uses SQL queries to export follow-back reports from SEER*DMS and sends these reports to field representatives who communicate with the hospitals via secure external systems. For follow-back to physicians, especially dermatologists and urologists, the registry created a web-based application (App) for sharing case information and sending requests. Case forms also are sent

to physicians on occasion. In summary, the registry uses external processes, creates data query reports, and uses AFL Manager.

In response to questions from Marina about quality checking, the New York registry representative explained that dermatologists and many other physicians are with privately-owned health systems and report from outpatient settings that are not connected with a hospital. Data from physicians cannot be collected in the same manner as the Certified Tumor Registrar (CTR) would report information. Follow back to physicians primarily involves casefinding rather than quality checking. App is designed for North American Association of Central Cancer Registries (NAACCR) reporting variables and includes a wide range of selection lists. App is designed for treatment information obtained from a pathology report, but information obtained from paper reports can be entered to complete missing information. The registry's electronic reporting application has modules for melanomas, prostate cancers, leukemias, lymphomas, and hemopoietic cancers. The registry primarily provides laboratory information to facilities but is looking forward to learning more about the FB Manager.

The Iowa registry performs all data exchanges with hospitals and abstractors through a secure Managed File Transfer (MFT) site. Typically, AFLs are used in casefinding, and Excel spreadsheets are created and circulated back for responses. Follow back is performed to address quality control (QC) questions (or specific case questions). Mail merge is performed, and a memo is created, or information can remain in the Excel form. For follow back to physicians, no electronic system is currently available, and forms are used to collect the information. Responses to data requests can be created through data search SQL. Information is extracted and posted to the secure MFT site, which most facilities can access with a password.

The Connecticut registry posts follow-back lists to a secure FTP site and sends formatted, follow-back lists to hospitals. Most treatment information is requested by phone from hospital registrars.

The Georgia registry has a secure File Transfer Protocol (FTP) portal. The registry creates lists from the AFL Manager, including DC only lists, that are returned to the facilities and regional coordinators. Registry staff are interested in using the FB Manager to ask questions to facilities and communicate with physicians. When asked whether these would be *ad hoc* questions from CTRs as they review cases, the registry representative replied in the affirmative and explained that the manager usually communicates with facilities when they do not respond to queries about HL7 abstracts. Another Georgia registry representative noted that registry staff occasionally have questions about an abstract from a facility. The chain of communication is from the editor to the supervisor, then to the regional coordinator.

The Utah registry uses the FB Manager for questions about data from a facility, usually during visual editing at the central registry. The editor also has the option of sending an FBN. Typically, follow-back lists are generated monthly, reviewed, and sent via a secure Box folder.

The New Mexico registry has a follow-back letter within SEER*DMS that the editors can complete and send to an individual, facility, or a physician via postal mail. This delivery method may need to change because of the teleworking in place for hospital registry staff in Albuquerque. Information or updates provided back to hospitals are sent via an FTP.

The Seattle registry uses FBN to develop monthly lists for their own staff, who have access to hospital charts, to review reportability and address questions. FBNs are created when reporting back to the hospital registrar regarding the same "primary" issues. The registry generates Excel lists for its staff and registrars to access via a secure FTP. Registrars also are provided with a web-based application to review data and consolidate coded data items, but the application cannot work with text information. For

physicians, FBNs are generated, and responses are faxed back to the registry. Quarterly, the registry uses a process outside of SEER*DMS to query physicians on the race of their patients.

Participants discussed follow-up procedures for hospitals.

A Georgia registry representative observed that a few larger facilities request treatment information for patients every 4 to 6 weeks and those lists of 50 to 60 patients are sent via encrypted email. The registry is seeking a process that is more efficient than having to look up each patient to get this information. The Seattle registry provides consolidated treatment information, but no details on modality or treating hospital.

The Illinois registry noted that facility-specific information is considered confidential under state law and is not shared.

The Connecticut registry provides information to hospitals, but the process of using SQL queries is labor-intensive. A .NET application was created locally in a format that is acceptable for METRIQ® or CNExT, and cases are manually posted to the ST Web Client portal. This registry is interested in having a similar application in SEER*DMS.

The Greater California registry shares follow-up files that are requested and then sent to hospitals outside of SEER*DMS. Scott Riddle agreed to share information about approaches for automatically processing and sharing these files information for more efficient follow-up updates.

The Seattle registry uses a process that involves METRIQ®, CNExT, and Oncolog and was created in NAACCR13. This process likely is state-specific. The registry IT staff run a monthly program that extracts data from SEER*DMS and sends it to specific hospitals. Linda agreed to contact the IT staff for further details.

The Louisiana registry sends follow-up information in a manner similar to the Connecticut, Seattle, and Greater California registries and also performs linkages on data items the hospitals send. The registry IT staff uses Apache Groovy for this process to generate files in the proper format.

The Idaho registry recently received requests for follow-up information from hospitals on “date of last contact” and vital status and have solicited services from a vendor that uses the Rocky Mountain software. The NAACCR XML files necessary for this process that were generated by SEER*DMS did not include hospital-specific identifiers for matching records. Accession numbers could be used for these linkages. Linda agreed to check on the NAACCR XML file conversion issue, noting that the functionality to perform this task is supported in SEER*DMS. The Louisiana registry representative added that they have an import process that creates follow-up files that include name, date-of-birth, accession number, and other variables for linkage purposes.

Registries confirmed either having secure email or FTP to support follow-back and follow-up activities and highlighted further details and challenges.

The Greater California registry uses the GoAnywhere FTP, which is versatile, can handle multiple facilities under one account, and supports secure email transfers, all on one server with bidirectional communication capabilities.

The Iowa registry representative described their processes in detail regarding the FB Manger and noted that hard copies must be sent because facilities are not set up in SEER*DMS to ask certain questions. The registry sends this information via secure webpage or server. Secure folders for physicians are not created

because of regular logins necessary to maintain access. User accounts created in the FTP platform have worked well. The New Mexico registry has the same limitation as Iowa regarding communication with physicians.

The New York registry representative asked whether IMS could consider creating and managing a central physician portal.

Marina proposed establishing a working group to help IMS/NCI develop the functionalities discussed in today's workshop.

2022–2023 Development Projects Related to Follow Back

Linda reminded the CCAB of the original 2000–2005 follow-back and casefinding goals. The primary objective of SEER*DMS was to collect metadata required to support external processes being used in registries. The 2022 objectives are to reduce the manual burden by streamlining processes, ensure quality across processes, and make the system available to more registries.

NCI has plans to review and enhance SEER*DMS functionality across registries and design and develop an ancillary system that would interface with facilities that provide data to registries. The primary objective of Phase 1 of this task is to design very secure connections to registry-facility data transfer systems and facilitate communication between the central registry and facilities. An FTP for SEER*DMS would be housed in individual registries but also accept national data. Additionally, Phase 1 could provide feedback on completeness of data submissions to inform follow-back processes.

Marina called emphasized that follow-back is a priority. NCI wants to analyze registry needs to determine what can be improved and what needs to be developed to reduce the overall burden.

Next Steps

The November 7, 2022, workshop will focus on auto-consolidation modules and manual consolidation:

- Suzanne will generate an invite to the CCAB members and extend the invitation to other interested registry staff.
- IMS and NCI will review the discussion notes and post final minutes to the SEER*DMS portal. Participants can contact Linda or Mariana with comments on the minutes.