SEER*DMS Change Control Advisory Board (CCAB) Users Group
Teleconference
May 19, 2025
12:00 p.m. to 1:30 p.m. EDT

Representatives from NCI, IMS, the Scientific Consulting Group, Inc. (SCG), and 27 cancer registries participated in the SEER*DMS CCAB Users Group conference call on May 19, 2025. Participants included:

REGISTRIES:

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

NCI: Marina Matatova, Steve Friedman, Valentina Petkov, Sylkk Ansah

IMS: Suzanne Adams, Linda Coyle, Chuck May, Ginger Carter, Nikki Schussler, Jennifer Stevens, James King

SCG: Lily Neff, rapporteur

Action Items

- IMS and NCI agreed to review the registry-requested features (e.g., email notification when downloads are not completed, registry users be copied on emails, ability to use a registry naming system, AFL processing status) to identify additional features that can be implemented in the upcoming year.
- IMS will complete a security analysis to determine if exported data can be uploaded to SEER*DMS and shared through SEER*Transfer.
- Registries will reach out to IMS and NCI with any additional feedback.
- IMS and NCI plan to launch the FB Data Package feature by early July.

Overview of Meeting **Linda Coyle, Marina Matatova**

During the past several years, multiple follow-back categories—including case finding, data updates, quality improvement, registry data exchange, case updates, clinical documents, disease index, and case finding audits—have been discussed in meetings among registries, IMS, and NCI. Case finding is a request for abstracts based on a path report and death certificate data on SEER*DMS. Data updates are files or reports in either a registry-specific or vendor-specific layout (e.g., EXT-31 layout in CNeXT, ERS, and IMPAQ-METRIQ file formats) that can be sent as follow-up information to the facility. Quality improvement focuses on requests made by ODS staff for standard reports or listings. In SEER*DMS, when an ODS staff is reviewing a case, a "Follow-back Need" can be created which places the case back into a queue for facility review.

The primary goal of this meeting was to discuss the new follow-back category features in SEER*DMS and SEER*Transfer that will be released in summer 2025; these are case finding, data updates, and quality improvement. Screenshots and a live demonstration using synthetic data were provided.

Follow-back (FB) Data Packages **Linda Coyle, James King, Chuck May, Marina Matatova**

Workflows that benefit early incidence efforts are being prioritized. New functionalities will be implemented that support the creation, management, and transfer of data packages from registries to reporting facilities. SEER*DMS will include the creation and approval of the FB Data Package. Once approved, authorized facility staff will be able to access and download the data package in SEER*Transfer.

Three new system permissions will be implemented to control the creation, approval, and downloads of FB Data Packages. To use SEER*Transfer, facilities will need to sign an End User License Agreement with IMS. With the release of these new tools, SEER*Transfer will have two primary functions: (1) facilities can send data (e.g., path reports, abstracts) to registries, and (2) facilities can receive FB Data Packages from registries.

Linda presented a workflow schematic and screenshots of the systems to create, approve, and send FB Data Packages. A registry user would either run a report or export a filtered list (e.g., AFLs, FBNs). When the user clicks "Send to Facility," the FB Data Package is created. The "Export to Facility" option will create the FB Data Package from a filtered list in the AFL, DC, or FBN manager. A manager page refers to the different modules (e.g., AFL, worklist). The "Send to Facility" and "Export to Facility" options will only be visible to users with permission to create FB Data Packages. Linda emphasized that the data must be appropriate for the selected facility, and creating the FB Data Package is only available after filtering and specifying a facility. This prevents data leaks to the incorrect facility. In the "Create Follow-back Package" window, the user will be prompted to review the facility information, select a transfer method (i.e., SEER*Transfer or manual submission), and choose a recipient.

Approved registry users will receive an email notification that a FB Data Package has been created and is awaiting approval. An approved registry user would then access and review the created package; the package's files can be downloaded as part of the review process. The Title's default is the report title, but the "Title" and "Description" fields can be altered for specificity and clarity. The Source field provides the report output and parameters used to create the report. Parameters include vendor profile, start DX year, end DX year, vital status, reporting facilities, compression type, and whether restricted release CTCs were excluded. The "Facility", "Source", "Created", and "Created By" fields are read only. The permitted user can accept or reject the package; rejection of the package will delete the file. When the package is rejected, there is an option for the user to enter a reason. If the package is accepted, the file is retained, and it becomes accessible in SEER*Transfer.

Several SEER*Transfer facility users can be selected to receive the FB Data Package. The designated facility user(s) would receive an email notification with a link to access the FB Data Package. The email notification currently provides the title of the package; IMS is determining what additional fields will be displayed in the email. The user would then log in to SEER*Transfer to download the package. Chuck emphasized that SEER*Transfer does not store any data in its database because it is outside the firewall. Although the data is downloaded through SEER*Transfer, it comes from SEER*DMS. On the Follow-back manager in SEER*DMS, under the History tab, the registry will be able to view whether the package has been downloaded, the number of downloads, and the user(s) who downloaded the package. The creation and approval of the package can be tracked on the History tab as well. The Details tab allows users to download individual ID files or the FB Data Package altogether.

A development version with synthetic data was demonstrated. IMS is continuing to develop this interface; the core functionality of sharing data externally from SEER*DMS is the priority. A two-step confirmation and approval process will be used to ensure data is shared with the correct facility.

Discussion

Marina Matatova requested feedback from the registries regarding these new functionalities.

Valerie Yoder from the Utah registry questioned whether a data package originating from an AFL or DC is only available based on the source facility or can it be from the chart review facility. IMS will allow data packages to be created from the chart review facility as well.

Registries agreed that a single recipient should be selected for each FB Data Package. If two users can download the package, one would be selected as primary while the other would be a backup. Both users must have the correct facility credentials and permissions to access the data.

Randi Rycroft queried how a secondary facility user would know that a FB Data Package is available to download if the primary user is out on leave. Scott Riddle from the Greater California registry noted that their registry uses a manual request. When a package is ready for download, they reply to the individual requesting the package. If other individuals are copied on the email, they "Reply all" to ensure everyone is notified. Andrea Sipin from the Los Angeles registry commented that their registry uses a secure portal to communicate and exchange files with hospitals. Registry staff that complete follow backs know the main and alternative contacts to message about packages, so this is not a concern.

Erin Hammell from the Minnesota registry asked whether an alert is received when the package is not downloaded within a certain timeframe. Linda noted that an alert is provided for file exchanges, and this feature would be considered for FB Data Packages.

Valerie asked if one user can be registered to download data packages for multiple facilities, which is required if a hospital registry or contracting agency supports multiple hospitals. This feature will be supported.

Mona Highsmith from the Minnesota registry asked if all data fields would be exported from the file. She requested the ability to choose data fields to export. There may be discrepancies in data fields between facilities (e.g., medical record identifiers for a path lab and ordering facility). Internal commentary and communications with facilities could be included in separate comment fields. Linda responded that it is dependent on the extract file format, which varies by vendor and registry. When creating an exported list, not all columns from the manager (e.g., AFL manager) need to be exported. A later functionality could incorporate data field selection.

Jason Brubaker and Jennifer Hafterson recommended that the user who approves the package should be copied on the email that goes to the designated facility user. This provides easier monitoring of potential out-of-office staff and follow-ups for package downloads.

Scott Riddle requested the ability to change the file name because their registry has a naming convention that staff are familiar with. Currently, additional steps are needed to rename files, so a more streamlined approach would be beneficial. The option to allow a user to align files with a registry naming system will be reviewed. If this feature is implemented, it will be important to ensure the timestamp remains when files are created.

There will be an option to include metadata files in the .zip file, but this will not be the default.

Andrea Sipin and Scott Riddle recommended an expiration option in the approval process of the FB Data Package. Chuck explained that the expired FB Data packages will no longer be available on SEER*Transfer, but all the original data exists on SEER*DMS. An approved user can reactivate an expired data package, if needed.

After discussion, it was concluded that a package that is rejected will not have the original data file and history retained. Registries agreed that the rejected packages are most likely parameter mistakes that don't need to be retained. A record will be kept that a package was created and rejected for audit logs and administrative review. The reason for rejection should be recorded in the log as well.

Erin Hammell questioned if the processing status of AFLs automatically changes when the package is built. IMS will discuss incorporating this option to change the processing status; the feature would be available after the package has been approved.

Registries export data in an Excel or CVS file and complete modifications. Several registries requested using SEER*Transfer to exchange modified data files created and managed by the registry. The modified files could be uploaded to SEER*DMS, and the FB Data Package manager could be used to track these. A use case will be added for this request to the list of FB categories. A concern that needs to be addressed is how to guarantee that data files are shared with the correct facilities to prevent data leakages. Safety mechanisms (e.g., a pop-up screen to review the data file content, confirmation of recipient facility) will need to be implemented for data being uploaded and shared.

The first deployment of this feature will focus on extracts that are currently on SEER*DMS. IMS and NCI will complete a security analysis and review these requests to prioritize additional features in the upcoming year.

Next Steps **CCAB**

The next regular CCAB meeting will be announced shortly.