

REGISTRAR PIP

November 2024 Registrar PIP New Challenges for an Old Requirement: Follow-Up



Background

We have received a number of comments and questions from registrars in our region concerned about not meeting the Commission on Cancer (CoC)'s **Standard 6.5** that addresses **Follow-Up of Patients**. Admittedly, there have been procedural and data access changes at the central registry which creates new challenges for all of us to meet the various standard setter expectations for follow-up each month. Before getting into the specifics, we're going on a quick trip down memory lane.

From the mid 1970's to the late 1990's, CSS and hospital registry staff coordinated efforts to perform **active** follow-up for patients in our respective registry databases. Active follow-up in our region required CSS to generate the monthly physician letters needed by the hospital registrars who distributed them to their reporting physicians. If the physician did not respond to the letter, the hospital registrar often opted to contact the patient or a family member for the needed follow-up information. CSS supplemented the active follow-up effort by linking its database to the Washington State death records to obtain date and cause of death information. When our databases were much smaller and patients didn't change their place of residence so often, these follow-up procedures were usually enough for us to achieve the goals established by our standard setters.

Over the years as the number of patients in the central and hospital databases grew and the population became more mobile, it was necessary to expand our passive follow-up efforts. **Passive** follow-up involves updating information via file linkages which includes patient data submitted by reporting facilities as well as nonmedical data provided by other organizations. It became even more important to find additional passive sources of follow-up after CSS stopped producing centralized follow-up letters in 2010, which was the result of moving from our inhouse developed database system to SEER*DMS.

Data linkages between various organizations and a central registry have been the backbone of passive follow-up efforts for decades. The more recorded interactions a patient (or their specimen) has with a state/federal agency or a medically-related facility (e.g., hospital, doctor's office or laboratory) that CSS has access to, the greater the chance some follow-up information can be obtained when we link the registry with those outside files. Critical to this effort is that these outside files have good patient demographic information because it is necessary to link the files successfully. Obviously, we need the date of the patient interaction(s) with the outside organization or there is no point in doing a linkage. That date of interaction is compared to the date of last contact in the registry to determine whether we can update the database.

CSS provides registrars a manual (i.e., Excel format) and an electronic (i.e., shared follow-up file) report option to use to update their hospital database with new follow-up dates made to the central registry database during the prior month. The shared follow-up files have formats specific to each vendor (e.g., C/NET Solutions, Onco Inc, Elekta).

Introduction

Next, we need to remind ourselves (or learn) the differences in the Surveillance, Epidemiology, and End Results (SEER) Program's expectations for central registries and the Commission on Cancer's (CoC) expectations for their reporting hospitals. The SEER Program has established four follow-up goals for its central registries based on the patient age at diagnosis and tumor behavior.

- Age < 20, invasive tumors (90%)
- Age 20-64, invasive tumors (90%)
- Age 65+, invasive tumors (95%)
- In-situ, all ages (90%)



The Commission on Cancer (CoC) has two follow-up goals for its reporting hospitals that considers the length of time between the program's first accreditation date and the most current year of completed cases.

- Most current year of completed cases through 15 years before or the program's first accreditation date, whichever is shorter (80%)
- Most current year of completed cases through 5 years before or the program's first accreditation date, whichever is shorter (90%)

One might think that when CSS successfully reaches the four SEER follow-up goals, which it has routinely and successfully done in the past, hospitals would automatically meet the CoC Standard 6.5. After all, it appears the SEER Program's follow-up expectations are higher, right? The issue is that one cannot only consider the follow-up percentage goals between the two programs. Let's just say, it appears **timing is everything!**

CoC defines "delinquent" or "lost to follow-up" as when a living patient's known date of last contact is **older than 15 months from the current calendar month**. For example, a patient with a date of last contact of 01/01/22 was considered delinquent by 04/01/23 per the CoC standard.

SEER's definition is different. Delinquency is measured by the failure to bring the patient's date of last contact into the **specified calendar year** for a file submission deadline. By this measure, a living patient (diagnosed 1974 through 2022) with a known date of last contact of at least 01/01/22 is not yet considered delinquent for our November 2024 file submission. However, beginning in December 2024, that patient is considered delinquent and we must bring the patient's date of last contact into 2023, whether 01/01/2023 or 12/31/2023, or into 2024 to be considered current.

The take away message is that **date of last contact month** impacts the CoC standard. This is a more difficult standard to meet. For the history of CSS, we have aimed for the 15-month measure, previously by using our centralized active follow-up method, and currently by using electronic sources because we do know we will meet the SEER benchmarks if the hospitals are meeting the CoC benchmarks.

The SEER and CoC difference in defining whether a case is lost to follow-up is the reason every electronic source CSS previously used to update follow-up was considered essential. It took a combination of all the sources to help both the central registry and the hospitals continuously achieve follow-up goals every month. CSS has been committed to updating follow-up from passive sources and providing reports to registrars because we recognize it has become more difficult for hospital registrars to keep up with their growing volume of follow-up. Even though some of the sources only moved the date of last contact by a couple of months, we've learned those few months mattered, especially around survey time. With the loss or the reduced effectiveness of some of the follow-up sources, reaching the CoC standard setter follow-up goals monthly is more difficult. However, there are certain points throughout the year when all those goals are routinely met in the CSS database. As you might guess, it occurs after certain linkages have been completed.

The "Have Nots"

The Voter Registration and the Department of Licensing linkages started in the early 1990's. During the past year, state mandated changes and a new data usage requirement resulted in these linkages being either less effective and/or unable to continue to be performed.

- **Voter Registration file:** Initially, we had to perform multiple linkages to check for potential updates because we were only provided data at the county level for some counties. The linkage was streamlined when a single statewide file became available around 2000. Unfortunately, starting in November 2023, the decision by Washington State Secretary of State to **suppress the month and day of birth** for voters negatively impacted the value of the Voter Registration file for follow-up linkage. Remember, as already indicated above, good demographics are needed to perform any

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linkage. We no longer have the complete date of birth, which is considered a critical data item for linkage. Given the number of elections that occur every year, this is a big loss involving 2 to 4 million records that historically had potential to be linked to the CSS database.

- **Department of Motor Vehicle file:** This file was more helpful initially to confirm residency at diagnosis and to obtain follow-up dates. However, it became less effective over time as the Department of Licensing extended the length of time between **drivers' license renewal** moved from every 4 years to **every 8 years**. If people are interacting with the Department of Motor Vehicles less frequently, the value of the file for follow-up purposes is reduced over time. Added to that, the Department of Licensing wanted CSS to carry a contractual amount of cyber insurance, which was cost prohibitive given the tens of millions of records involved.

The advantage of both these sources was that, even though they typically improved the date of last contact by only a matter of months, these sources in combination with all the other sources routinely used, was enough for hospitals to achieve their follow-up goals each month. In particular, the Voter Registration file historically moved many patients forward to November, enabling most hospitals to always be within the 15-month CoC standard.

The "Haves"

- **Monthly** - These files used for casefinding are also used to update follow-up. Once found and entered into the registry, many cancer patients reappear at the same facility or another one which provides an opportunity to move the date of last contact in the CSS database.
 - ➔ **Disease index files**
 - ➔ **E-Path files**
- **Quarterly** - Another multi-purpose file is the State-wide death file. CSS used to be sent this file once a year; but it is now provided quarterly. The death files are used to update the date of death and other death information (e.g., cause of death, death certificate number). They are also used to identify new reportable patients not found on the monthly casefinding sources mentioned above.
- **Annually** - SEER signed agreements with the National Center of Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC) and the Social Security Administration (SSA) to pay for one linkage per agency per year for CSS. We initially included all the patients in our database who were lost to follow-up in the linkage request. Unfortunately, one of the SEER cost cutting measures made years ago was to restrict who we could include for the linkage. Only patients who were residents of the SEER counties at the time of diagnosis are allowed to be included in the linkage. Non-Washington state and non-SEER Washington residents are no longer allowed to be included in this linkage. This change in SEER policy negatively impacted the large referral hospitals who see a significant number of patients from outside the state, and patients from eastern and southwestern Washington state.
 - ➔ **NCHS' National Death Index (NDI+):** The primary purpose of this linkage is finding death information for patients who have moved and lived out of state at the time of their death. This linkage is typically requested every summer.
 - ➔ **Social Security Administration (SSA):** This is the most effective follow-up linkage performed. Table 1 demonstrates the impact of this linkage in helping us reach our goals.

Table I
Pre and Post Social Security Administration Linage Follow-Up Percentages
1995-2003 Diagnoses Cases as of August 15, 2024 ¹

Follow-up Group			Before SSA Linkage				After SSA Linkage				
SEER Follow-up Groups	Dx Years	Year Followed into	Numerator	Denominator	Goal	Result	Numerator	Denominator	Goal	Result	Additional # Needed to Reach Goal
age <20, invasive	1995-2021	2022	5,238	5,728	90%	91.45	5,247	5,728	90%	91.60	
age 20-64, invasive	1995-2021	2022	235,421	242,160	90%	97.22	235,864	242,160	90%	97.40	
age 65+, invasive	1995-2021	2022	249,363	251,431	95%	99.18	249,427	251,431	95%	99.20	
In-situ, all ages	1995-2021	2022	46,172	48,381	90%	95.43	46,373	48,381	90%	95.85	
SEER Follow-up Groups	Dx Years	Year Followed into	Numerator	Denominator	Goal	Result	Numerator	Denominator	Goal	Result	Additional # Needed to Reach Goal
age <20, invasive	1995-2022	2023	4,889	5,952	90%	82.14	4,955	5,952	90%	83.25	402
age 20-64, invasive	1995-2022	2023	239,113	252,064	90%	94.86	240,480	252,064	90%	95.40	
age 65+, invasive	1995-2022	2023	259,992	264,043	95%	98.47	260,298	264,043	95%	98.58	
In-situ, all ages	1995-2022	2023	46,691	51,498	90%	90.67	47,298	51,498	90%	91.85	
SEER Follow-up Groups	Dx Years ¹	Year Followed into	Numerator	Denominator	Goal	Result	Numerator	Denominator	Goal	Result	Additional # Needed to Reach Goal
age <20, invasive	1995-2023	2024	2,412	6,138	90%	39.30	4,282	6,138	90%	69.77	1,242
age 20-64, invasive	1995-2023	2024	149,876	261,626	90%	57.29	241,485	261,626	90%	92.30	
age 65+, invasive	1995-2023	2024	226,744	275,797	95%	82.21	269,079	275,797	95%	97.56	
In-situ, all ages	1995-2023	2024	21,524	54,340	90%	39.61	47,657	54,340	90%	87.70	1,249

Note 1: This table shows the follow-up benchmark standings for the upcoming three SEER submissions (November 2024, 2025, and 2026).

Note 2: Casefinding for 2023 is not yet complete due to e-path from two laboratories being delinquent, CY 2023 disease index finishing up and 2023 death clearance about to start.

In general, as Table 1 shows, CSS is in exceptionally good shape for the upcoming November 2024 submission. Typically at this point, we are delinquent in the age < 20 category but we had a new source, Lexis Nexis, and were able to bring those patients into 2022 before the SSA submission.

We are actually looking for this year's 2024 SSA results to enable us to meet the benchmarks for the November 2025 submission except for the age < 20 category and to position us well for November 2026. The burden of obtaining follow-up is so great on our volume that we want to position ourselves well as early as possible.

Looking at the last section of Table 1 for the November 2026 submission, in spite of the fact that the number of reportable cases will change by an additional 7%-10% after all the 2023 cases have been reported, historical trends have always proven that the SSA linkage moves the two largest of the four SEER follow-up groups into compliance. The current status indicates results are on track to do so again for the November 2026 SEER submission:

- **91,595 patients** were successfully followed in the **age 20-64, invasive group** moving the follow-up rate from **57.29%** to **92.30%**.
- **42,335 patients** were successfully followed in the **age 65+, invasive group** moving the follow-up rate from **82.21%** to **97.56%**.

The follow-up rates significantly improved for the other two SEER groups as well.

- **1,870 patients** were successfully followed in the **age <20, invasive group** moving the follow-up rate from **39.30%** to **69.77%**, leaving 1,242 more to find by November 2026.

- **26,132 patients** were successfully followed in the **in-situ, all ages group** which moved the follow-up rate from **39.61%** to **87.70%**. leaving 1,249 more to find by November 2026.

Historical trends indicate the regular monthly and quarterly follow-up files, which we will continue to process between November 2024 through November 2026, will likely be all that is necessary to push the **in-situ, all ages group** over the 90% goal. However, we typically must perform manual look-up procedures to find the remaining children lost to follow-up during the summer before the November SEER annual file submission because those regular files usually identify only about two-thirds of the children with age <20 we need to reach the 90% goal.

Historically, the DOL file had helped tremendously with the age < 20 group as these patients began to celebrate birthdays around the time they qualified to get a driver's permit. We will observe the impact of this lost source but it may prove to be countered by the use of Lexus Nexis, which will help us locate the "lost" patients who were children at diagnosis and are now adults. This is a tedious manual lookup, limited by contract to two CSS staff members, for as long as the SEER program pays an expensive monthly fee for the authorized two users.

Why Not More SSA Linkages?

The SSA linkage is an inter-agency linkage between the National Cancer Institute's SEER Program and SSA. We submit a "finders file" in early March. Our request is added to an SSA's linkage request wait list. We have no control over when the linkage will be performed or when we will receive the linkage results. It can take months to receive a response. Once we receive the results, they are uploaded into SEER*DMS. When hospital registrars receive their next follow-up report from CSS and upload the results into their databases, the hospitals' successful follow-up rate will probably be at one of the highest points seen throughout the year. The only month where hospitals will likely have a higher successful follow-up percentage is November, the month CSS typically reaches its highest rate of successful follow-up.

With results like that, why not request this linkage be done more than once a year? While the SSA linkage is highly effective, it is also expensive. There is a **per person charge** to have the linkage performed. In other words, the more patients we submit, the more we are charged to have this linkage done. SEER's expectation is that its registries actively pursue less expensive local sources of follow-up for linkage to reduce the number of patients we need to submit for the SSA linkage. We at CSS can relate to the hospital registrars request that this linkage be done more often given its effectiveness. We have made that same request in the past. Unfortunately, from a cost-benefit perspective, SEER has determined performing a linkage once a year is all that is necessary for its central registries to be able to reach the follow-up goals defined for its program by the annual November file submission.

Tweaking the Voter Registration Matching Algorithm –

Given this is a presidential election year and turnout is expected to be high, we want to be able to take advantage of the Voter Registration file to help us improve follow-up rates. However, we cannot use the matching algorithm used in the past now that birth month and day were suppressed beginning with the November 2023 Voter Registration file. We are evaluating how to tweak the matching algorithm to accurately identify patients who voted recently and who are also in the registry database. We waited until the 2024 SSA file linkage was completed to reduce the number of patients involved in a series of tests we will need to run to evaluate the effectiveness of the new matching algorithm. We will request the November 2024 Voter Registration file in December.

From our November 2023 linkage, we know we will be matching fewer women (due to name changes). There will be no review of any possible matches involving patients with even slight differences in the spelling of first or last name. Without a full birthdate, possible matches in this situation are too difficult to process with confidence. Instead, we will need to evaluate the number of matches with living patients for a given name, sex, and year of birth that occur at the city and county level. We are looking for single matches. With these tweaks to the matching algorithm, we anticipate we will still move a large number of patients from the 3/1/2024 SSA date to 11/5/2024, helping hospitals meet the CoC 15-month standard.

Conclusion

There are multiple reasons we perform follow-up procedures. The primary purpose is to evaluate cancer care outcomes. To this end, successful **active** follow-up procedures help us learn information regarding the patient medical status, whether they had any additional treatment after leaving the facility, and whether they were diagnosed with another cancer. Depending on what is available in linkage files, some of those same things can also apply to **passive** follow-up procedures. However, I think if we are being honest with ourselves, we have to admit that the “biggies,” as it relates to any passive follow-up linkage procedures, are moving lots of **date of last contact** dates forward and learning whether or not our patients are still alive as of that new date. The reason? Our standard setters have established follow-up goals for central and hospital registries that are tied to those dates. Those goals also turn out to be one measure by which our registry performance is evaluated.

Registrars have asked why they are now seeing such variability throughout the year in their monthly successful follow-up rates. It's clear there has been an impact on hospital registrars' ability to maintain a consistent monthly successful follow-up rate since CSS lost access to some of the electronic sources we previously used in passive linkage procedures. This article is our attempt to explain what happened, why it happened, and the ramifications to us all because it happened. We will continue to pursue other electronic sources to help improve the consistency of the monthly reporting. If anyone has a suggestion of an electronic source we could pursue, please let us know about it. Until then, registrars may need to expand their active follow-up procedures to supplement the passive linkages CSS performs in order to reach the expected successful follow-up goals every month.