

REGISTRAR PIP

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Introduction:

This PIP issue consists of a report we sent to SEER as SEER and other standard setters meet (virtually, with appropriate social distancing) in May to discuss how to capture COVID-19 information. Our region, as the first hit, has a unique perspective.

We know that capturing the COVID information is also important to your hospital administration. Please send to mpotts@fredhutch.org any information on COVID data collection that you would like her to convey to the standard setters.

We wish all of you well during this very difficult time. We appreciate the work that you have continued to do and we understand that you are facing challenges at home and at work. Take care and let's all keep washing our hands.

COVID-19 Impact on Cancer Diagnosis and Treatment Seattle-Puget Sound SEER Registry's Early Experience May 1, 2020 Mary Potts, RHIA, CPA, CTR

King County, the most populous county in Washington State and the 13th-most populous county in the country, was the first hot spot for COVID-19 in the United States. The first death in the State due to COVID-19 was on 2/26/20. Governor Jay Inslee signed the "Stay Home, Stay Healthy" order for all Washingtonians on 3/23/20. Grocery stores, doctor's offices and other essential businesses were to remain open. Inslee's emergency order prohibited all social, spiritual and recreational gatherings, including weddings and funerals. State parks, wildlife areas, water access areas and hiking trails closed 3/24/20.

What impact did we observe the COVID-19 pandemic have on the diagnosis and treatment of cancer patients in our region? To address the first part of that question related to the diagnosis of cancer, it might prove helpful to provide a little background on the Puget Sound SEER registry's casefinding auditing procedures because they are likely different from those performed by other central registries. The advantage of these procedures is that it allowed us to immediately identify the delay in diagnosis coincided with the date of the Governor's "Stay Home, Stay Healthy" order.

In the Puget Sound SEER registry we do not perform casefinding audits a year or more after diagnosis following the file submissions of abstracts from our reporting facilities, which is typically the timing of performing this activity for central registries. The timing of that type of audit is to identify cases the hospital registrar was supposed to submit to the central registry but did not. Instead, we perform casefinding audits before we receive any abstracts from the reporting facilities. Essentially, we inform the hospital registrars of the case abstracts we expect them to report to the central registry based on our independent review of casefinding sources available to us.

We identify the number of incident cases from pathology sources within 24 hours of receiving the daily laboratory pathology files. Casefinding involving monthly disease index files occurs one to three months after pathology casefinding. The reason for the delay in disease index casefinding is associated with the length of time it generally takes the hospital medical records staff to complete their required coding of all diagnoses and procedures associated with every patient encounter at their facility for an entire month and their ability to generate and transfer the appropriate subset of those records to the central registry.

[Process Improvement Pointers](#) • [Feedback/Questions to Registrar-PIP@FredHutch.org](mailto:Registrar-PIP@FredHutch.org)

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As part of our casefinding procedures, we routinely track and compare the current (2020) year-to-date's observed/expected numbers weekly. Table 1 indicates that the average number of cases identified in the six-week period following the announcement of the 3/23/20 "Stay Home, Stay Healthy" order represents approximately 70% of the number of cases identified in the six-week period prior to the order.

Table 1
Weekly Volume of 2019-2020 Diagnosed Incidence Cases
Identified From 2/17/20 through 4/24/20

Week Interval	2019	2020	Total
02-10-2020 to 02-14-2020	145	537	682
02-17-2020 to 02-21-2020	82	524	606
02-24-2020 to 02-28-2020	140	538	678
03-02-2020 to 03-06-2020	95	579	674
03-09-2020 to 03-13-2020	62	604	666
03-16-2020 to 03-20-2020	75	610	685
03-23-2020 to 03-27-2020	74	465	539
03-30-2020 to 04-03-2020	59	415	474
04-06-2020 to 04-10-2020	52	377	429
04-13-2020 to 04-17-2020	53	335	388
04-20-2020 to 04-24-2020	58	450	508
04-27-2020 to 05-01-2020	70	370	440
Total	965	5,804	6,769

665

Weekly

Average

463

Weekly

Average

We are quick to recognize the delay described for our region will probably vary by region and by type and number of facilities (e.g., large teaching facilities, moderate sized, and small community hospitals) serving the population in the different geographic areas.

Reporting Delay

We started reviewing the EMRs during the week of March 30 to April 3 to determine if we could identify COVID-19 related reasons for the sudden underreporting. The following reasons were documented as some of the reasons for diagnosis delay:

- Patients expressed concerns about being exposed to the virus
- COVID-19 testing was required prior to being seen in some of the clinics for oncology consultations
- Telemedicine options replacing outpatient visits for consultations
- An inability to be referred in a timely manner to one of the major oncology referral centers because these centers also happened to be some of the primary facilities handling a larger number of COVID-19 patients

As we continue to do the type of tracking shown in Table 1, we will be able to identify when and if we will resume the pre-COVID-19 level of cancer reporting. We will also be able to identify the potential impact on patients' access to timely diagnostic and treatment services as a result of the gradual lifting of the "Stay Home, Stay Healthy" order in Washington State.

COVID-19 Coding in ICD-10

Our central registry team has remote access to the electronic medical record systems of most hospitals in our region. We decided to check how COVID-19 testing was initially being captured and coded by medical record departments in our area to consider how we might capture test results in the central registry files via linkage. We have not seen widespread adoption of the World Health Organization (WHO) codes yet - even at our largest teaching facilities. Initially, COVID-19 has been captured using the following codes and definitions which will need to be added to SEER casefinding list:

- **Z20.9** Contact with and (suspected) exposure to unspecified communicable disease
- **Z11.59** Encounter for screening for other viral diseases

Randi Rycroft, Manager of Idaho SEER registry, suggested the following might also identify cases of interest:

- **Z75.3** Unavailability and inaccessibility of health-care facilities

The following are the new ICD-10 COVID-19 related codes according to the WHO website (<https://www.who.int/classifications/icd/covid19/en/>):

- **U07.1** "COVID-19, virus identified" is assigned to a disease diagnosis of COVID-19 confirmed by laboratory testing.
- **U07.2** "COVID-19, virus not identified" is assigned to a clinical or epidemiological diagnosis of COVID-19 where laboratory confirmation is inconclusive or not available.

Both U07.1 and U07.2 may be used for mortality coding as cause of death. (NOTE: The Washington State first quarter death certificate file contained records with U071.1 codes.)

We also checked the Centers for Disease Control and Prevention (CDC) website (<https://www.cdc.gov/nchs/data/icd/COVID-19-guidelines-final.pdf>) for guidelines related to ICD-10 coding associated with COVID-19. The document titled, "**ICD-10-CM Official Coding and Reporting Guidelines**" is effective from April 1, 2020 through September 30, 2020 and covers such topics and coding issues related to:

- Definition for a "confirmed" case (Get ready for another flavor of ambiguous terminology!)
- Acute respiratory illness due to COVID-19
- Exposure to COVID-19 (possible exposure r/o after evaluation (**Z03.818**) vs actual exposure to someone but did not test positive themselves (**Z20.828**))
- Screening for asymptomatic individuals for COVID (no exposure and tests are unknown or negative (**Z11.59**))

We don't know how much variability there will be with each hospital medical records department applying ICD-10 codes related to COVID-19. Given that WHO didn't release their notification of the need to use the new codes until March 24, 2020, there might be some challenges figuring out codes used by those parts of the country hit early with the disease. Seattle was the first "hot spot" for COVID-19 in the country, so that may be a reason many of the late February through April cases are not coded as now required.

The later the virus hit other communities, the greater the chance the appropriate WHO codes released in late March will be used. For the regions where the virus struck first, we may need to broaden our code selection to find all the cases we want using a combination of some of the following outlined in the CDC instructions released

on February 20, 2020 (<https://www.cdc.gov/nchs/data/icd/ICD-10-CM-Official-Coding-Gudance-Interim-Advice-coronavirus-feb-20-2020.pdf>):

- **B97.29** Other coronavirus as the cause of diseases classified elsewhere

Based on ICD-10-CM coding guidelines, B97.29 should be used as an additional code if the virus is responsible for such diseases as pneumonia, classified as:

- ✓ J12.89 Other viral pneumonia or
- ✓ A41.89 Other specified sepsis

- **B97.21** SARS-associated coronavirus as the cause of diseases classified elsewhere
- **Z20.828** Contact with and (suspected) exposure to other viral communicable diseases (to report an encounter with a patient infected with any form of the virus, coders can use

Of note, in its press release, CMS announced the release of a new Healthcare Common Procedure Coding System (HCPCS) code for providers and laboratories to test patients for SARS-CoV-2, which is **U0001**.

One Proposed COVID-19 Coding Scheme

According to Cathryn Phillips, Manager of the Connecticut SEER registry, one or more of the reporting facilities in that region using METRIQ for their abstracting software will be collecting COVID-19 information using the coding scheme for the four user-defined data items in Table 2.

**Table 2
COVID-19
User Defined Fields**

COVID-19 (UDF Pt 2)	0 - Presumptive
	1 - Positive
	2 - Negative
	3 - Test Not Given
	4 - Positive Immune Response
	9 - Test Unknown if Given
COVID-19 First Positive Date (UDF PT 124)	99/99/9999
COVID-19 RX Plan (UDF15?)	1 - RX Change/Modified/Postponed
	2 - No RX Plan Change
	9 - Unknown
COVID Cause of Death (UDF Pt 3)	1 - Related
	2 - Unrelated
	9 - Unknown

On 4/30/20, we submitted a question to Sandra Gamber at Elekta, METRIQ’s parent company, asking whether this coding scheme is being rolled out to all METRIQ customers or whether we need to contact our users individually to learn their data collection plans. Ms. Gamber’s response:

... METRIQ is not issuing any fields to be collected for COVID-19. The long answer to your question is that we would only do that if it is brought forward by the Standard Setters and approved using the official NAACCR channels. It sounds like that will happen as the NAACCR listserv said that a Task Force will convene (I think next

week). Even if the NAACCR Uniform Data Standards (UDS) WG approves new data items related to COVID-19, it would not get into vendor software until their next release for v21.

We have not received the v21 final specifications yet (Volume II, NAACCR Implementation Guidelines, etc.) so we are looking at the end of this year before v21 comes out. Therefore, our METRIQ users are taking advantage of creating User Defined Fields (UDF) to create their own field names, codes and descriptions. Keep in mind, this data will not be exported to central registries until they contact us to say they want to receive it, and the earliest it could be worked into our product would be our next release (end of 2020).

We only have a handful of METRIQ clients so far that notified us that they are creating UDF's for COVID-19 collection. At this point, they are creating them just so they can run reports for their own hospital administration.

The short answer to your question is that you would need to reach out to the METRIQ hospitals to provide them the details of what to collect in the UDF's. Just remember, none of this will be exported right away because the Elekta engineers would need to be notified to add it to the state export and then have time to work it into our next METRIQ release.

Other vendors will likely have the same response to the question we submitted to Elekta, but it might prove interesting to check what options, if anything, other vendors are incorporating into their systems to help with this data collection so central registries can adequately prepare for the receipt and storage of this information.

Central Registry Receipt and Storage of COVID-19 Data

Ms. Phillips submitted an issue (#8475) to the Information Management System's (IMS) Squish on 4/30/20 requesting the central registries be capable of receiving and storing the COVID-19 data captured by hospital registrars. Fabian Depry with IMS responded that he needed the following NAACCR XML for each field before moving forward:

- NAACCR ID
- NAACCR Number
- Data Level
- Data Type

Mr. Depry proposed the following:

First field

Name: COVID-19
NAACCR XML ID: covid19
Data Level: Patient
Data Type: digits
Length: 1

Second field

Name: COVID-19 First Positive Date
NAACCR XML ID: covid19FirstPositiveDate
Data Level: Patient
Data Type: date
Length: 8

Third field

Name: COVID-19 RX Plan
NAACCR XML ID: covid19RxPlan
Data Level: Tumor
Data Type: digits
Length: 1

Fourth field

Name: COVID-19 Cause of Death
NAACCR XML ID: covid19CauseOfDeath
Data Level: Patient
Data Type: digits
Length: 1

According to Mr. Depry, given that the NAACCR XML workgroup is discussing assisting the community with standardizing some of the non-NAACCR items that States and registries collect, adding COVID-19 to the discussion seemed reasonable to be considered.

Potential Linkages with Infectious Disease Units

Jenna Mazreku, from the California Cancer Registry, indicated that many states are collecting COVID-19 related data within their infectious disease departments/branches. She recommended national registry-related workgroups tasked with making data collection recommendations consider what is already being done by other groups in order to enhance the potential of future linkages between the datasets. Consistency in data collection across agencies will reduce the need for future crosswalks and adjustments to put the data from one scheme into another.

Initial Cancer Treatment Changes Observed (very informally captured)

As our team was reviewing records trying to determine the reason for the drop in incidence reporting, we were struck not only by the documentation regarding why there was a delay related to patients being seen, but we noticed once patients were diagnosed, they were not moving to surgery/transplants as quickly as they typically did. A reason associated with COVID-19 was usually cited.

Some anecdotal observations are listed below:

- **Breast** (Early stage cases: Opting to temporize with neoadjuvant endocrine therapy as an approach stating it would have been recommended for 5 years following her surgery. Instead, they were going to start with it and follow these patients closely.)
- **Endometrium** (Offering progestational IUD for early stage cases and/or simply delaying the surgery for these cases.)
- **Heme/Lymphoid** (Opting to hold off on performing transplants as long as possible opting instead to continue some patients on "maintenance" chemotherapy until it is safe to do the planned transplant because physicians believed these patients were already so immunosuppressed.)
- **Melanoma** (Delaying almost all the wide local excision and sentinel lymph node procedures.)
- **Prostate** (Early stage cases put on a "watchful wait" protocol temporarily with surgery planned once it was safe to do so. For other patients, physicians discussed the need to use hormonal therapy to temporize during the COVID outbreak.)

We thought the following related topic was an interesting idea and decided to throw it into the mix for consideration too. In late April, a member of the staff noticed a registrar made a post on the NCRA Facebook page floating the idea of creating a field to capture the reason for treatment delay. The registrar suggested the first few code definitions that might be considered in a hierarchical coding scheme such as:

- Insurance
- Public health/pandemic
- Patient choice
- Family decision
- Etc.

A week or so after discussing my findings with the registry supervisory staff, we were on a SEER*Educate conference call with members of the NCI SEER staff on April 20th. At the end of our meeting, Serban Negoita casually asked about the impact of COVID-19 on our operations. We told him about our experiences to date. In response, he asked whether we'd consider participating on the COVID-19 Task Forces being created. That's how I was "drafted" as a volunteer. I indicated to Dr. Negoita I'd summarize what we'd learned prior to the meeting after we'd actually had our staff check the records of all the facilities in our region to see if their observed findings were similar to initial findings.

Treatment Change Recommendations

Before sending the staff to check the records, I decided to check to see if there were any treatment change recommendations associated with COVID-19 recently published for physicians. I was looking for something more comprehensive than my short list of anecdotal observations. I found an article published on 4/8/20 titled "Management of Cancer Surgery Cases During the COVID-19 Pandemic: Considerations." <https://link.springer.com/article/10.1245/s10434-020-08461-2>.

This article provided guidelines for the following types of malignancies:

- Breast
- Colorectal
- Endocrine tumors
- Gastric and Esophageal
- Hepato-Pancreato-Biliary
- Melanoma
- Peritoneal Surface
- Sarcoma

Generally, for surgical patients we observed higher priority being given to those patients with a life threatening diagnosis and those for which a more immediate surgery date would result in either an improvement in their quality or the length of their lives.

The two primary radiation treatment priorities observed address the needs of patients with rapidly growing tumors and those for which radiotherapy was already underway before COVID-19 broke out in our region. In addition, according to a post on the American Society for Radiation Oncology (ASTRO) website (<https://www.astro.org/Daily-Practice/COVID-19-Recommendations-and-Information/Summary>), the following COVID-19 related message was posted:

Recognizing the potential for staff reductions, radiation oncologists should follow appropriate evidence-based guidelines (e.g., NCCN) while striving for the shortest possible course of radiotherapy (e.g., single-fraction treatment for bone pain, hypofractionation where appropriate, e.g., breast, prostate).

We did observe delayed radiation treatment for breast cancer patients on adjuvant chemotherapy, prostate cancer patients, and brain/CNS patients with benign/borderline histologies.

Considerations for chemotherapy treatment during the COVID-19 pandemic have been set forth by the American Society of Clinical Oncology (ASCO). They have outlined the following practice points oncologists are to consider for treating patients with systemic therapy (<https://www.asco.org/asco-coronavirus-information/care-individuals-cancer-during-covid-19>):

- For patients in deep remission who are receiving maintenance therapy, stopping chemotherapy may be an option.
- Some patients may be able to switch chemotherapy from IV to oral therapies, which would decrease the frequency of clinic visits but would require greater vigilance by the health care team to be sure that patients are taking their medicine correctly.

- Decisions on modifying or withholding chemotherapy should include consideration of the indication for chemotherapy and the goals of care as well as where the patient is in the treatment course and their tolerance of treatment. For example, the risk/benefit assessment for proceeding with chemotherapy in patients with untreated extensive small cell lung cancer is different from that for patients on maintenance pemetrexed for metastatic non-small cell lung cancer.
- If local transmission affects a particular cancer center, reasonable options may include giving a chemotherapy break for two weeks, arranging infusion at an unaffected satellite unit, or arranging treatment with another facility that is not affected.
- Consider whether home infusion of chemotherapy drugs is medically and logistically feasible for the patient, medical team and caregivers.
- In some settings, delays or modifying adjuvant treatment may pose a higher risk of compromised disease control and long-term survival than in others.
- Prophylactic growth factors as would be used in high-risk chemotherapy regimens as well as prophylactic antibiotics may be of potential value in maintaining the overall health of the patient and make them less vulnerable to potential COVID-19 complications.
- In cases where the absolute benefit of adjuvant chemotherapy may be quite small, and where non-immunosuppressive options are available (e.g. hormonal therapy in ER+ early-stage breast cancer), risk of infection with COVID-19 may be considered as an additional factor in weighing the different options available to the patient.

With more detailed information about how clinicians approached patient care in this new environment, I think it will be much easier for registrars to recognize the changes they find in the documentation.

Re-opening Strategies

Hospitals are discussing various re-opening strategies. We were able to learn the strategy one large facility plans for reopening. For example, they will be opening their breast imaging service in early May, scheduling only for 50% capacity and monitor for two weeks. Assuming their successful monitoring benchmark is met, they will increase 15% capacity every two weeks until they are functioning at full capacity. In mid-May, they will phase in elective procedures following the same type of scheduling methodology.

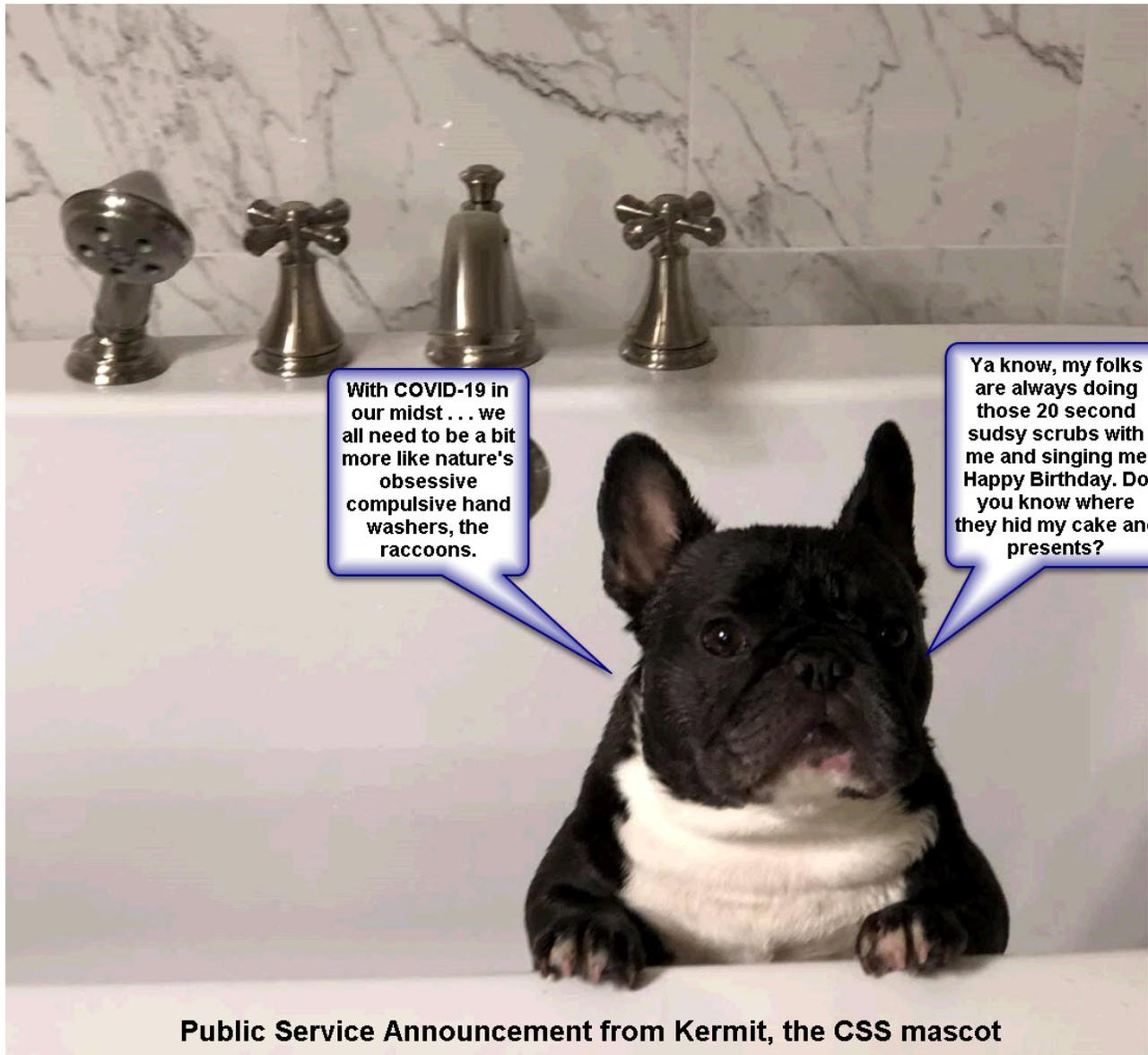
Our reporting area covers 13 counties. We anticipate that hospitals located in the hardest hit (and most urban) counties will reopen in a similar phased approach as the one described above. Hospitals in our more rural counties face their own challenges. They might not have as many COVID patients; however, they also do not have as many resources needed to handle that special patient population. We have historic counts of pathology reports by reporting hospitals, so we will be able to monitor at the hospital ePath level when each returns to full capacity.

We are also aware the hospital registry staffs in the hardest hit counties in our region have had their budgets cut as the hospitals with large attached outpatient facilities with now greatly reduced patient encounters struggle to meet the financial challenges of the COVID crisis. Central registries dependent upon hospital registry abstracts will be faced with delayed reporting due to registry staffing issues.

Summary

The larger cancer registry community is now faced with how to quickly create and implement a single meaningful data set used during chart review to supplement linkages with infectious disease departments to collect data on COVID-19. In the best of times, there are challenges in adding data items.

As we prepare to meet this challenge for COVID-19, can we create a data set of generic “pandemic descriptors” that would always be part of the NAACCR record description? New codes that would represent a different infectious disease for an existing data item are easier for software vendors to implement quickly. While we hope that we are experiencing a once in every hundred-year situation, we could prepare for the ongoing ability to more quickly capture this type of information in the future.



With COVID-19 in our midst . . . we all need to be a bit more like nature's obsessive compulsive hand washers, the raccoons.

Ya know, my folks are always doing those 20 second sudsy scrubs with me and singing me Happy Birthday. Do you know where they hid my cake and presents?

Public Service Announcement from Kermit, the CSS mascot