SUMMARY

The Alabama Statewide Cancer Registry (ASCR) strives to achieve Gold Standard for Registry Certification and NPCR Registry of Distinction, a distinction received every year since 2004. The ASCR staff collects and provides high quality data through program coordination and external partnerships. The impact of the COVID-19 pandemic has affected staff performance, facility reporting, and collaborative partnerships that support programs and organizations seeking to improve cancer outcomes.

CHALLENGE

The ASCR experienced various challenges during COVID-19 pandemic that either prevented or delayed central cancer registry daily operations. While working from home, ASCR staff encountered disruptions due to inadequate or the lack of equipment to perform daily job responsibilities. In addition to primary job responsibilities, various staff were assigned to COVID duties onsite as well as assignments requiring travel to other locations throughout the state. The ASCR faced staff turnover and vacancies coupled with the difficult task of recruiting and retaining CTRs. Position vacancies and a limited pool of CTRs contributed to a significant back log in operational activities and presented obstacles that hindered cancer registry daily operations. Furthermore, reporting facilities experienced similar challenges with staff reassignments and furloughs that tremendously slowed or halted cancer data reporting.

SOLUTION

To address challenges, the ASCR staff participated in 3 NCRA coding and abstracting virtual trainings, and the NCRA virtual conference which offered invaluable information for staff new to cancer registry. The ASCR staff and reporting facilities continue to view the monthly webinars accessible via Fundamental Learning Collaborative for the Cancer Surveillance Community (FLcSC). Although unable to attend face-to-face meetings, the accessibility of personnel training through webcast platforms provided the opportunity to view remotely and avoid disruptions with work schedules. Daily meetings were held where the staff got together to provide updates, brainstorm ideas and everyone pitched in to catch up on projects that had fallen behind. Assisting in staff training, the Education and Training Coordinator played an integral part in engaging the ASCR staff with updates and processes required by NPCR Program Standards. The ASCR staff provided countless hours of training for new or temporary staff at the reporting facilities.

RESULTS

ASCR staff worked tirelessly to perform their job responsibilities and demonstrated a strong team approach by supporting their colleagues in their roles. The staff utilized daily huddles to prioritize critical tasks, eliminate the backlog, and identify areas of improvement to maintain timely, accurate, and complete cancer data reporting. Through WebEx trainings and data submission extensions, reporting facilities were able to return to the data reporting schedule and meet deadlines for data submission. Because of the dedication and determination of the ASCR staff and the efforts of the reporting facilities during a pandemic, both the NPCR Registry of Distinction and the NAACCR Gold Standard Registry Certification was achieved.

SUSTAINING SUCCESS

The ASCR will continue to provide educational trainings and webinars for staff and reporting sources. The ASCR aims to fill vacant positions and remains committed to recruiting and retaining CTRs to ensure accurate, timely, complete, and quality data is submitted. The ASCR is committed to maintaining consistent achievement of federal standards.

REGISTRY CONTACT INFORMATION

334-206-7035
https://www.alabamapublichealth.gov/ascr/index.html
SUMMARY
In March 2019, the Alaska Cancer Registry (ACR) began receiving electronic files via secure email attachments in clinical document architecture (CDA) format from Providence Health System physician offices that use the Epic Electronic Health Record (EHR) software as part of the Meaningful Use initiative. After about 1.5 years of consistently reporting a small number of cases using this method, the caseload from this reporting source unexpectedly increased from about 5 per month to almost 200 per month over a relatively short period of time. As a result, ACR worked with Providence’s IT staff to transition to a web-based secure FTP site, and with its Department’s IT staff to develop a BizTalk application that downloads the CDA files from the FTP site twice a day to ACR’s secure data network.

CHALLENGE
Providence Health System started reporting CDA files to ACR in March 2019 for their physician offices using the Epic EHR software. At that time, ACR received 5 or fewer files per month through secure email attachments, one tumor record per file, one file per email. These files were then manually uploaded to the physician module of NPCR’s eMaRC Plus software, where they were converted to the NAACCR record layout. Given the small caseload from this reporting source, this seemed like a reasonable method of transmission until the caseload trend dramatically increased after September 2020. By July 2021, we had our highest monthly submission of 185 files (Figure 1). What started as a practical method of transmission quickly became unsustainable, as the large number of monthly emails was taking too much ACR staff time to process.

SOLUTION
By April 2021, it was quite evident that the number of transmitted files would continue to increase into the foreseeable future. At that time, ACR’s data analyst approached Providence Health System’s IT staff, shared the current challenge with the large caseload, and suggested that perhaps a web-based secure FTP site would be a better solution for transmitting so many electronic files monthly. Their IT staff agreed and proceeded to put that solution in place.

RESULTS
Within the space of a week, Providence Health System’s IT staff had set up a secure FTP site and started routing their CDA files to the site for ACR’s data analyst to download. ACR was using the application WinSCP for downloading the files, which was also a manual process. ACR approached its health department’s IT staff to automate the download process to reduce ACR staff time further. By the beginning of May 2021, the health department’s IT staff had developed a BizTalk application that downloaded the CDA files to ACR’s secure data server twice a day.

SUSTAINING SUCCESS
This project is an excellent example of how a registry can “work smarter, not harder” in response to changes in registry workload. The collaboration between ACR and the IT staff at Providence and the health department went very smoothly. Both software solutions they developed have worked flawlessly since they were put in place during the first part of 2021. In addition, since our travel was suspended for all state employees in 2020 and 2021, we could utilize underspent funding to automate this internal process.

REGISTRY CONTACT INFORMATION
907-269-0995
http://dhss.alaska.gov/dph/VitalStats/Pages/cancer/registry.aspx
Historically, the Arizona Cancer Registry (ACR) has found challenges in both the hiring of experienced cancer registrars and in retaining new cancer registrars once they have gained experience. What we believe contributed to this challenge is that hospital cancer registries in Arizona typically offer higher wages. Using information from the National Cancer Registrars Association (NCRA) Salary Considerations for Cancer Registrars, 2017 Survey Data and information shared from major Arizona hospital systems, the ACR wrote a proposal to our internal agency Human Resources that thoroughly documented an evaluation of several internal cancer registrar positions. The ACR has successfully implemented new position descriptions that include a CTR requirement with an associated higher pay scale.

**CHALLENGE**

It has been difficult to attract experienced cancer registrars to Arizona Cancer Registry (ACR) positions. It has also been challenging to retain new cancer registrars once they have gained experience and are trained.

In addition, the ACR has also found it hard to consistently achieve the CDC NPCR Program Standards for the following performance measures:

- A designated certified tumor registrar (CTR) is responsible for the quality assurance program.
- Quality assurance activities should be conducted by qualified, experienced CTRs or CTR-eligible staff.
- A designated education and training coordinator who is a qualified, experienced CTR.

**SOLUTION**

We met with agency Human Resources and upper-management staff and shared concerns related to staff turnover and causes of employee separation. We submitted a proposal that included an extensive evaluation of positions that included the following:

- Explanations of how the positions are critical to the department’s mission and vision
- Shared information related to the turnover rate for each of the positions
- Issues that turnover rates cause
- Average tenure for the positions
- Salary comparisons with the market
  - How does the Arizona Cancer Registry compare to other Arizona hospitals?
  - How does the Arizona Cancer Registry compare to other states?
- Position-specific barriers to recruitment
- An accounting of each cancer registrar budgeted position from year to year
- The time commitment needed to train new employees due to our complex training program

We were able to demonstrate how our positions are not comparable to hospitals or other central registries by using the last salary survey conducted by the NCRA and salary information provided by three local hospital systems.

We successfully revised the positions descriptions to include a CTR credential requirement. The requirement allows the employee to achieve the CTR credential within so many years of hire, depending upon what type of position they were hired into. We were able to revise all major positions, which include all registrars in the Operations section, the Operations Manager, the Quality Assurance Manager, as well as the Training Manager. In addition, we were able to increase the pay scale so that these positions would be comparable to hospital registry positions. A benefit to this is that we have started to attract Certified Tumor Registrars as well as Registered Health Information Technicians to positions. We now feel we have a solid foundation to recruit and retain cancer registrars.

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**SUSTAINING SUCCESS**

To sustain success, we must revisit position descriptions and the salary structure regularly to ensure that we offer a level of financial compensation in our positions within the central registry that is comparable to and competitive with hospital registrar pay and compensation. We also intend to pursue and develop other ways to make our positions more enticing to registrars in the long term, such as remote work opportunities and flexible schedules. In addition, we must continue to provide opportunities for employee engagement, so they feel invested in the activities of the registry and empowered in their positions. These elements work together to foster a positive culture and work environment, which is very important to the ACR and our agency.

**REGISTRY CONTACT INFORMATION**

602-542-7320
SUMMARY
COVID-19 is a novel, severe acute respiratory virus which was first reported in Wuhan, China in December 2019. By March 20, 2020, there were more than 234,000 cases confirmed worldwide and more than 9,800 registered deaths. Because it’s known that persons with compromised immune systems suffer from the most severe form of COVID-19, staff at the Arkansas Central Cancer Registry (ACCR) conducted a linkage to study the distribution and severity of COVID-19 among cancer patients in Arkansas. The initial linkage was done in 2020 and the results published in Arkansas Family Physicians Journal.

CHALLENGE
The fundamental challenge for the cancer community during this pandemic is the risk of contracting and developing severe complications of COVID-19. Most people treated for cancer in the past are likely to have gained normal immune function back, but each person is different, and they should talk to their doctor about their personal situation. However, precautionary measures should still be taken. Preventive measures include regular handwashing, avoiding close contact, wearing a mask, covering a cough or sneeze, and cleaning and disinfecting surfaces.

Another major challenge the cancer community faced was the pause of elective procedures at the beginning of the pandemic, such as cancer screenings, which can lead to cancers being diagnosed at a later stage of development going forward, which can lead to reduced chances of survival.

At the same time, there is also concern of delayed treatment among cancer patients. During normal times, fear and anxiety play a major role during patients’ disease. This is complicated by the added fear of contracting COVID-19, which could have a great impact on treatment refusals and cancer survivorship. These challenges bring importance to understanding the short- and long-term health effects of this disease on this patient population.

SOLUTION
To gain a better understanding of the impact of COVID-19 on Arkansas cancer patients, a linkage was performed between the Arkansas Central Cancer Registry dataset, 1996-2020 (2019-2020 provisional), and the COVID-19 dataset at the Arkansas Department of Health on March 1st, 2021.

The ACCR collects high quality and complete data and has been consistently certified as a Registry of Distinction by NPCR. The COVID-19 dataset was not complete, this data were reported rapidly with little time for quality assessment, the linkage may have missed cases.

Standard dual probabilistic linkage methodology based on the Fellegi and Sunter model was used to perform a match between the two sets. The variables used for the match were first name, last name, sex, race, telephone, birthdate, street address, city, and zip code. This linkage matched 390,685 patients with cancer diagnosed from 1996 to 2020 with 343,269 patients who had tested positive for COVID-19 from March 11, 2020, to March 1, 2021. We found that 10,623 cancer survivors had tested positive for COVID-19.

RESULTS
Additional analysis showed that:
- More than half of the cancer patients testing positive for COVID-19 were women and the nearly one-third of the patients were between the ages of 65 and 74. This age distribution is like the median age at diagnosis among Arkansas cancer patients.
- Female breast, prostate, colorectal and melanoma of the skin were the most prevalent cancers among survivors who tested positive for COVID-19, which are the most common cancer types in survivors in general.
- Patients diagnosed with cancer in 2018 and 2019 were the largest group with a COVID-19 infection, likely because there are more cancer survivors during more recent diagnosis years than in the past.
- White men and women (80%) had a higher rate of COVID-19 infections than black men and women (15%). This is like the general population of cancer patients.
- Most cancer survivors diagnosed with COVID-19 in Arkansas recovered from their infection.
- The first cancer survivor in Arkansas died on April 1, 2020. Among the cancer patients who were infected with COVID-19 and died, 75% succumbed to COVID-19.

SUSTAINING SUCCESS
Current hospital safety guidelines for screenings and cancer treatment are in place, being followed and relaying effective messaging about why this is important. Further, cancer registry data will be critical in measuring the impact of a pandemic on the delivery of cancer care in Arkansas.

We presented these updated linkage results in June 2021 at a CDC townhall.

REGISTRY CONTACT INFORMATION
501-681-2463
https://www.healthy.arkansas.gov/programs-services/topics/arkansas-cancer-registry

REFERENCES
SUMMARY
Funded by the Centers for Disease Control and Prevention (CDC), the California Cancer Registry (CCR) worked with multiple partners to conduct a pilot project collecting and processing genomic biomarker data that was not yet part of the registry data warehouse or national data standards (novel data items). Two approaches were implemented: (1) electronic pathology data collection utilizing standards defined by the College of American Pathologists (CAP) and (2) manual data collection based on federal standards developed by the North American Association of Central Cancer Registries (NAACCR). The pilot found that the collection of novel prognostic factors is possible but not efficient at the population level. However, lessons learned from the pilot may be useful in designing systems to acquire novel data items for targeted research studies.

CHALLENGE
Two critical challenges were encountered in this pilot:

1. Data mapping: Translation of electronic data in the CAP electronic cancer checklist format to NAACCR standard formats was a challenge due to the specialized technical nature of the task and the time required.

2. Data Use: It is well known that data use drives data quality. Identification of potential partners to use the resulting genomic data for research purposes was a challenge.

SOLUTION
To overcome the mapping challenge, California collaborated with the CDC to procure resources to complete the translation effort. This required planning and tracking on the parts of both partners. California has not identified a solution to the data use challenge. This contributed to our recommendation to focus on and facilitate targeted collection of novel prognostic factor data based on targeted requests by researchers with a pre-defined use case and sub-population foci.

RESULTS
The pilot process successfully collected both electronic and manual biomarker data. Collaboration with the CDC, the Cancer Registry of Greater California, and the College of American Pathologist was integral to this success. California captured structured biomarker data from 42 unique facilities through electronic data streams after working extensively with CDC to ensure data integrity as it flowed from the reporting source (electronic message) through eMaRC to the CCR interface engine. In addition, California manually captured biomarker data from six reporting entities. Though data capture was successful, the workload involved in maintaining this data capture through either route is not practical on an ongoing, population-based level unless a clear and cogent need is expressed by the research community.

SUSTAINING SUCCESS
Though this pilot did not find population-based collection of novel prognostic factor data to be a practical approach, findings point to the value of learning from the pilot to develop operational models to procure novel data for targeted data collection initiatives. In collaboration with CDC partners, California will publish findings from the pilot to encourage development and implementation of these operational processes. If supported by the state, California could create research grants to promote application of this model to a variety of cancer prognostic factors including genomic information, imaging, and treatment data.

REGISTRY CONTACT INFORMATION
916-731-2500
www.ccrcal.org
SUMMARY
All-Payer Claims Databases (APCD) serve as a valuable repository for public and private claims data for health care services provided to insured individuals within a state. Linked with Cancer Registry data, the APCD data can potentially provide longitudinal data to study cancer care and outcomes across multiple payers. The Colorado Central Cancer Registry (CCCR) linked cancer registry data with APCD data from the Center for Improving Value in Health Care (CIVHC), a non-profit organization authorized by the state of Colorado to collect claims data. Research partners from the University of Colorado Anschutz Medical Campus (CU) evaluated the quality and completeness of the linked data. While the overall match rate was high, nearly one third of all matches did not have a plan in the APCD at the time of cancer diagnosis.

CHALLENGE
Cancer registry data contains a vast wealth of information on patient and tumor-level diagnosis and staging data but may not adequately capture treatment information beyond the first course of treatment. Claims data contain patient-level longitudinal information on cancer screening, treatment, and payment information but lack the precise diagnosis date, cancer stage, tumor characteristics, and vital status found in cancer registry data. Linking these two sources of information can significantly expand the capability of each source but can be time-consuming to perform and there may be limitations on data release due to privacy concerns.

SOLUTION
To minimize the release of personally identifiable information (PII) and Personal Health Information (PHI), CIVHC, CU, and the CCCR worked together to create a minimally identifiable linked dataset. CIVHC provided a patient finder file to the CCCR with patient identifiers (APCD member ID, Social Security Number (SSN), date of birth (DOB), last name, first name and sex) for all individuals 21 years of age and older that appeared at least once in the APCD from 2012 to 2017. The CCCR linked the patient finder file with the CCCR database using Match*Pro software and returned only the list of matching APCD member IDs to CIVHC. CIVHC extracted all claims data for linked individuals and provided them to the CU researchers. The CCCR provided minimally identifiable information for both linked and non-linked patients, along with the APCD member ID for the matches. CU combined the two data files by APCD member ID. Initial analyses include an evaluation of linkage quality and a subsequent evaluation of insurance validity, comparing the value of Primary Payer at DX to the enrolled insurance plan within the APCD.

RESULTS
Of the 146,884 patients first diagnosed with cancer between 2012 and 2017, 136,613 (93%) were linked to the APCD finder file. Of the matches, two-thirds were exact matches on the five identifiers, another quarter were missing SSN but matched on all other identifiers, and the remaining individuals included partial matches identified through manual review. The overall match rate for the six-year period was high, though when the analysis was restricted to a time window around diagnosis, nearly one third of all matches did not have a health plan in the APCD, resulting in a lower linkage rate at the time of cancer diagnosis. However, with baseline information available from the registry, claims made after diagnosis could still be used for research. As the linkage covered multiple years, it is likely that these individuals were covered by plans that did not submit claims data or were uninsured at the time of diagnosis. According to the Primary Payer at DX field from the registry, most of these individuals had a private insurance plan (58%), were uninsured (3%), or had other health insurance plans (17%). The APCD does not include all private insurance plans, and does not include claims data for the uninsured, highlighting some of the limitations of the dataset. When comparing Primary Payer at DX to health plan enrollment from the APCD for those that linked, there was a high positive predictive value of the registry classification for Medicaid (97%) and private insurance (86%) for those under age 65, meaning that if the registry coded that insurance type, it was usually correct. There was also a high positive predictive value of Traditional Medicare (74%) and Medicare Advantage (81%) for those over 65. However, the sensitivity – the probability that the registry correctly identifies the type of health plan for those who have the plan – for each of those categories was considerably lower than the positive predictive value. Additionally, the registry did not accurately capture dual patients (those enrolled in both Medicaid and Medicare) with more than two-thirds of those classified as dually insured being enrolled in either Medicaid or Medicare, but not both, according to the APCD data.

SUSTAINING SUCCESS
Many manuscripts regarding the linkage and initial analyses are awaiting publication. Researchers at CU also continue to pursue other proposed research questions using the linked APCD/CCCR dataset. Supplementing this research with additional states that can link APCD data to cancer registry data would facilitate comparisons and help to evaluate data quality. For the CCCR, with fewer than one in ten matches requiring manual review, future linkages with the APCD dataset are feasible. The biggest barriers to linkage are related to administrative and/or privacy concerns. Additionally, the CCCR is currently in the process of negotiating expanded access to the CIVHC APCD dataset to improve data quality and completeness of data within the registry. Based on the results of the insurance validity analysis, the CCCR will be providing additional instruction and coding clarification to facility abstractors to further improve the quality of the Primary Payer at DX field.

REGISTRY CONTACT INFORMATION
303-692-2540
https://www.colorado.gov/pacific/cdphe/canceregistry
**Addressing the Breast Cancer Burden in Delaware through Partnerships**

The Division of Public Health's (DPH) Screening for Life Program (SFL) provides preventive breast cancer screenings and/or diagnostic procedures at no cost to eligible enrolled women. Those enrolled in the program have no out-of-pocket expenses. A Reduced Out-of-Pocket Expenses program is in place for communities with people of increased risk for cancer such as women with lower income and lower education. Eligibility for the program is determined by risk factors and guidelines based on age, timeframes for preventative breast cancer screenings, income eligibility, and insurance status. Even if individuals have health insurance, they are eligible for SFL benefits if their insurance does not cover preventative screening, and if their deductible is 10% more than their income.

The goal of patient-based navigation is to eliminate any barriers the patient faces while obtaining a screening, such as financial hardships or transportation. Patients are also referred to other services such as cancer treatment and tobacco cessation programs. Utilizing data from the Delaware Cancer Registry, target zip codes with a higher incidence of late-stage breast cancer cases are identified. This is an all-in-one service where patients can enroll in the SFL and receive referrals to Delaware’s Cancer Treatment Program, which assists patients with the cost for cancer treatment.

Providers helped increase breast cancer screening by successfully using patient reminder cards. Providers use both electronic health records and monthly mailed breast cancer screening reminder cards to remind patients of upcoming medical appointments more efficiently. There is also promotion for preventative breast cancer screenings in high-risk demographics that include Black and White women that may pool women from lower income and education levels.

Reaching these populations through people in their communities is an effective way to increase screening. DPH has representation at community outreach events and partners with mobile health clinics to inform the importance of preventative breast screening efforts in targeted zip codes. To ensure that communities and partners are well informed on how to outreach, an informational presentation is available that community-based organizations can distribute to their members and clients. Providers are also notified of additional programs if cost is a factor.

Marketing campaigns are in place to provide this information right into the community. There are ongoing partnerships with hair salons and screening events at churches in targeted zip codes locations with a higher incidence of late-stage cases.

**RESULTS**

Data from the 2018 BRFSS provides information on breast cancer screening among Delaware females. Of Delaware females 40 years of age and older, 79% reported having a mammogram in the last two years. Delaware females 40 years of age and older, 79% reported having a mammogram in the last two years. Additionally, Delaware females 40 years of age and older who hold a college degree have a higher prevalence of mammogram of 87% compared to Delaware females with less than a high school diploma at 65.9%.

Although cancer screening has increased overall, further improvements may benefit women with lower income and education. Therefore, it is important to reach those communities to continue increasing screening to reduce mortality by making screening accessible to all Delaware women regardless of financial hardships or education levels.

**SOLUTION**

Delaware implemented evidence-based interventions to increase cancer screening awareness to the people who are at increased risk. These interventions targeted populations in zip codes with a higher incidence of late-stage breast cancer cases. Some of these solutions include cost reduction programs such as Screening for Life reduce financial burden. It also includes Patient Navigation, portals, screening reminder calls or mail, community-based cancer screening campaigns, community outreach at churches or hair salons, and digital media.

According to the 2013-2017 Incidence and Mortality Report, incidence rates for breast cancer increased 6% in non-Hispanic White females (2003-2007 rate: 125.5 per 100,000; 2013-2017 rate: 137.6 per 100,000). Incidence rates for breast cancer increased 3% in non-Hispanic African American females (2003-2007 rate: 133.3 per 100,000; 2013-2017 rate: 137.7 per 100,000). Additionally, in 2013-2017 68% female breast cancers diagnosed at the local stage; 25% at the regional stage; 6% at the distant stage; while 2% had an unknown stage.

The results of marketing campaign efforts are nationally recognized, such as the campaign Sister to Sister, that highlights the importance of breast cancer screening to people who are at increased risk for cancer. The tactics include partnerships and screening events at churches, which in their own community members are there to outreach to their community and collaborating with mobile health vans to educate the population of breast cancer risk. Hair salons, who have diverse audiences consisting of African American and White women in targeted zip codes, are receptive to receiving SFL preventative cancer screening materials and sharing them with their patrons. This holistic approach meets individuals in a non-clinical setting.

Digital media is produced to reach a wider range of audience for cancer screening efforts. Digital media in English, Spanish, and Haitian Creole are created to communicate to individuals in their native language. Digital preventative breast screening ads and commercials virtually educate and engage individuals. The Delaware Breast Cancer Coalition (DBC) and SFL partnership helps tailor marketing campaigns to targeted demographics that are highly impacted by breast cancer diagnosis and mortality. Brochures, flyers, and social media posts about preventative breast cancer screening services were shared with provider offices and are housed on the Healthy Delaware website.

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SUMMARY
In February of 2021, the District of Columbia Cancer Registry (DCCR) began successfully using the virtual educational platform FLCCSC (Fundamental Learning Collaborative for the Cancer Surveillance Community) and was able to provide continuous web-based educational training courses to all DCCR reporting facilities/staff during pandemic times. In addition to virtual course availability and with aim to improve FLCCSC’s future learning benefits to the cancer community, DCCR recommends the creation of a new document upload feature on the FLCCSC platform to allow reporting facilities/staff access to important state registry related documents.

CHALLENGE
During the COVID19 pandemic, DCCR and most of DCCR’s reporting facility staff transitioned into teleworking environments leaving several DC hospital cancer registry staff without access to monthly NAACCR webinars and other learning opportunities that were previously available in-person.

SOLUTION
The successful implementation of FLCCSC at DCCR provided instant online learning access to all DC reporting facilities/staff. Monthly NAACCR webinar courses, DCCR’s annual educational conference courses, and DCCR internal ETC training courses were now conveniently available virtually, including all downloadable course documents, CE hour certificates, web lecture links, and Q&A reports.

RESULTS
Overall, DCCR successfully enrolled and registered 33 students that currently have access to 14 cancer registry related courses. Total course enrollment accounts to 100 of which 40 were passed and 60 are still active.

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SUSTAINING SUCCESS
FLCCSC continues to be actively recognized as a valuable web based educational platform through positive feedback received from DC reporting facilities. To improve FLCCSC’s future learning success, DCCR recommends expanding FLCCSC platform capabilities to include a separate document upload option. This new feature could allow all reporting facilities/staff immediate access to important state registry related documents such as procedural manual, hospital reportable list, and text field requirements.

REGISTRY CONTACT INFORMATION
https://dchealth.dc.gov/service/cancer-registry-0
SUMMARY
Fundamental Learning Collaborative for the Central Surveillance Community (FLccSC) is a web-based portal allowing Central Cancer Registries (CCR) or other entities to customize a fully functioning state-specific Learning Management System (LMS). FLccSC was developed collaboratively by the Florida Cancer Data System and the South Carolina Central Cancer Registry. The initial development was funded by the respective State Departments of Health and the CDC/NPCR and is currently funded by CDC via the National Association of Chronic Disease Directors (NACDD).

CHALLENGE
Collaboratively creating FLccSC resulted from 18 months of weekly meetings between staff of the FCDS and SCCCR. There were three significant challenges with the development, implementation, and maintenance of FLccSC.

Initially, the challenge was the ease of use and the ability to create unique/stand-alone websites for each FLccSC member united around a central program. Secondly, once created and deployed, sharing the cost among the CCR was a challenge to recruiting members to join. At first, only eight (8) CCR's requested access to FLccSC, each paying $4,200 annually. Thirdly, once CDC funded the project, the challenge was recruiting members to join when there was no annual fee for membership.

SOLUTION
Initial Challenge – central registries created FLccSC for central registries. Therefore, the developers were sensitive to the IT strengths and weaknesses of our users. FLccSC was deployed as a fully functioning LMS that was comprised of two state-specific URL’s: (1) a front end where the students accessed the educational content and (2) a back end that allowed the site administrator from each state the ability to develop and maintain their state-specific educational platform using original content or content made available by other states.

Second Challenge – FCDS and SCCCR established an information website detailing FLccSC’s capabilities, and all the forms required to access FLccSC. This was followed by blast emails and phone calls to individual states to recruit members. However, not all registries had the annual fee in their respective budgets to join FLccSC.

Third Challenge – Once CDC and NACDD funded FLccSC, the challenge transitioned from CCR’s lack of funding into demonstrating how FLccSC could assist CCRs with their educational outreach. CDC was very helpful with that challenge by contacting all the state Education and Training Coordinators (ETCs).

RESULTS
The combination of all the successful efforts over the past three (3) years can be demonstrated by FLccSC’s user evolution. As of 9/30/2020, FLccSC began with eight (8) members and has grown to 45 (Table 1). The increase in the utilization of FLccSC using different metrics further elaborates on the success of the collaborative learning management system, FLccSC (displayed in Figures 1 through 4 below).

SUSTAINING SUCCESS
The ability to sustain the FLccSC success is continued funding for the program, which funds system maintenance/enhancements/upgrades and the help desk. In addition, CCR’s are using FLccSC as an integral component of their educational endeavors. As of 9/30/2021, FLccSC members represent the data gathering professionals responsible for abstracting 94% of the United States annual incidence cases. Continuing education for these individuals is essential for timely and accurate reporting of the national cancer data.

REGISTRY CONTACT INFORMATION
305-243-4073
flccsc-info.fcdslms.med.miami.edu
fcds.med.miami.edu

Table 1 – FLccSC Members as of 9/30/2021

<table>
<thead>
<tr>
<th>Alabama</th>
<th>Idaho</th>
<th>Montana</th>
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<tr>
<td>Wisconsin</td>
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</tr>
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Figure 1 – 31% increase in the number of Students and Enrollments in one year

Figure 2 – FLccSC Increase in Number of Original and MAACCR Courses

Figure 3 – FLccSC Increase in Number of Shared Courses

Figure 4 – FLccSC Increase in Number of Imported Courses
2021 NPCR GEORGIA SUCCESS STORY

Use Extension for Community Healthcare Outcomes (ECHO) Platform to Improve Training During COVID-19

SUMMARY
In 2021, the Georgia Cancer Registry (GCR) used the Georgia Department of Public Health (DPH) ECHO platform to conduct virtual training. Georgia Cancer Registry ECHO provided successful means for Georgia cancer registrars to share cases and discuss coding issues securely. In addition, bi-monthly discussion reduced the feeling of disconnect between the GCR staff and Georgia hospital registrars.

CHALLENGE
In 2020 and during the pandemic, the GCR staff found it difficult to maintain communication with the hospitals. As a result, cancer reporting completeness and timeliness dropped significantly. At the same time, GCR staff received a directive from the DPH Commissioner and Health Officer not to enforce any policies or regulations that could harm Georgia hospitals.

SOLUTION
Considering the pandemic and the DPH Commissioner and Health Officer communications, the GCR partnered with the Georgia DPH Project ECHO - Moving Knowledge (unm.edu), led by the Georgia office of Telehealth, Telemedicine, and Rural Health Initiatives. This office has a license from the University of New Mexico to establish and host ECHO spokes. GCR applied and received approval to conduct training every other month and provide Continuing Education Units (CEU) to cancer registrars when they participate in the live sessions. DPH ECHO staff provided technical assistance and maintained a list of registered and participating members of the Cancer Registry ECHO. Additionally, DPH ECHO staff documented the duration of each attendee’s participation so that GCR could evaluate participants with the quality of abstraction.

RESULTS
GCR, in partnership with DPH ECHO staff, hosted 6 Cancer Registry ECHOs. Hospitals’ participants in the ECHO ranged between 60-100, with one planning ECHO hosted in August 2021. The planning ECHO was used to evaluate hospitals’ satisfaction with the platform and willingness to participate in the 2022 Cancer Registry ECHO. Although the response was overwhelmingly positive, hospital registrars requested to increase the length from 60 minutes to 90 minutes. As a result, hospitals registrars volunteered to facilitate ECHO sessions. For example, they suggested having a physician speaker from their hospitals and sharing cases with abstracting and coding challenges for training purposes. Finally, they wanted more frequent ECHOs (monthly vs. every other month) and requested topics related to cancer registry operations in addition to registry data entry challenges.

SUSTAINING SUCCESS
GCR staff will maintain the Cancer Registry ECHO in 2022. Once the state authorizes travel, GCR plans to maintain these sessions as cancer registrars agree that the ECHO platform has been useful in continuing education, enhancing abstracting skills, and reducing travel costs to the hospitals and the GCR staff. GCR currently does not provide funds to the Office of Telehealth, Telemedicine, and Rural Health Initiatives. However, Cancer Registry ECHO adds a needed expansion to the program.

REGISTRY CONTACT INFORMATION
404-657-2588
Idaho welcomes the 2nd highest number of refugees per capita among US states. Idaho public health agencies wanted to characterize cancer among refugees, but no population-based data were available for analysis. Thus, the Cancer Data Registry of Idaho (CDRI) and the Idaho Department of Health and Welfare (IDHW) linked data from the Centers for Disease Control and Prevention’s (CDC) Electronic Disease Surveillance System (EDS) and the Idaho health registry database. For this reason, it is the first time that EDN and cancer registry data have been linked to characterize cancer among refugees. In doing so, we demonstrate proof of concept and insight that can guide cancer prevention and control efforts among refugees resettled to Idaho.

CHALLENGE
Refugees are persons who are unable or unwilling to return to their country of nationality “because of persecution or a well-founded fear of persecution due to race, religion, nationality, membership in a particular social group, or political opinion.” (U.S. Immigration and Nationality Act, Sect. 101[a][42]). A median of 816 refugees were resettled to Idaho per year during 2009 through 2019 from a diverse set of home countries, including Afghanistan, the Democratic Republic of Congo, Iraq, Iran, and Syria. In 2020, Idaho welcomed 2,913 refugees per 100,000 people — second only to Florida among US states in the number of refugees per capita. 

Refugees are diverse with disparate cultural backgrounds; yet, also share unique life experiences of trauma and involuntary displacement relative to the general population. Because of this, refugees may have unique health profiles relative to the populations where they are resettled. For example, in Idaho, refugees have been shown to have an elevated prevalence of chronic medical (e.g., diabetes) and psychological (e.g., post-traumatic stress disorder) conditions. Population-based descriptions of cancer burden among refugees have primarily been conducted in European nations.14 In this study, we describe the cancer experience among refugees mainly consists of interview data focused on health-related outcomes and identified areas for enhanced cancer prevention and control efforts among refugees resettled to Idaho.

SUMMARY
In response to the challenge of characterizing cancer among the refugee population, CDRI and IDHW collaborated to leverage data available in EDN and identify refugees and refugees with cancer. We describe the findings from this linkage and propose strategies to improve cancer surveillance and health promotion for refugees resettled to Idaho.

IDHW provided CDRI with data on all refugees resettled to Idaho during 2008–2019. CDRI included data on refugees with cancer from the EDN system; however, this data did not include immigration data on legal permanent immigrants, refugees, asylees, and parolees. CDRI and IDHW collaborated to leverage data available in EDN and identify refugees. In response to the challenge of characterizing cancer in the refugee population, CDRI and IDHW decided to develop a novel solution. To determine if refugees had higher-than-expected cancer incidence, we needed to calculate the expected number of incident cases in the refugee population compared to the SEER-18 referent population (the general U.S. population). To do this, we linked EDN and CDRI data and identified refugees among Idaho’s population. As the number of cancers of benign and borderline tumors of the brain and other nervous system tumors (defined by a non-appearance, i.e., zero, and time period specific SIR-referent incidence ratio) in the time the arrival in Idaho through the entire period of follow-up was lower than the expected cancer cases in the IDAHO population, except for cancers of the central nervous system. The number of cancers of the central nervous system among refugees was statistically significantly higher than expected based on the SEIR-referent population.

With support from IDHW, we were able to identify potential partners at local public health districts and health systems where refugees are currently resettled. In addition, CDRI and local public health partners intend to connect with the relatively small number of providers in Idaho that treat and screen Idaho’s refugees.

Table 1: Malignant and benign and borderline malignant tumors diagnosed during 2008–2019 for all refugees resettled to Idaho during 2008–2019, as classified by the SEER Surveillance-22 (SEER-22) registry and compared to SEIR – (the Idaho Suburban) referent rates. 

<table>
<thead>
<tr>
<th>Site</th>
<th>SEIR</th>
<th>SEER</th>
<th>Observed</th>
<th>Expected</th>
<th>O/E Ratio</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
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<tr>
<td>Leukemia</td>
<td>4</td>
<td>3.10</td>
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<td>0.35</td>
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<td>1.57</td>
<td>0.72</td>
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<td>Lung and Bronchus</td>
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<td>8.73</td>
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<td>1.70</td>
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<td>0.64</td>
<td>6.25#</td>
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<td>Digestive System</td>
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<td>0.75</td>
<td>0.42</td>
<td>1.24</td>
<td>1</td>
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</tbody>
</table>

Table 2: Finding Cancer Among Refugees Resettled to Idaho: Leveraging Existing Data to Characterize a Unique Population SUCCESS STORY

For all malignant cancer sites combined, refugees had a lower-than-expected number of cancer diagnoses (57 observed versus 95.6 expected), with an observed-to-expected (O/E) ratio of 0.59 and 95% confidence interval (95% CI) of 0.44, 0.77 (Table 2). Cases of female breast cancer and cancers of the male genital system (defined by a lower-than-expected number of cancers of the prostate) were also statistically significantly lower among refugees than in the SEIR-referent population. For most other comparisons, the number of cancer diagnoses in refugees was statistically equivalent to the SEIR-referent population, except for cancers of the central nervous system. The number of cancers of the central nervous system among refugees was statistically significantly higher than expected based on the SEIR-referent population.


REFERENCES

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

For all malignant cancer sites combined, refugees had a lower-than-expected number of cancer diagnoses (57 observed versus 95.6 expected), with an observed-to-expected (O/E) ratio of 0.59 and 95% confidence interval (95% CI) of 0.44, 0.77 (Table 2). Cases of female breast cancer and cancers of the male genital system (defined by a lower-than-expected number of cancers of the prostate) were also statistically significantly lower among refugees than in the SEIR-referent population. For most other comparisons, the number of cancer diagnoses in refugees was statistically equivalent to the SEIR-referent population, except for cancers of the central nervous system. The number of cancers of the central nervous system among refugees was statistically significantly higher than expected based on the SEIR-referent population.

With support from IDHW, we were able to identify potential partners at local public health districts and health systems where refugees are currently resettled. In addition, CDRI and local public health partners intend to connect with the relatively small number of providers in Idaho that treat and screen Idaho’s refugees.

REGISTRY CONTACT INFORMATION

202-338-5000  https://www.idcancer.org/
SUMMARY
The Illinois State Cancer Registry (ISCR) created a tool to track and report duplicate cases identified in case consolidation activities by submitting hospital, abstractor, primary site, and reason cases that are duplicates. Reports will be used to assist in training plans.

CHALLENGE
ISCR wanted to implement a time-effective method to educate abstractors, to reduce duplicate cases, to improve data quality in both the hospital and central registry, and to reduce the time hospital staff spend abstracting duplicates and the time central registry staff spend identifying and deleting duplicate records.

SOLUTION
ISCR created a Duplicate Database, using Microsoft Access, to store and track duplicate case information. The database houses demographic and tumor information, the reason the case was a duplicate (from a defined set of reasons), and a comment field used to explain in detail why the cases are duplicates. The database can quantify duplicates by reason the case is a duplicate, by reporting hospital, by abstractor, by primary site, and by diagnosis date. Two standard reports are output: a letter for each duplicate case and an administrative report summarizing duplicate cases letters generated each month by submitting hospital and reason case is a duplicate. Ad hoc reports can be created to allow ISCR staff to identify training needs and develop appropriate training plans and materials at a hospital and/or statewide level. Once a month, letters describing duplicate cases identified in that month are sent to reporting hospitals using a secure site. Hospital staff only need to reply to the letter if they disagree with ISCR.

RESULTS
ISCR staff began using the Duplicate Database February 1, 2021. Between March and August of 2021, ISCR sent reports to reporting hospitals for a total of 237 duplicate cases. Each month between 22 and 99 letters were sent to 9 to 50 hospitals. As shown in Table 1, below, the most common reason facilities submitted duplicate cases was failure to correctly apply the multiple primary rules (51% of all duplicates). The second most common reason was submitting cases with differences in demographic fields (the hospital failed to recognize the cases were for the same person).

The Duplicate Database project is new, and the hospitals have only had a few months to apply any abstracting changes in response to the letters received, so it is too early to assess the effectiveness of this tool in reducing the number of duplicate cases. However, hospitals that submitted the greatest number of duplicates appear to be showing a decrease in the number of duplicates over time. The hospital that submitted the most duplicate cases to date has shown a decrease from 18 duplicate cases in a month to only one or two per month.

Other than the time required to input cases in the database, this project has not placed additional time demands on ISCR staff. ISCR has received no negative feedback from hospital registries in response to the duplicate letters and hospitals have contacted ISCR only three times because they disagreed the cases were duplicates. One hospital identified and corrected software issues that were resulting in the resubmission of previously submitted cases. Only one case reported by ISCR as a duplicate was determined in the end to not be a duplicate record because the registrar had accidentally submitted a case with incorrect tumor information.

SUSTAINING SUCCESS
ISCR will continue to use the Duplicate Database and monitor the effectiveness of this training tool. As hospital registry staff change over time and new solid tumor rules are implemented, it is anticipated the database and letters will remain a good training tool that requires minimal time input for both central registry staff and hospital staff.

REGISTRY CONTACT INFORMATION
217-785-1873
Indiana State Cancer Registry: Sanjay Kumar

Implementing CTR (Certified Tumor Registrar) of the Month

National Program of Cancer Registries

SUMMARY
Indiana State Cancer Registry (ISCR) is implementing a program to recognize staff and/or colleagues for their outstanding performance. The recognition is awarded to an individual each month based on CTR timeliness of data submissions and data quality. The CTR of the Month and their respective hospitals and health systems will be featured in section communications.

CHALLENGE
The impact of COVID-19 on hospitals and health systems is a challenge for the ISCR. CTRs are experiencing increased stress and time constraints which can impact their ability to track submissions, ensure the quality of data, and submit reports on time. Overcoming this challenge is central in ensuring that the ISCR is a useful and impactful tool in helping to reduce the burden of cancer in Indiana.

SOLUTION
Partnering hospitals and health systems and their CTRs have indicated their need for support. The ISCR aims to provide that support through monthly recognition of CTRs and monthly education webinars.

The recognition underscores and promotes the contributions of each individual CTR while encouraging recognition within their hospital and health system. The monthly education webinars afford CTRs the opportunity to be aware of any changes or issues that might arise in their daily work by allowing them more certainty in planning and executing their reporting and helping to ensure accurate tracking, quality data and timely reporting. ISCR is also working on monthly webinars that will provide CEs for participating CTRs.

RESULTS
The ISCR hopes to see increased participation in its continuing education seminars. CTR of the Month recognition for individuals and their hospitals and health systems will enhance CTR satisfaction and create more collaboration. All efforts will enhance greater camaraderie and fellowship among central registry and reporting registries’ staff.

SUSTAINING SUCCESS
The success will be sustained through monthly seminars to retain National Cancer Registrars Association (NCRA) recognition and the continued participation from reporting facilities.

REGISTRY CONTACT INFORMATION
317-234-2945
https://www.in.gov/isdh/24968.htm
SUMMARY
The digital document management system is a good alternative when physical office is becoming limited.

SOLUTION AND RESULTS
Virtual space is becoming the norm when office space is taken away in real time from registries. The Kansas Cancer Registry started a digital document management system in 2003. The system started with scanning/capturing paper documents into digital images, followed by indexing to begin the process of building the database to include each document. Critical information such as reporting facilities, type of reports, date of diagnosis was captured. Management reports allow the management team to appropriately evaluate timeliness, completeness, and data quality pertaining to reporting facilities and personnel that is needed to meet the KCR and NPCR objectives.

SUSTAINING SUCCESS
The digital document management system requires a Registry management team’s constant attention toward changing technology improvements but for continued viability this system can work in a non-physical environment during times when physical space is at a premium.

REGISTRY CONTACT INFORMATION
913-488-4722
https://apps.kumc.edu/kcr/
SUMMARY

Electronic pathology (ePath) reports continue to be a critical primary source of cancer diagnosis information for cancer registries. The Kentucky Cancer Registry (KCR) currently receives the majority of ePath reports directly from hospital-based pathology labs, but a significant number of reports for Kentucky cases are generated by national pathology labs. NPCR has been instrumental in developing a reporting infrastructure for the national labs. KCR has developed processes and procedures to begin receiving ePath reports from national labs through a relatively new interface to the Association of Public Health Laboratories Informatics Messaging Services (APHL/AIMS) with the help of the Kentucky Department of Health (KYDOH) and the NPCR Program.

CHALLENGE

A growing number of ePath reports for cancer patients in the state of Kentucky originate from national reporting sources. These pathology reports are critical for KCR to maintain population-based cancer surveillance in the state. However, national reporting labs contend with requests to report to many different end points in different states utilizing a variety of transport protocols. Establishing and maintaining multiple point-to-point connections in a secure, maintainable manner, can be challenging. Consequently, national reporting labs would greatly benefit from an efficient, centralized method of sending multiple data streams to multiple state endpoints while ensuring the security and auditability of the data. Moreover, Kentucky and other states would greatly benefit from a single data provider that aggregates ePath reports from all national reporting sources through a single reporting interface, thus reducing staffing and other resources required at the central registry.

SOLUTION

APHL/AIMS is a secure, cloud-based platform for public health reporting used by federal agencies, regional commercial laboratories and hospitals, State Health Information Exchanges, and 50 state public health jurisdictions [1]. With assistance from the NPCR Program and the KYDOH, KCR has established a connection to APHL/AIMS for receiving electronic pathology reports from a variety of national reporting sources. Data flows from national reporting sources to APHL/AIMS, and then to the KYDOH where they are held for daily batch transmissions to KCR. To support this new incoming data source, KCR has developed and tested automated software to process APHL/AIMS reports for incorporation into its ePath repository. This solution should be scalable as additional national labs develop the capacity to transmit through APHL/AIMS. We anticipate that only minimal changes may be needed to onboard additional national labs. In addition, test reports were checked for validity and reportability as a final step before enabling the daily batch process for receiving data.

RESULTS

KCR is still in the implementation and testing phase of this project but has successfully received hundreds of electronic pathology reports and incorporated them into the KCR ePath repository. Only limited informatics support was required of KCR staff since most of the electronic interface and transport configuration was handled by APHL/AIMS and the KYDOH. Most of the work on the KCR side was to develop automated software scripts for moving files into its repository. Early results are encouraging and suggest that the APHL/AIMS interface may prove to be a good solution for national lab reporting. This will ultimately lead to an increase in completeness and timeliness for cancer reporting in the state of Kentucky.

SUSTAINING SUCCESS

KCR plans to conclude testing and implementation for transition to the production phase by the end of 2021. The registry will continue to monitor incoming APHL/AIMS pathology reports for reportability and validity and will track the volume of reporting through this new method. KCR intends to continue to work with the NPCR program to identify additional national reporting sources that can transmit data through APHL/AIMS. As a result of this solution, we anticipate this effort will be sustainable with our existing resources.

REGISTRY CONTACT INFORMATION

859-619-1521
https://www.kcr.uky.edu/

REFERENCES

https://www.aphl.org/programs/informatics/Pages/aims_platform.aspx
SUMMARY

Death Clearance (DC) is vital to maintaining a high-quality population-based cancer registry. However, ensuring that no cancers are missed is both resource intensive and time consuming. The Louisiana Tumor Registry (LTR) consistently researches ways to innovate processes in case finding. In 2016, LTR began investigating registry specific uses for the Louisiana State Hospital Inpatient Discharge Data (HIDD), which we first gained access to in 2012. We found that the HIDD was a useful source to identify clinically diagnosed cases and then set out to pilot if the HIDD could assist in DC Follow-back.

CHALLENGE

DC follow-back is the process of verifying the cancer cause of death listed on a death certificate for those whose cancer is not in the LTR Database. A clinical source that diagnosed and/or treated the cancer is required. Many potential cancer cases die in hospice care, nursing facilities, or in their homes; leaving the only follow-back source to be the doctor who signed off on the death certificate. Our registry DC staff spend valuable time chasing false leads, often spending days at local hospice facilities scoring records to locate a diagnosing facility or referring physician from medical records. LTR needed a way to streamline the process of locating someone actively connected to the patient’s cancer care.

SOLUTION

The HIDD covers 75% of all hospital inpatient bed utilization in Louisiana. By linking the DC file with the HIDD, LTR was able to locate the hospital admissions directly preceding the patient’s death. We provided the DC follow-back staff with the facility name, discharge date, and discharge status for all admissions linked to an individual on the death list. The DC staff could begin their follow-back by reaching out directly to these facilities or through LTR’s increased access to electronic medical records.

RESULTS

This innovative practice has improved the efficiency of the DC process as we have maintained success in reaching our DC goals. However, its full potential was not revealed until the onset of the COVID-19 Pandemic lockdown, in March 2020, coincided with LTR’s yearly DC processing. LTR staff transitioned to “Work from Home” and many facilities limited access to resources outside of COVID care. LTR was still able to link with the HIDD and circulate the linkage results to DC staff throughout the state. Staff were met with minimal resistance as they could focus the request for data. The 2020 HIDD linkage for death year 2018 found hospital discharge information on 57% of unconfirmed cancer deaths. Staff were able to conduct Death Clearance as usual, reaching LTR’s internal deadline of August 2020 and achieving a Death Certificate Only rate of 0.95% for the 2018 diagnosis year.

SUSTAINING SUCCESS

To sustain success, we will continue annual linkages of the HIDD with death certificates.

REGISTRY CONTACT INFORMATION

504-568-5757
https://sph.lsuhsc.edu/louisiana-tumor-registry/
Program Manager recruited seven members to serve on the Cancer Inquiry Group: the state Lead Environmental Epidemiologist, the state Lead Chronic Disease Epidemiologist, two MCR Epidemiologists, the Director of Data, Research and Vital Statistics (where MCR is housed), the MCR Program Manager, the MCR Data Quality Manager (who is a Certified Tumor Registrar) and an Epidemic Intelligence Service officer assigned to Maine CDC (ME CDC) with extensive background in cancer epidemiology. The group met for the first time in April 2021 and meets on a quarterly basis if there are inquiries to review.

MCR epidemiologists developed an established workflow and several templates and tools to guide this work. First, a structured questionnaire intake form outlines the information that the MCR epidemiologist gathers from the concerned constituent. Next, a standardized incidence ratio calculator tool and background data review template guide the preliminary analysis completed prior to the Cancer Inquiry Group meeting. The data review template includes relevant information about the cancer(s), the town(s) or geographic area, and environmental exposures of concern. It includes a section for registry data such as a case listing and analysis of local, county, and state rates to compare trends and present standardized incidence ratios (SIR). Based on the first two Cancer Inquiry Group meetings, the group revised a list of eight decision criteria to help summarize the level of concern, next steps, and recommendations.

RESULTS
In the first nine months of 2021, the Maine Cancer Registry received ten cancer inquiries. Three inquiries were addressed via telephone conversations and email without review by the committee, and the remaining inquiries were reviewed by the Cancer Inquiry Group in quarterly meetings held in April and August 2021. The inquiries provided an opportunity to revise the intake form, update the background data review template, and test the SIR calculator tool.

At the same time, MCR reviewed inquiries received over the last two decades and created a reference table that can be used to identify inquiries by location or specific cancer site. This provides an overview of how the MCR responded previously to different types of concerns which may guide responses to inquiries in the future (e.g., groups of cancer among teachers in a school). In addition, it documents whether MCR previously investigated cancer in a certain area. The MCR regularly receive requests from internal partners such as environmental health or from external constituents asking “Has MCR investigated cancer in ____ town?” The review provides a single point of reference rather than relying on staff memory or searching through archive files.

A few key lessons have emerged from this work thus far. First, having consistent protocol, tools, and templates for reviewing and responding to an inquiry allows the group to determine next steps in a timely manner. Second, a multi-disciplinary group with different areas of expertise from certified tumor registries to environmental and chronic disease epidemiologists strengthens the Cancer Inquiry Group discussions and decision-making. Third, having an index of resources for constituents improves our response, especially when in most cases the group does not pursue further epidemiologic investigation. Resources range from information about how the state supports testing well water and soil for contaminants to information about cancer prevention, screening, and diagnosis. Fourth, clear communication and follow-up with all relevant parties (both the constituent as well as local elected officials and others, as appropriate) helps to ensure that all concerned parties are aware of the MCR review and response. This is especially relevant in situations where the same concern is referred to MCR through multiple channels.

SUSTAINING SUCCESS
The MCR Cancer Inquiry Group will continue to work on establishing standards for analysis, communication, referral, and outreach in response to constituent cancer concerns. Furthermore, MCR will consider how to better connect and integrate with Maine CDC environmental health resources as well as Maine CDC cancer prevention and control colleagues to provide appropriate resources to concerned constituents. We will continue to document trends and consult with neighboring states when concerns are in border towns. Once updated cancer cluster guidance is available from CDC, those recommendations will be incorporated into existing protocols and procedures.

REGISTRY CONTACT INFORMATION
207-287-5272

2. MMWR Provisional & Trendy Data Home | SD | CDC. Accessed August 26, 2020.
SUMMARY
The Maryland Cancer Registry (MCR) developed a data release coversheet as a clear way of describing the data that researchers will receive.

CHALLENGE
Researchers requesting registry data did not always understand what was included and excluded in their requested data sets. The specifications of each released data set provided to researchers were also not documented.

SOLUTION
MCR staff developed a data release coversheet to reassure researchers of the integrity of the MCR disclosure. The data release coversheet is used for line listed data, which is often based on a data request of all the cases of a certain gender, race, time frame, primary site, stage, and/or location.

On the coversheet, the "Source of the Data" notes the data set used, which is named after the date extracted. For linkages, the data source is the most recent cut to contain the most matches. Data cuts occur at least quarterly. For line listed requests, static data are used. Since the data set changes continuously, as new cases are reported and consolidated, the MCR cuts a static data set once per year for the MCR’s official numbers. This allows the MCR to answer questions about the official figures and to replicate those numbers at any time in the future.

The last two sections of the data release coversheet describe the inclusion or exclusion of data from other sources, such as data from other states or death data. The MCR adheres to certain terms and conditions that may prohibit or limit the re-release of data from certain sources. For example, the number of cases from interstate data exchange and the states are noted. If data are solely received from interstate data exchange, data are not released. However, if there are many cases from another state, the researcher can contact that state and request that they allow the MCR to release that data. Data received from the Veteran’s Administration are not released and data received solely from the Maryland Vital Statistics Administration are not released without a sign off on the Institutional Review Board (IRB) request from the Vital Statistics Department. If a sign off has been received from the Vital Statistics Administration, then all requested variables, death date, cause of death, and vital status can be released. Only date of death and vital status can be released if the death information was received from the National Death Index (NDI).

RESULTS
As a result of the data release coversheet, MCR staff have answered fewer questions by researchers. Researchers commented that the instructions were clearer and easier to follow. If there are questions or a need for additional variables, the MCR staff knows which data to use and what has been released.

SUSTAINING SUCCESS
The data release coversheet improved communications with researchers, and the MCR will revise the coversheet as changes are made in the registry community.

REGISTRY CONTACT INFORMATION
410-767-5459
SUMMARY
This success story describes the collaborative process in which the Massachusetts Comprehensive Cancer Prevention and Control Network (MCCPCN) worked with the Massachusetts Cancer Registry (MCR) and the Prostate Cancer Workgroup to conduct an in-depth analysis of MCR data. This resulted in a manuscript1, which discussed racial differences in the treatment and outcomes for prostate cancer in Massachusetts. Additionally, the MCCPCN conducted a qualitative study using key informant interviews (KIIs) to identify perceived barriers to prostate cancer treatment for Black non-Hispanic (NH) men. The MCCPCN and the Prostate Cancer Workgroup used quantitative and qualitative data from KIIs to guide the development of interventions aimed at ensuring equitable treatment for prostate cancer in Massachusetts.

CHALLENGES
- Length of time for the manuscript to go through the internal peer review process and approval prior to submission.
- Delays in conducting key informant interviews due to the COVID-19 pandemic.
- Resignation of two prominent positions from the MCCPCN which affected project continuity.

SOLUTION
- The MCCPCN and members of the Prostate Cancer Workgroup used MCR data to examine prostate cancer disparities between Black non-Hispanic and White non-Hispanic men.
- Based on the results of the in-depth data analysis, the Prostate Cancer Workgroup decided to conduct a qualitative study using key informant interviews (KIIs) to identify perceived barriers to prostate cancer treatment for Black non-Hispanic men.
- Members of the Prostate Cancer Workgroup were instrumental in helping identify key informants and providing contact lists for people to interview.
- The pandemic made it easier for members of the Prostate Cancer Workgroup to organize meetings as some oncologists were teleworking and not at hospitals.

RESULTS
Quantitative Results
Black non-Hispanic men were significantly less likely to receive treatment for prostate cancer than White non-Hispanic men. Men with public insurance experienced lower odds of definitive therapy compared to men with private insurance. Despite the lower odds of definitive therapy, Black non-Hispanic men in Massachusetts had a 17% lower cancer-specific mortality hazard ratio compared to White non-Hispanic men.

Qualitative Results
- There is a growing awareness that disparities in prostate cancer treatment exists.
- Factors that affect prostate cancer treatment include access to care, health literacy, socioeconomic status and financial concerns.
- Prostate cancer treatment decision-making is affected by factors such as medical and research mistrust, tolerance of side effects, shared decision-making, family support, and severity of disease.
- Disparities in prostate cancer treatment can be addressed through patient education, decision tools, improved communication, and the use of community health workers and patient navigators.

SUSTAINING SUCCESS
The MCR continues to collaborate with its partners on several projects including publication of the study results and collaboration with the Prostate Cancer Workgroup on a grant to address prostate cancer treatment disparities in Massachusetts by working with selected hospitals.

REGISTRY CONTACT INFORMATION
617-624-5662
https://www.mass.gov/massachusetts-cancer-registry

SOURCE
1 Racial differences in the treatment and outcomes for prostate cancer in Massachusetts. Available at: https://acsjournals.onlinelibrary.wiley.com/doi/full/10.1002/cncr.33564
SUMMARY
Our team identified over 78,000 patient records needing improvements in the Social Security Number and vital status fields. These data points were updated using linkage results provided by LexisNexis.

CHALLENGE:
Frequently, incoming records to MCSP supplied all 9’s in the SSN field. Other times, records were submitted with a masked SSN (such as leading 8s, followed by the last 4 actual digits). This issue makes data linkages more difficult as the SSN is customarily a strong and unique patient identifier. As a result, this weakness in the incoming data inhibits linkages with death records. How can this weakness be remedied through a data quality initiative?

SOLUTION
LexisNexis provides a robust linkage to patient identities by running algorithms against a wide variety of sources (to include credit histories, licenses, etc.). First, the candidate records from the cancer Registry were selected from the database. From the consolidated data set, SQL queries extracted a set of demographic data for 70,979 patients. Additionally, 4,833 records were selected from the "pending consolidation" queue. Lastly, 2,473 unprocessed records were included for consideration. These records were enumerated with a state-specific ID, for correlating the results back to the internal CRS Plus patient IDs.

RESULT
The total records sent outbound to LexisNexis included 78,285 rows. The results were returned to MCSP in a spreadsheet with the same row count including “best matches” from the LexisNexis linkages. Within these results, the “best SSN” was reliably supplied 66,645 times (85.1%). Separately, vital status information was included for 9,062 patients who were linked to deceased identities from the Social Security Administration or death records. This included dates of death and last known addresses.

We developed processes using local SQL databases and/or Excel to generate database update scripts to apply to our registry database. In the first round of updates, patient SSNs were updated for consolidated patient records from the linkage results. Fields that were updated from death information included Vital Status, ICD Revision Number, Death Cause, Date of Last Contact, and several MI-specific fields used for tracking/auditing purposes. In the second round of updates, the patient date-of-birth was also updated, as the date supplied by Lexis Nexus were consistently more precise than the previously stored dates.

For records which had been pending consolidation or were unprocessed, a supplemental worksheet was created from the results to aide data consolidators with best matching information. Lastly, a 60,696 patient current addresses were updated via scripts from the LexisNexis results.

SUSTAINING SUCCESS
Fortifying the data intake process is the first level of defense against incomplete data. To prevent the accumulation of unknown SSNs, MCSP created an updated metafile with state-specific error checking. In a state-specific field, a "reason for unknown SSN" must be supplied whenever such a circumstance arises. This check will act as an ongoing reminder and request for follow-back by the facility to obtain these data.

The process of updating the CRS Plus database has been documented, so that future linkages may be performed in the same or similar manner.

REGISTRY CONTACT INFORMATION
AlversonG@michigan.gov
https://www.michigan.gov/dhhs/0,5885,7-339-71551_7426_5221-16586--,00.html
SUMMARY
Breast cancer screening rates dropped precipitously after U.S. states locked down in response to the COVID-19 pandemic. The Minnesota Cancer Reporting System (MCRS) and the Minnesota Sage Breast and Cervical Cancer Screening Program (Sage) collaborated to develop and disseminate data analyses for partners and stakeholders to support and facilitate robust efforts to increase breast cancer screening rates.

CHALLENGE
Millions of U.S. women delayed routine breast cancer screening procedures after the SARS-CoV-2 pandemic locked down states in the spring of 2020. Minnesota’s senior U.S. Senator, Amy Klobuchar, shared in a recent interview with local reporters that she was diagnosed and subsequently treated for stage 1A breast cancer following a mammogram that she had delayed due to COVID-19. She urged all women in MN not to delay their routine screening (https://www.npr.org/live-updates/biden-covid-vaping-fda#sen-klobuchar-says-she-was-treated-for-breast-cancer-earlier-this-year).

SOLUTION
In response to screening delays stemming from the COVID-19 pandemic, health care systems, the Minnesota Cancer Alliance (MCA), the American Cancer Society (ACS) individually and in collaboration with the Minnesota Department of Health (MDH) initiated robust efforts to increase awareness of the importance of screening for breast cancer, and the programs and resources available for women in Minnesota. To educate and motivate health professionals and consumers and inform and focus outreach efforts, MDH’s Minnesota Cancer Reporting System (MCRS) developed two fact sheets and a facts and figures report in collaboration with Minnesota’s Sage Breast and Cervical Cancer Screening Program (Sage). MCRS also developed an online dashboard for use in program planning and decision-making, as well as state and local media campaigns during October’s Breast Cancer Awareness Month.

RESULTS
MCRS publications were widely disseminated with promotional and other information through traditional and social media outlets, website links, newsletters, educational and training presentations, and other outreach efforts though Sage, the Minnesota Cancer Alliance, the American Indian Cancer Foundation, and the American Cancer Society.

- Breast Cancer Survival in Minnesota Fact and Figures report provided up-to-date estimates of relative survival for breast cancer in Minnesota. This report documented improvements in survival overall and by stage, as well as substantial declines in breast cancer mortality which provides evidence of real progress made in the fight against breast cancer since the 1990s.

- The Breast Cancer Disparities Fact Sheet and the Need for Early Detection and Treatment of Breast Cancer Fact Sheet highlighted racial and ethnic disparities in the incidence, mortality, and survival from breast cancer among Minnesota women. Population-based findings such as these were used to help inform cancer screening awareness and outreach for communities of increased risk.

SUSTAINING SUCCESS
Maintaining the progress Minnesota has made and improving breast cancer outcomes for women who are at increased risk for cancer remain important priorities. Data analyses that account for the social determinants of health can help guide and inform programs, policymaking, and educational outreach. MCRS and Sage will continue to collaborate on analyses of MCRS and other data and develop effective data dissemination plans with partners and communities impacted at state and local levels. Soliciting feedback from diverse partners and people at higher risk of cancer will be an important source of information on which to improve the usefulness of cancer registry data in breast cancer prevention and control.

REGISTRY CONTACT INFORMATION
651-201-5900
https://www.health.state.mn.us/data/mcrs/index.html
SUMMARY
With limited resources, it is always necessary to use data and evidence-based interventions to drive cancer control. Much of the work is done by lay volunteers or professionals who are not familiar with the data. The Mississippi Cancer Registry and the Mississippi Cancer Control Program partnered to offer an education session for the MP3C Regional Coalition Chairs and Co-Chairs to help them understand the cancer data available for use and to cover data on cancers that are high in their areas and/or of particular interest to their regional coalition members.

CHALLENGE
Cancer control resources are limited. To utilize them effectively, those working in this area are encouraged to use data to drive their work and to use evidence-based interventions to do the necessary work. Data is readily available online for Mississippi and for the United States, on CDC’s United States Cancer Statistics webpage (USCS). However, for many working in cancer control, the data can be difficult to understand and determine how to use. When overwhelmed by difficult information or an overwhelming amount of information, sometimes feelings and emotions drive the work rather than data.

SOLUTION
On Monday, November 9, 2020, the Mississippi Cancer Registry Director, and the Mississippi Comprehensive Cancer Control Epidemiologist, presented a training to the MP3C Regional Coalition Chairs and Co-Chairs to educate them on statistical terms and interpretation of data. Also, the chairs and co-chairs were provided with training on regional data for cancers that are a focus in the state cancer plan and specific to that coalition. They were taught how to use rates and counts, how to interpret rates, and limitations of the cancer data available. They were also presented with data specific to their region with breakdowns by county when possible. We provided them with one-page sheets with the information on their region for reference. We shared links to the online data sources to review with their new knowledge. They were also encouraged to contact the Mississippi Cancer Registry Director or the Mississippi Cancer Control Program Epidemiologist for assistance with finding or interpreting any data they encounter.

RESULTS
MP3C Regional Coalition Chairs and Co-Chairs indicated that they appreciated the instruction and the region-specific data in the evaluations of the meeting. Their understanding of the statistical terms increased, as well as their awareness of the needs in their region.

Data was presented on HPV-related cancers. The low vaccination rates coupled with high HPV-related cancer rates were of interest to the regional coalition for the counties in central Mississippi. They chose to partner with the Mississippi HPV roundtable on the initiatives that group is working on such as provider and client reminders and back-to-school activities.

SUSTAINING SUCCESS
This training will be an annual event. MP3C Chairs and Co-Chairs will be polled to determine what they are interested in learning and what data they may need. This will be supplemented with any other data that the Mississippi Cancer Registry Director and Mississippi Comprehensive Cancer Control Program Epidemiologist deem would be helpful for the coalitions. These two data staff will also continue to build a rapport with the regional coalition chairs and co-chairs to be a resource for finding and interpreting data used to make programmatic decisions.

REGISTRY CONTACT INFORMATION
601-815-5482
https://www.umc.edu/cancerinstitute/Cancer-Research/CancerRegistries/Mississippi%20Cancer%20Registry/HOME-PAGE-CONTENT.html
SUMMARY
Use of project management tools such as Trello, Asana, Jira, Clickup, and others allowed us to explore the capabilities for cancer registry project and time management. It also allowed MCR management to expand the scope with the following application:

- Trello is a useful tool for tracking, planning, organizing of activities, and management of projects
- Trello is used in the registry for repetitive, large projects such as upgrading of CRS+ products, annual data submission, data modernization project, and annual linkages
- Trello is a useful tool to not only manage the project but also helps to keep necessary documentation and communications at hand

CHALLENGE
2021 has been challenging, with a longer than expected upgrade process of the CRS+ products. In addition, other changes and upgrades have required ongoing attention simultaneously such as the DMI project, pathology reporting, annual data submission, and the DCO process. These projects need to be simultaneously tracked and organized.

SOLUTION
In 2021, MCR had to go through upgrading and upgrade related tasks that involve all CRS+ products that took longer than expected. With several new employees we were able to review some of our processes and decided we needed a project management tool that can be easily accessed and updated by all team members. Trello is a newer tool that can be utilized for various uses. Once the tool was introduced and made available to everyone in the registry, we identified the projects in need of project management mainly annual and ongoing projects.

RESULTS
We were able to create the following boards for project management at MCR:
1) MCR monthly meetings, 2) MCR Informatics Projects, 3) Data Modernization Workgroups, 4) MCR Registry Plus Upgrades, 5) MCR Plan budget, and 6) Pathology Reporting, that are now accessible to each member of the team/board with activities/tasks assigned and due dates. We found that the central Trello boards have made keeping everyone informed easier. We were able to present Trello, one of several project management tools, at the RPUG meeting to share with other registries.

SUSTAINING SUCCESS
The following lessons learned can be integrated into registry processes:
- Presenting at RPUG to share with other interested registries and learn from other CCRs how they process and what they use for project management in CCR
- Empowering the whole CCR team to be an active member of the process and project management in the MCR
- Providing quick overviews for management to see where we stand and what we need to get accomplished before our annual submissions
- Decreasing time spent to organize projects, leading to other more efficient ways to manage certain processes in the registry for example the data submission process
- Updating the board can be done by any team member, as Trello operates in real-time, resulting in up-to-date boards and communication

REGISTRY CONTACT INFORMATION
573-882-7775
http://mcr.umh.edu
The Statewide Voter File Proves Useful to Obtain Physical Address for Cases with Only P.O. Box Reported

SUMMARY

Physical address is essential to correctly geocode and assign cancer cases to the correct census tract for sub-county analysis. However, many rural areas do not get mail delivery at their home and instead use a PO Box for mail. This has led to 15% of cases reported to the Montana Central Tumor Registry (MCTR) to be reported with only a PO Box for address at diagnosis and no physical address. The publicly available statewide voter file contains both the mailing and physical address for all registered voters in Montana. Linking cancer cases to the statewide voter file resulted in 4,311 cancer cases diagnosed from 2008 to 2019 to have a physical address added where they previously only had a PO Box. The increased proportion of cases with a valid physical address resulted in increased precision for geocoding so that 91% of cases diagnosed in 2019 were able to be geocoded to the street level or better.

CHALLENGE

Physical address is a required field for reporting cases of cancer in Montana. However, many rural areas don’t have mail delivery at their home and instead use a PO Box for mail. Hospitals and other cancer reporters may only have the mailing address in these cases. This resulted in about 15% of cancer cases being reported to the tumor registry with only a PO Box and no physical address. Physical address is used to geocode cases and assign them to the appropriate census tract. PO Box only cases are assigned to the center of their zip code when geocoded and have a high likelihood of being classified to the wrong census tract. Additionally, the zip code of a person’s PO Box is not necessarily the same as the zip code where they live. Census tract designation is useful for analysis of sub-county areas in response to cancer cluster concerns raised by the public or in response to known environmental contamination. One such investigation revealed a census tract that appeared to have significantly higher incidence of cancer but upon further investigation it was clear that all the excess cancer cases were assigned to the census tract based on zip code alone. The higher incidence was only a result of census tract misclassification.

SOLUTION

The Montana Secretary of State’s office maintains a database of all registered voters in Montana which includes the voter’s name, date of birth, mailing address, physical address, and voter eligible date (the date when that person is eligible to vote at the given physical address). This data, the statewide voter file, is publicly available for purchase. The MCTR had some unspent funds due to travel cancelations through 2020 and decided to purchase the statewide voter file and assess its usefulness to obtain physical address for cases that were reported with only a PO Box for address at diagnosis. MatchPro software was used to match all cancer cases reported to the MCTR as of November 2, 2020, and diagnosed from 2008 to 2019. Cases were matched to voters based on first, middle, and last name and full date of birth using the default MatchPro settings for cut off values and blocking. Cases with only a partial match of first name, last name, or date of birth were manually reviewed to weed out false positive matches. If only one of those three variables didn’t match exactly and the mismatched variable was close (i.e., only one digit difference in the date or a common nickname for the first name listed in other file) then the case was considered a true match.

As the voter file provides current address at the time of download and does not provide address history, the linkage needed to not only assess whether it was linked to the correct person but to also determine whether the person lived at that address at the time of their cancer diagnosis. All matching cases with only a PO Box for address at diagnosis or with GIS coordinate quality of 6 or higher (zip code centroid or less precise) were manually reviewed to assess whether the mailing address in the voter file matched the reported address in the tumor registry. If the mailing address wasn’t at least within the same town the case was eliminated, then cases with matching mailing addresses were assessed to compare date of diagnosis to the voter eligible date. If the voter eligible date was prior to their date of diagnosis their physical address in the voter file was imported into the registry. This ensured that the case must have been eligible to vote at the physical address in the voter file before they were diagnosed, and they had not registered to vote at a different address up until the time of the linkage.

RESULTS

Linkage with the statewide voter file resulted in 4,311 cases having a physical address added to their record where there was previously only a PO Box for address at diagnosis. The proportion of PO Box only cases that were able to be matched increased as year of diagnosis became more recent. About 20% of PO Box only cases diagnosed in 2008 to 2011 had a physical address added, while over half (54%) of PO Box only cases diagnosed in 2019 were able to be linked. The additional physical addresses led to a significant improvement in the GIS coordinate quality for all diagnosis years and the magnitude of the improvement increased as the year of diagnosis became more recent (Figure). Ninety-one percent of cases diagnosed in 2019 were able to be geocoded to the street level or more precisely. There was a corresponding decrease in the proportion of cases geocoded to the PO Box zip centroid, less than 2% of cases diagnosed in 2018 and 2019. The proportion of cases with a physical address that were still geocoded to the centroid of their zip code did not change for diagnosis years 2008 to 2017. However, there was an increase in the proportion of cases geocoded to the zip code centroid diagnosed in 2018 and 2019 indicating that some of the physical address imported from the voter file could not be geocoded precisely.

SUSTAINING SUCCESS

MCTR will continue linking to the statewide voter file annually. MCTR will also work with Alias tables and reviewing uncertain matching addresses to improve the precision of non-standard physical addresses.

REGISTRY CONTACT INFORMATION

406-444-2832
https://dphhs.mt.gov/publichealth/cancer/tumorregistry
SUMMARY

The Nebraska Cancer Registry resolved to automate data quality control activities for electronic cancer pathology reports in Health Level Seven (HL7) format from laboratories. To do so, it needed to summarize common types of errors in the HL7 messages and provide solutions.

CHALLENGE

The Nebraska Cancer Registry (NCR) started to receive consistent electronic pathology (ePath) reporting in HL7 format in March 2021. The ePath reports originated from four local and national laboratories comprising more than 95% of the pathology report volume in Nebraska. The volume of data prohibited the continued use of manual error detection and error correction methods for data quality control activities. Furthermore, new errors were encountered with the engagement of more reporting laboratories, making the data quality control activities even more difficult.

Below is a summary of the most common types of issues observed in the HL7 messages:

• Required data items were missing. Laboratories must frequently depend upon ordering facilities to gather data elements such as race and ethnicity.

• Laboratory sent excess segments or data items, causing errors or failure when eMaRC Plus attempted to import files. For example, a laboratory sent two sets of batch segments in one file and caused failure in importing the first batch to eMaRC Plus.

• Laboratory sent data items in the wrong segment or used the incorrect delimiter in the message, causing inaccuracy in the final abstract. For example, a laboratory used wrong delimiters in OBR-32 (Principal result interpreter) data field, which made eMaRC Plus fail to capture the interpreter’s name.

• The health information system of a laboratory didn’t have the technical capability to comply with the required North American Association of Central Cancer Registries (NAACCR) Pathology Laboratory Electronic Reporting Standards, Volume V. For example, one laboratory’s health information system could send only one OBX segment, resulting in an extra-long text field in OBX-5. This text field might exceed the maximum character length allowance and face the risk of truncation during the auto-abstraction process in eMaRC Plus.

SOLUTION

Prior to onboarding, the new laboratory was required to send test HL7 messages for validation in both eMaRC Plus and the Rocky Mountain Cancer Data Systems. The Informatician reviewed the structure of the HL7 messages, and the Certified Tumor Registrars (CTRs) reviewed the converted abstract in NAACCR format. If the test messages required further improvement, feedback was provided to the sending laboratory on the modifications that must be made to their HL7 messages.

Due to the high volume of data, the team developed an automated Java program to detect and correct the errors in the HL7 messages. The program was run internally by the NCR before data transmission to eMaRC Plus. The program integrated a main program that handled the common errors across multiple laboratories and laboratory specific subprograms with each subprogram handling the unique errors that belonged to a particular laboratory. The main program read new messages from the sFTP generation of additional data using the content of Central Cancer Registries (NAACCR) protocol, to further enhance these services, such as generation of additional data using the content already present in HL7 messages provided by laboratories.

REGISTRY CONTACT INFORMATION

402-326-3226

http://dhhs.ne.gov/Pages/Cancer-Registry.aspx
cases, fees, and administrative penalties from 457.250 also outlines the reporting of cancer information would be missed. State Law NRS reported by the hospital, but the treatment because the case was already reported by the provider does not report the information in the registry system. For example, in unreported cancer cases or missed treatment information for a financially sustainable method to fund consistently growing operational costs.

Until recently, complete, and high-quality cancer cases were reported through hospital cancer registries because cancer cases were primarily diagnosed and treated in hospitals. With advances in medicine, patients are now often diagnosed and treated outside the hospital setting. This shift has resulted in under-reporting of cancer cases to the Nevada Central Cancer Registry (NCCR). Prior to the passage of Assembly Bill (AB)471 during the 2021 Legislative session, Nevada State law, Nevada Revised Statute (NRS) 457230, exempted a provider of health care who diagnoses or provides treatment from reporting if the patient is directly referred or previously admitted to a hospital, medical laboratory or other facility that provides screening, diagnostic or therapeutic services. This language exempted providers of health care from reporting, which has resulted in unreported cancer cases or missed treatment information in the registry system. For example, if a provider refers a patient to a hospital but the patient decides to go to a treatment provider group or treatment facility, the case could be missed if the provider/treatment facility does not report the case.

Another example is if a hospital referred a patient after surgery to a provider for treatment. The provider does not report the information because the case was already reported by the hospital. The diagnosis and surgery would be reported by the hospital, but the treatment information would be missed. State Law NRS 457250 also outlines the reporting of cancer cases, fees, and administrative penalties from a health care facility. The definition of a health care facility specified in NRS 162A.740 does not include the other facilities and providers of health care that are outlined under NRS 457230. This existing regulatory language limited the registry’s authority to improve and enforce cancer reporting. The registry informed the Office of Finance in the Office of the Governor about the impact of potential language changes for reporting improvement, as well as, adding a fee for licensure and renewal of radiation machines to support the growing registry operations.

Currently NCCR has six full-time equivalent positions (FTEs) including a program manager, database manager, biostatistician, program administrative assistant, and two certified tumor registrars (CTRs). However, at one point the registry had a total of 10 FTEs working within the registry. During the 2008 recession, the State of Nevada Health and Human Services Department instated furloughs and layoffs for employees. The NCCR unfortunately lost four FTE’s which included: two full-time CTRs, to perform data collection and abstracting; one administrative assistant 3, who provided office administrative support and operation support in the form of follow back assistance, data entering, and onboarding new providers; and a quality assurance manager who participated in all the data quality improvement and assurance projects. The registry was unable to reinstate the positions lost during the recession until this year. At the request of the Office of Finance in the Office of the Governor, NCCR provided information for a financially sustainable method to support the reinstatement of two registry positions.

After much research by the entire NCCR team, including calling other US registries and inquiring how they are currently funded other than through the National Program of Cancer Registries (NPCR) or the Surveillance, Epidemiology, and End Results (SEER), the Registry also worked with workgroups and community partners affected by the policy change and decided to include an additional fee at the time of re-application of certain health facilities and medical laboratories, which would go directly to NCCR operations. This solution was possibly the most reasonable and equitable considering the additional fees are only up to 8% of total reapplication cost and it does not affect any providers directly. It is anticipated that this fee will not hinder providers from reporting cancer data to the NCCR. The fees for hospitals, medical facilities, and the medical laboratories, range from as low as $8 to high as $438 for some of the larger facilities in Nevada.

Involvement by partners and the people impacted by adoption of this new regulation will be critical. The NCCR Program Manager is working with a small workgroup of both internal DHHS agency leaders and external partners to align regulations to the changes in the statutes. Communicating changes once regulations are written and adopted into law will also be key in sustaining success.

775-684-5968  
https://dpbh.nv.gov/Programs/NCCR/Nevada_Central_Cancer_Registry_(NCCR)_-_Home/
SUMMARY
Pediatric cancer data from 1987 onwards were independently audited for data quality.

CHALLENGE
New Hampshire and the Northeast have some of the highest childhood cancer rates in the country, according to a published paper by the Centers for Disease Control and Prevention (CDC). This finding and results of a prior investigation into higher-than-expected rates of two childhood cancers in the Seacoast area have generated concerns about possible environmental causes of these cancers. In response, the New Hampshire State Legislature set aside funds to explore childhood cancer issues in the Granite State. This state funding has allowed a group of cross-disciplinary childhood cancer and environmental health experts to further investigate childhood cancers in New Hampshire. The challenge was to investigate whether there was a significantly high cancer rate, and to communicate with the public during any further investigation, to make the process understandable and transparent.

SOLUTION
A commonly used method to assess cancer data quality is a recoding audit. In this process, text and other contextual data within the registry record are used to code each case. Recoding audits therefore involve independently reassigning codes to abstracted text information but not reviewing the source documents. The pre- and post- data are compared to identify differences, estimate rates of agreement, and to identify problems in data collection and interpretation. The childhood cancer data were audited by independent Certified Tumor Registrars contracted from Registry Partners, Inc. to review 2036 records for the period 1986-2020 for all patients aged <20 years at diagnosis. The key 47 variables reviewed for each case, for a total of 95,692 variables reviewed in all records, for an accuracy rate of 99.8%. Most errors were in coding Stage, Laterality, and Grade. For a small number of variables, some differences were identified relating to missing values.

RESULTS
Of the 47 key variables reviewed, there were 22 variables with no differences across all records. A total of 154 differences were detected in any of the 95,692 variables reviewed in all records, for an accuracy rate of 99.8%. Most errors were in coding Stage, Laterality, and Grade. For a small number of variables, some differences were identified relating to missing values.

Overall, the accuracy rate was excellent (99.8%) for NHSCR Childhood Cancer data. This means that we can be confident in the quality of data collected on these patients.

SUSTAINING SUCCESS
Ongoing, periodic recoding audits will be critical to ensure high quality cancer data.

REGISTRY CONTACT INFORMATION
603-653-6265
https://geiselmed.dartmouth.edu/nhscr/
SUMMARY

The New Jersey State Cancer Registry (NJSRC) has successfully implemented a linkage protocol combining data from the New Jersey Division of Pension and Benefits (NJDP&B), NJSRC, and the National Center for Health Statistics’s National Death Index (NDI). The combined dataset will serve as the basis for a cancer mortality study among one of the largest population-based cohorts of professional firefighters. The results from this study will inform state, national, and international agencies interested in advancing scientific knowledge of occupational exposures in a population considered to be at higher risk for cancer but for whom sufficient research is lacking.

CHALLENGE

Although firefighting was classified as possibly carcinogenic to humans (Group 2B) in 2010 by the International Agency for Research on Cancer (IARC), the Firefighter Cancer Registry Act was passed in 2007 mandating the development of a cancer registry among firefighters, a population-based cohort of firefighters that could serve as the basis for a Firefighter Cancer Registry does not exist in New Jersey. New Jersey is home to more Superfund sites than any other state and more than 38,000 firefighters who are at higher risk of exposure to toxic and carcinogenic chemicals in part due to a larger number of chemical industries and pollutants in the state. Capturing cancer and mortality data for a special population like firefighters also presented a challenge as residential mobility, retirements, and job migration within and out of state makes complete follow-up of the cohort difficult if not impossible. In fact, almost 25 percent of this cohort moved out of state after retirement. We therefore sought to utilize data sources that would not only provide a large, identifiable cohort of firefighters but provide complete information on cancer mortality while maximizing our resources; and ultimately inform prevention strategies to reduce cancer incidence and mortality among firefighters.

SOLUTION

The NJSRC collaborated with occupational and cancer epidemiologist, Dr. Judith Graber, Associate Professor at the Rutgers School of Public Health, Department of Biostatistics and Epidemiology, to establish a statewide cohort of career firefighters in the State of New Jersey. We engaged with administrators at the NJDP&B to discuss the project and present the rationale for requesting their data. We successfully executed a Data Use Agreement between the NJDP&B and NJSRC. The DUA also included terms under which the NJSRC would serve as an honest broker to link NJDP&B data to the National Death Index (NDI) to obtain information on deaths that occurred out of state. Once an agreement with NJDP&B was established, the NJSRC also negotiated a DUA with NDI with the appropriate signatories on behalf of investigators at Rutgers, separate and apart from the NJSRC’s DUA for cancer registry follow-up at the NJDOH. The honest broker process is described in Figure 1.

RESULTS

First responder (fire/police) data from the NJDP&B from 1/1/1944 to 12/31/2018 included name, social security number (SSN), date of birth, gender, employer information, city/state of employer, and dates of enrollment, last contribution, retirement, and death (if applicable). Of the 122,257 NJDP&B records, we captured information for 118,936 unique fire/police members (2,968 missing SSN, 18 missing date of birth). Of these, 2,487 (14.5%) linked to a cancer diagnosis in the NJSRC and, according to NJSRC follow-up data, 1,460 (62.7%) were deceased. The remaining 14,701 male firefighters did not match a record in NJSRC so were sent to NDI for linkage. NDI was able to provide death information on 99% (n=1,442) of the 1,460 firefighters who were known to be deceased but had an unknown cause of death. NDI provided death information on 2.4% (n=305) of the 12,800 firefighters for whom vital status was unknown (or last known alive). As a result of these successful linkages between the NJSRC, NJDP&B, and the NDI, this study of mortality will include information on total of 3,608 (21%) deceased male firefighters in New Jersey.

The male firefighter cohort contained a total of 17,248 members. Of these, 2,487 (14.5%) linked to a cancer diagnosis in the NJSRC and, according to NJSRC follow-up data, 1,460 (62.7%) were deceased. The remaining 14,701 male firefighters did not match a record in NJSRC so were sent to NDI for linkage. NDI was able to provide death information on 99% (n=1,442) of the 1,460 firefighters who were known to be deceased but had an unknown cause of death. NDI provided death information on 2.4% (n=305) of the 12,800 firefighters for whom vital status was unknown (or last known alive). As a result of these successful linkages between the NJSRC, NJDP&B, and the NDI, this study of mortality will include information on total of 3,608 (21%) deceased male firefighters in New Jersey.

SUSTAINING SUCCESS

The NJSRC plans to move on to the next step in this project, which is to analyze the data and generate standardized mortality ratios (SMR) comparing the mortality rate of the NJ firefighter cohort to the general NJ population. Because we know that a large proportion of NJ’s firefighter cohort move out of state, we are seeking an opportunity to conduct a linkage project with the Virtual Pooled Registry Cancer Linkage System (VPR-CLS) to assess incidence. We believe this will be possible given the success we had in negotiating and securing the appropriate data use agreements from key partners. Future linkages may also be conducted to update vital status and cause of death information.

REGISTRY CONTACT INFORMATION

609-633-0500
https://www.state.nj.us/health/ces/
SUMMARY
The New York State Cancer Registry (NYSCR) worked with reporting facilities to increase the percentage of cases reported by electronic pathology report (ePath) from 15.7% in 2014 to 44.8% in 2019. This increase has allowed the NYSCR to collaborate with researchers on patient contact studies involving rapid case ascertainment (RCA), such as studies with prospective assessment of clinical and treatment-related factors and studies seeking to assess pre-diagnostic exposures as close as possible to the time of diagnosis. Additional improvements in the percent of cases reported to cancer registries by ePath will further enable patient contact research studies and will ensure the representativeness of the patients contacted.

CHALLENGE
For studies of patient outcomes, researchers often are interested in contacting and enrolling cancer patients in a study soon after diagnosis. Potential benefits of RCA include assessment of pre-diagnostic exposures closer to the time of diagnosis, which may decrease recall bias, and prospective assessment of clinical and treatment-related factors including treatment decision-making, barriers to treatment, and quality of life. In addition, in studies of highly fatal cancers and transient populations, RCA may maximize participation and reduce the number of patients who are unable to be reached.

Electonic pathology reporting to cancer registries can help facilitate research studies involving RCA and build collaborations with researchers. Maximizing the number of facilities with ePath reporting capabilities increases the number of patients available for contact soon after diagnosis and the representativeness of the sample. However, the onboarding process is slow and requires commitment and dedicated resources by the facility for implementation and continued support of ePath reporting.

SOLUTION
The NYSCR Pathology Laboratory Reporting Team has worked with reporting facilities over the past seven years to increase the number of facilities with ePath reporting capabilities. Although additional work remains, these efforts have increased the percent of cases reported by ePath and has allowed the NYSCR to collaborate with researchers on studies requiring RCA. For these studies, the NYSCR has also used additional case identification approaches to include cases not reported by ePath and to help improve the representativeness of the study sample, such as working directly with reporting facilities without ePath capabilities to identify additional cases soon after diagnosis or extending the time window for identification and enrollment of cases.

RESULTS
As a result of these efforts, the percent of cases reported to the NYSCR by ePath within three months after diagnosis increased over time from 15.7% in 2014 to 44.8% in 2019. The percent of cases reported by ePath varied by cancer site, and case characteristics including age, race/ethnicity, and stage at diagnosis differed for cases reported and those not reported by ePath. These results indicate that additional work on the part of both the NYSCR and reporting facilities is needed to continue to increase the number of facilities with ePath reporting capabilities, as well as to sustain current ePath reporting efforts. In the meantime, approaches to include cases not reported by ePath in RCA studies will help to improve the representativeness of the study sample.

SUSTAINING SUCCESS
The NYSCR is continuing to work with additional facilities to enable them to submit ePath reports. However, this onboarding process is slow and requires commitment and dedicated resources by the facility for implementation and continued support of ePath reporting. This long-term commitment can be cost prohibitive for smaller or under-resourced reporting facilities. Approaches to streamline the ePath reporting process and to minimize the cost of ePath reporting will benefit cancer registries and the entire cancer research community.

REGISTRY CONTACT INFORMATION
518-474-2255
SUMMARY

Death Clearance (DC) is a labor- and time-intensive project. The North Carolina Central Cancer Registry (NCCCR) has tested and implemented several processes that seek to improve the success rate of follow-back efforts for the DC process and to reduce the Death Certificate Only (DCO) percentage in its annual submission to CDC’s National Program of Cancer Registries (NPCR). In addition, linkages with the Hospital Discharge Dataset (HDD) have proven invaluable over the past several years, and continuous improvement steps are taken to maximize the benefit of this resource.

CHALLENGE

Reducing the percentage of DCO cases using HDD data and evaluating the impact over time.

SOLUTION

The HDD contains a massive amount of information. As a result, any practical use of the data requires it pared down to a subset of the cancer population. Therefore, we decided to test its value by using the portion of the HDD that matched with cases in the annual DC list.

In 2018, a linkage was completed between the 2016 DCO cases, a subset of the 2016 DC caseload, and the 2016 HDD. Of the 578 DCO cases, 65% (378) matched to at least one visit in the 2016 HDD regardless of diagnosis. The entire 2017 DC list was linked, with promising results, to the HDD for 2014-2017. However, there was a large volume of matches using four (4) years of data, over 3,000. As a result, we decided to limit matches to those with a cancer-related diagnosis (783). We added the 378 cases from 2016 and 783 cases from 2017 to our follow-back efforts for 2017 death certificates and sent them to the corresponding hospitals. We requested that missed cases, according to our expanded reportability requirements for DC cases, be reported. The response was good for an initial test—34% for 2016 and 37% for 2017 DC cases.

Table 1: Cases Requested v. Submitted

<table>
<thead>
<tr>
<th>Year of Follow Back/DC Processing</th>
<th>Death Year</th>
<th># of HDD Matched Cases Include in Follow Back</th>
<th>% of Cases Reported by the Facility with the HDD visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>2019*</td>
<td>2016</td>
<td>378</td>
<td>34%</td>
</tr>
<tr>
<td>2019*</td>
<td>2017</td>
<td>783</td>
<td>37%</td>
</tr>
<tr>
<td>2020</td>
<td>2018</td>
<td>506</td>
<td>64%</td>
</tr>
<tr>
<td>2021</td>
<td>2019</td>
<td>422</td>
<td>57% (preliminary)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>64% (expected)**</td>
</tr>
</tbody>
</table>

* Test year
** Follow-back ongoing. Additional cases expected.

RESULTS

Overall results of the first four years have been good. The first year had the lowest percentage of returned abstracts, with marked increases after that, as shown in Table 1 below.

Considered the response to and the success rate of the first run, we integrated the HDD linkage into our annual DC process for 2018 and 2019 death certificates. Near the start of the DC process each year, linkages are performed with the HDD for that death year and the three years prior. The resulting matches for all linkages are filtered down to cancer-related diagnoses only, duplicates are removed, and the resulting list of cases with visit information is disseminated to the matching hospitals. This is done as early in the DC cycle as possible to maximize the time allowed for hospitals to research and abstract the cases.

There have been positive results for the CCR as well. Cases received from hospitals tend to be more complete than those received from other sources, and the percentage of submitted requested cases has increased over time. The associated diagnosis information that is tied to the hospital in the HDD is especially helpful in targeting the best sources of information. Sometimes multiple hospitals are matched to a single DC case. When this is the case, we request a review by each hospital involved, resulting in a more complete abstract once consolidated in the registry database. This means that some DC cases had two or more hospital-based follow-back leads at the onset—the HDD facility and the facility recorded as the place of death—increasing the chance for successful follow-back and streamlining the follow-back effort. Also, since we are no longer relying solely on the limited information on the death certificate, our chances of successfully disposing cases on the DC list have improved dramatically.

Successful disposition of the case from DC means a lower DCO percentage overall, which is a factor in the completeness of the central registry’s data. Our submissions to NPCR have had consistently lower DC percentages since we started using the HDD data, as shown in Table 2 below.

Table 2: DCO Percentages: 2015-2019 Deaths

<table>
<thead>
<tr>
<th>Year of Follow Back/DC Processing</th>
<th>Death Year</th>
<th>DCO %</th>
</tr>
</thead>
<tbody>
<tr>
<td>2017</td>
<td>2015</td>
<td>0.93</td>
</tr>
<tr>
<td>2018</td>
<td>2016</td>
<td>0.96</td>
</tr>
<tr>
<td>2019*</td>
<td>2017</td>
<td>0.84</td>
</tr>
<tr>
<td>2020</td>
<td>2018</td>
<td>0.72</td>
</tr>
<tr>
<td>2021*</td>
<td>2019 TBD</td>
<td>0.64</td>
</tr>
</tbody>
</table>

SUSTAINING SUCCESS

After four years’ worth of data showing that the linkage with the HDD has had a significant impact on DCO percentages, it has become part of our routine in the DC process. The success of the HDD efforts may lead us to consider using other sources of information that might be useful to improve case finding and completeness in the future.

REGISTRY CONTACT INFORMATION

919-792-5946
https://schs.dph.ncdhhs.gov/units/ccr/
SUMMARY
The North Dakota Statewide Cancer Registry (NDSCR) reports the ND cancer incidence and mortality rates annually by gender and county level. Can this be done at the sub-county level, which is a small territorial division within a county such as a census tract or census block level, while still ensuring that patient confidentiality is protected, and data is reliable.

The NDSCR, along with 21 NPCR registries, collaborated with the “Sub-County Cancer Data” pilot project conducted by CDC’s Division of Cancer Prevention and Control (DCPC) and the National Environmental Public Health (NCEH) Tracking Program. We believe local data such as sub-county data can highlight local variation, allow for a better understanding of environmental health processes and impacts, improve surveillance, and target interventions – all while ensuring patient confidentiality and data stability. At the end of the project, the project team was able to provide recommendations for the standard Nationally Consistent Data & Measures (NCDMs) for the spatial and temporal data aggregations for cancer display.

CHALLENGE
North Dakota is a small state with a population of 779,094 (2020). Reporting cancer data at the census tract level based on the census tract-level median case count thresholds to see how we could maximize the number of geographic units (i.e., have finer resolution data) and minimize suppression and instability. After many meetings and discussions, the project team came up with the recommendations for the standard Nationally Consistent Data & Measures (NCDMs) on which population thresholds were used for aggregation based on the census tract-level median case count for the selected cancer sites (see table below). This aggregated dataset can be mapped to display local, focused cancer data. The table and map below are examples that display ND cancer data at the sub-county level. These measures can be applied across the nation.

However, small area data such as sub-county data has its advantages: it can highlight local variation, allow for a better understanding of environmental health processes and impacts, improve surveillance, and target interventions. But tracking the sub-county geographies and finding the correct balance between too much or too little suppression has been an unsolved task especially for a small state like North Dakota. Challenges include unstable statistics and therefore will be suppressed if the case counts are fewer than 10 cases - due to data reliability and patient confidentiality concerns. So, to find a balance that maximizes the number of geographic units and minimizes suppression and instability is necessary.

SOLUTION
In 2019, CDC’s Division of Cancer Prevention and Control (DCPC) and the National Environmental Public Health (NCEH) Tracking Program conducted the “Sub-County Cancer Data” pilot project. The NDSCR participated in this project and worked on finding the best data level to display ND cancer data. The ND data are already geocoded to the census tract level, meaning the address information has been converted into geographic coordinates (latitude, longitude, and Census Tract value), so the NDSCR data meets the requirement for participation.

For this project, CDC provides each registry with information on the standardized sub-county geographies and guidance on how to test these geographies with cancer data. Each participating registry provided their cancer data with census tract information and tested various population thresholds to see how we could maximize the number of geographic units (i.e., have finer resolution data) and minimize suppression and instability. After many meetings and discussions, the project team came up with the recommendations for the standard Nationally Consistent Data & Measures (NCDMs) on which population thresholds were used for aggregation based on the census tract-level median case count for the selected cancer sites (see table below). This aggregated dataset can be mapped to display local, focused cancer data. The table and map below are examples that display ND cancer data at the sub-county level. These measures can be applied across the nation.

RESULTS
Through participating in this project, the NDSCR has helped to test displaying cancer data at the sub-county level while still ensuring patient confidentiality and data stability. It can reliably map the ND cancer data at the sub-county level based on the recommendation of “standard spatial and temporal aggregations for display” for the future. It may increase the availability and accessibility of sub-county data to investigate organ specific cancer statistics and extend the use of the central cancer registry.

SUSTAINING SUCCESS
The NDSCR will continue to support cancer data usage projects, such as these kinds of collaborative projects, and to provide ND cancer data for research.

REGISTRY CONTACT INFORMATION
701-777-0791 (Ext. 2868)
https://ndcancer.org/index.html
SUMMARY
The statewide cancer coalition, the Ohio Partners for Cancer Control (OPCC), used data from the Ohio Cancer Incidence Surveillance System (OCISS) to develop objectives for the Ohio Comprehensive Cancer Control Plan 2021-2030 (Cancer Plan). OCISS data will be used to evaluate progress of Ohio’s Cancer Plan.

CHALLENGE
Ohio’s 2015-2020 Cancer Plan needed to be revised. At the beginning of the process, the Executive Committee of the OPCC, which includes staff from the Ohio Department of Health’s Comprehensive Cancer Control Program, met to establish guiding principles for the cancer plan revision. Three of these guiding principles were: be data driven, include measurable goals, and attend to health equity.

SOLUTION
Starting in March 2020, topical workgroups met to develop objectives and strategies for Ohio’s Cancer Plan. Topical workgroups were expected to use data to identify objectives, as well as attend to health equity by looking at data to identify who in Ohio were disproportionately affected by cancer. If needed, workgroups received technical assistance from a Data Committee member. Once workgroups identified data-driven objectives that attended to health equity, they needed to include a measurable goal for each objective. Proposed objectives were reviewed by the Cancer Plan Revision Workgroup to determine if they met the criteria to be included in the Cancer Plan or needed to be revised. The objectives for the Cancer Plan were finalized in July of 2020.

RESULTS
Seventeen topical workgroups met throughout 2020 to develop objectives and strategies for Ohio’s Cancer Plan. The Plan includes 49 objectives, organized into three goal areas: Primary Prevention, Early Detection, and Quality of Life for Persons Affected by Cancer. OCISS data were used to develop data-driven objectives and to address health equity by identifying who in Ohio was disproportionately affected by cancer. For example, the Cervical Cancer Workgroup assessed the age-adjusted cervical cancer incidence rates and stage of diagnosis for various groups. The data showed women who were Hispanic or lived in a county designated to be Appalachian experienced the highest rates of cervical cancer in Ohio, while African American women were most likely diagnosed with cervical cancer at a more advanced stage. This led to the creation of the following objectives:

By 2030, reduce the rate of invasive cervical cancer, especially among groups experiencing disproportionate effects including Appalachian and Hispanic women to 7.5 per 100,000 population (baseline: 7.9 (all women); 10.8 (women living in Appalachian counties); 10.9 (Hispanic women).

By 2030, decrease the percentage of women diagnosed with cervical cancer at late stages (regional and/or distant stages), especially among groups experiencing disproportionate effects to 45% (baseline: 51.1% (all women); 61.2% (African American women); 55.0% (women living in metropolitan counties); 54.9% (women living in Appalachian counties); 53.8% (Hispanic women).

At the end of each year during Cancer Plan implementation, OCISS data will be used to evaluate whether progress is being made toward these objectives, and in 2030 to determine if these objectives were met.

SUSTAINING SUCCESS
Topical workgroups have shifted their focus from the development of Cancer Plan objectives and strategies to implementation. Throughout implementation, workgroups will continue to use data, including OCISS data, to guide their work as well as facilitate attention to health equity. Each year, progress made toward Cancer Plan objectives will be reported via a dashboard on the OPCC website. At the five-year mark, the Cancer Plan will be reviewed, and any needed revisions will be made.

REGISTRY CONTACT INFORMATION
614-752-2689
OCISS@odh.ohio.gov
https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/ohio-cancer-incidence-surveillance-system/welcome-to
With increased teleworking and no opportunity for in-person training, a method to provide easy access to Oklahoma cancer reporters for education and training was needed. Fundamental Learning Collaborative for the Cancer Surveillance Community (FLccSC) Learning Management System (LMS) was offered to state cancer registries to deliver education to cancer reporters more efficiently. FLccSC is a stand-alone web-based educational platform that allows each site administrator the ability to develop and maintain state-specific educational platform using original content or content made available by other states. The Oklahoma Central Cancer Registry (OCCR) took the opportunity to access FLccSC LMS enabling the team to manage and customize the home page, add educational modules, informational briefs, quizzes (videos, PDFs, etc.) and management reports. This provided Oklahoma cancer reporters an alternative method of receiving educational training while ensuring their safety during COVID-19.

In the past the OCCR ensured the Oklahoma cancer reporters received the required education and training to maintain cancer data standards set forth by the North American Association of Central Cancer Registries (NAACCR), as well as Centers for Disease Control and Prevention (CDC), National Program of Cancer Registries (NPCR). This included onsite cancer reporter training in abstracting, case finding, software usage and ongoing continuing education training of all cancer reporters. However, because of COVID-19 there were a greater number of people working from home, without access to cancer reporters’ onsite at healthcare facilities. Therefore, a new method of training delivery was needed that would accommodate Oklahoma cancer reporters. One of the best sources of continuing education for cancer reporters is the monthly NAACCR live webinars links, and ensured each reporter received the link and recorded attendance, which was time intensive. Starting October 2020, additional viewers had to be paid for separately for which OCCR could not fund. Additionally, the OCCR held an annual in-person education conference for Oklahoma cancer reporters. This was a great opportunity to bring Oklahoma cancer reporters up to speed with the changes in cancer abstraction. All these valuable in-person trainings were not possible and therefore creating a need for a different training delivery approach.

FLccSC is a cancer surveillance community educational collaboration between Florida and South Carolina and was offered at no cost to state cancer registries by NPCR. The OCCR team took this opportunity to develop upon the platform and deliver the much-needed training opportunities to the Oklahoma cancer reporters. Some of the courses currently available in the Oklahoma FLccSC include a recorded version of series of educational webinars presented by Denise Harrison, a nationally recognized cancer data educator. The Denise Harrison webinar series, ‘OCCR 2021 Summer Education Series,’ was funded through a contract made possible by OCCR’s CDC-NPCR funding. The webinar and training materials were uploaded and made available to all Oklahoma cancer reporters via FLccSC. With access to FLccSC, the ‘OCCR 2021 Summer Education Series’ recordings were available for viewing at reporters’ convenience and includes the ability to receive Certificates of Completion including Continuing Education Units (CEUs).

In addition to the summer education series, the OCCR added training resources to FLccSC for easy access such as: NAACCR education webinars, OCCR developed training recordings for software (Rocky Mountain Cancer Data System, WebPlus) use, pre and post training recordings for software (Rocky Mountain Cancer Data System, WebPlus) use, pre and post training surveys, general education on what cancer diseases to report, and how to identify reportable cancer patients in a facility’s medical record. Currently, the OCCR is working to develop additional courses that will aid one-on-one training for new cancer reporters.

Access to FLccSC was widely advertised to Oklahoma cancer reporters via mass emails in April 2021, which allowed reporters unlimited access to educational training at their convenience. The Oklahoma cancer reporter accessed FLccSC via a link on each states’ site. Once registered, the reporter can only see the LMS pages and content from their respective state. After the reporter successfully completes an educational module, they receive a Certificate of Completion including CEUs, where applicable. Certificates are automatically generated and can be printed by the reporter, which is more efficient than reporters waiting for an email notification. The graph below displays the Oklahoma cancer reporter enrollment and participation by month. Participation spiked during the ‘OCCR 2021 Summer Education Series’ and would average 22 course enrollments per month.

FLccSC’s flexibility helps drive the ongoing success for education and training delivery to Oklahoma cancer reporters. The OCCR will continue to add courses to address general abstracting skills and facility type specific training that includes software usage and abstracting principals. In May 2021, the OCCR conducted a survey to assess training needs for Oklahoma cancer reporters. The survey highlighted preferred topics and how much time would be available for the training. As a result of the survey, facilities targeted for continuing education will include small rural hospitals, dermatologists, pathologists, imaging facilities, and GI diagnostic facilities. As cancer data collecting has become more complicated, it has become time consuming to train new reporters, especially for small facilities where reporters wear many hats and staff turnover is high. Having pre-recorded comprehensive training in FLccSC reduces the time spent on initial education. The OCCR will continue using, and build upon, FLccSC platform as the OCCR has found it to be a valuable resource in training delivery.

Barbara Murray at barbaralm@health.ok.gov
The Oregon State Cancer Registry (OSCaR) is partnering with the Oregon Health and Science University (OHSU) to increase Certified Tumor Registrar (CTR) capacity and improve cancer data quality. This growing partnership has helped to see OSCaR’s CTR support grow by almost four-fold over the past two years. OSCaR is working to formalize this partnership through an intergovernmental agreement and further leverage OHSU’s extensive resources. The goal is to improve data quality while reducing the overall burden of cancer reporting.

**CHALLENGE**

Since its inception in 1996, OSCaR has been funded solely by the Centers for Disease Control and Prevention’s National Program of Cancer Registries. Moreover, as operating costs continue to rise every year and salaries may not be competitive with hospitals or other facilities to hire and retain CTRs, OSCaR has seen its CTR capacity shrink.

**SOLUTION**

OSCaR is partnering with OHSU to increase CTR capacity. In recent years this partnership was developed and maintained through a cancer case abstraction and quality assurance support contract that was small relative to overall operating costs. However, in recent years that contract has increased in size and scope. The driver for this partnership has been the value OHSU faculty and staff have seen in cancer data and the role that OHSU sees OSCaR play as Oregon’s central cancer registry. OHSU faculty and staff have been very involved with OSCaR’s research branch over the years. Many of them conducted research to assess cancer screening and treatment programs using OSCaR data. Now OSCaR is working on expanding the scope of this partnership even further through an intergovernmental agreement with OHSU. The end goal is to delegate all OSCaR operations to OHSU. The benefit of this agreement will allow OSCaR to leverage additional resources through the OHSU Hospital and associated Knight Cancer Institute. Resources include administration, information technology support, research infrastructure, and additional CTR capacity.

**RESULTS**

Since 2019, this partnership has seen OSCaR’s CTR capacity grow from 1 to almost four (4) full-time employees. In addition, current negotiations are underway to add at least another half-time employee with the possibility of garnering additional staff, including dedicated IT personnel to support software and database updates.

**SUSTAINING SUCCESS**

While OHSU is a dedicated partner, sustaining excellence with OSCaR operations will not be easy. Cancer reporting continues to drain the health systems and clinics required to report, so while quality assurance operations are improving, the drive to report will not likely increase. However, with additional capacity, OSCaR may likely take some of the burdens off small facilities that cannot easily absorb the costs of cancer reporting. For example, OSCaR CTRs could access smaller facility electronic systems directly to abstract cancer with more capacity. The result could turn a burden into a time-saving benefit for all.

**REGISTRY CONTACT INFORMATION**

971-673-1063  
Health leaders in the USAPI recognize how important the registry cancer data is for both programs, services, and external funding. In the wider Pacific, most do not have similar well-structured processes with clean and generally reliable data that has been collected for more than 10 years. Additional challenges include the inability to attend online training and virtual conferences live as the USAPI includes five different time zones, where a 2 PM Eastern training means a 5 AM or earlier start. The standards being discussed are more advanced and complicated than most of our registrars need for their work, which entails reporting only the National Program of Cancer Registries (NPCR) required data items (if they are available). Many of our registrars find it challenging to filter out the relevant information and we have been looking for ways to tailor this information for the Pacific context and make it accessible given the internet limitations.

**CHALLENGE**

Imagine yourself working in a typical USAPI setting, which for most is categorized by the World Bank as a moderate- or low-moderate income country. Lush tropics, unreliable air conditioning, periodic rolling blackouts, frequent tropical downpours and seasonal super typhoons are the norm. Small, but mighty, the USAPI jurisdictions have close-knit communities, and collaborations with registry staff throughout the islands, the Pacific Regional Central Cancer Registry is now able to provide more frequently updated training materials that are tailored to the USAPI.

**SUMMARY**

The U.S. Affiliated Pacific Island (USAPI) Jurisdictions face numerous challenges while collecting data to complete abstracts. The cancer-related resources are widely disparate across the jurisdictions, so many of the newer biomarkers and registry data items are not relevant to the USAPI. Even with the advent of online resources, the time zone differences and poor bandwidth in some areas create barriers to attending trainings delivered by standard setters or central registries with robust educational programs and platforms. More than half of the registrars in the USAPI are not Certified Tumor Registrar (CTR)-certified. Therefore, creating or finding customized training materials has been challenging. With the addition of a newly certified Central Registrar in Guam, and collaborations with registry staff throughout the islands, the Pacific Regional Central Cancer Registry is now able to provide more frequently updated training materials that are tailored to the USAPI.

**RESULTS**

We have developed a basic FLccSC site and developed two tailored modules focused on coding updates or addressing coding errors. Rapid-reaction zoom meetings based on the common coding errors learned via the monthly case reviews have already decreased the incoming abstract error rates by at least 25%.

Our feedback from the Pacific registrars who attend these zoom calls and online trainings expressed that they feel more engaged this way and that they find it easier to ask questions and ask for guidance if they don't know or are just uncertain about something.

**SUSTAINING SUCCESS**

As resources and infrastructure will remain substantially different in the USAPI compared to the rest of the U.S., stable funding and leveraging partnerships are required. Continued free or low-cost access to online platforms as Zoom, FLccSC, and webinars will help provide base resources upon which we can further tailor to the USAPI environment. We continue to utilize some NPCR funding to assist the non-certified registrars in their professional development, but we must account for many having a primary language other than English. While distance learning has been modestly successful, in-person training and technical assistance are critical for larger strategies around improving capacity, policies, or systems to improve cancer registration. Pacific-ized "boot camps" are also necessary for the newer registrars and for those being cross-trained to help with succession planning in each jurisdiction.

We remain grateful to our partners at the CDC and many colleagues across the United States who continue to learn and desire to help improve the health of U.S. Pacific Islanders who have paid a great toll and made many sacrifices on behalf of U.S. interests in global security.
SUMMARY
To ensure facility and internal staff understood the new histology coding rules within the 2018 Solid Tumor Manual, a focused review was done on Breast, Colon, Lung, Kidney, Head and Neck, and Urinary cases affected by the changes.

CHALLENGE
Due to staffing shortage the Pennsylvania Cancer Registry (PCR) was unable to provide any additional trainings. We relied on the trainings that were offered by the National Cancer Registrar Association (NCRA) and the North American Association of Central Cancer Registries (NAACCR) to convey the new rules. As a result, PCR did not have a good sense if registrars within Pennsylvania understood the new rules.

SOLUTION
The best way to determine the registrars understanding was to review cases that were submitted. PCR staff reviewed the 2018 Solid Tumor Manual and identified rule changes with the greatest impact on histology coding. Extracts were prepared to identify cases diagnosed in 2018-2019 that were potentially coded incorrectly. Text was reviewed to determine if errors were made.

RESULTS
The review resulted in the following breakdown of errors:

<table>
<thead>
<tr>
<th>Site</th>
<th>Total Errors Found</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>540</td>
</tr>
<tr>
<td>Colon</td>
<td>278</td>
</tr>
<tr>
<td>Head and Neck</td>
<td>216</td>
</tr>
<tr>
<td>Kidney</td>
<td>375</td>
</tr>
<tr>
<td>Lung</td>
<td>525</td>
</tr>
<tr>
<td>Urinary</td>
<td>140</td>
</tr>
</tbody>
</table>

Tip Sheets were developed for each site outlining the errors made with explanations on how they should be coded. The Tip Sheets were shared with registrars through FLccSC.

SUSTAINING SUCCESS
The same reviews will be done on 2020 cases to see if the Tip Sheets worked or if additional education is needed. This same process will be applied if other coding rules changes are released.

REGISTRY CONTACT INFORMATION
1-800-272-1850
https://www.health.pa.gov/topics/Reporting-Registries/Cancer-Registry/Pages/Cancer%20Registry.aspx
Geocode Cancer Site
Certainty Liver Breast Thyroid Cervix Total
0% 2 24 7 6 39
10% 78 848 193 170 1289
40% 25 230 45 27 327
70% 220 2375 578 287 3460
80% 382 4801 1009 535 6727
90% 43 632 111 129 925
Total 750 8910 1943 1164 12767

Cases that had 40% certainty or less are being reviewed individually by graduate students and PRCCR staff using a reference map created by PRPB GIS experts. This map has been custom made so that rural addresses can be located using longitude and latitude coordinates as well as the corresponding census tract number of any address on the map.

The review of 203 residential addresses of cervical cancer cases with ≤40% geocoding certainty showed that most of these cases had PO boxes or incomplete physical addresses. Using PRCCR pathology reports and health insurance claims data, the PRCCR epidemiologist was able to improve residential addresses of 178 cervical cancer cases. A total of 173 cancer cases were geocoded using the PRPB reference map. US Census Bureau 2010 Reference Maps were used to validate the census tract provided by the PRPB reference map. In addition, an official list of Puerto Rico’s Housing Department was used to complete and validate public housing addresses.

Results
Out of 12,767 cancer cases, PRPB was able to geocode 11,112 (87.0%) with at least 70% certainty: 7,808 (87.6%) of breast cancer, 1,538 (87.4%) of thyroid cancer, 645 (66.0%) liver and intrahepatic bile duct cancer, and 981 (82.6%) of cervical cancer. In addition, 173 cervical cancer addresses with ≤40% certainty were successfully reviewed and geocoded. This effort brought the successful geocoding of cervical cancer residential addresses with at least 70% certainty to 97.4% of all cases. Out of 93 PO boxes listed, 72 physical addresses were identified and geocoded with 100% certainty. This was an important breakthrough since PO boxes as residential addresses in the PRCCR database are a major limitation in geocoding.

A manual for geocoding was created for use at the PRCCR. We plan to complete the review and verification of the remaining cancer cases with ≤40% geocoding certainty. Furthermore, we seek to continue improving the geocoding process and training PRCCR staff as well as hospital registrars.

Sustaining Success
Collaboration with the PRPB helped us achieve an important landmark in our efforts to geocode residential addresses. This pilot project gave us an understanding of tools to improve geocoding of residential addresses and strategies to improve physical address documentation. Once geocoding of the four cancer sites reaches at least 95% with at least 70% certainty, the PRCCR will be able to initiate geospatial analysis studies with emphasis on cancer disparities at the census tract level. At this time there are three doctoral students that will benefit from the geocoding pilot project in their dissertation projects.

Registry Contact Information
787-772-6300 ext. 1800

Sources

2021 NPCR PUERTO RICO SUCCESS STORY
Puerto Rico Central Cancer Registry: Mariela Alvarado Ortiz, MPH, DrPHc; Carlos R. Torres Cintrón, MPH; Yadira Román Ruiz, BS, CTR; Diego E. Zavala Zegarra, PhD; Guillermo Tortelero Luna, MD, PhD

The Puerto Rico Central Cancer Registry - Geocoding Project: Right on Track

SUMMARY
Collaboration with the Puerto Rico Planning Board (PRPB) set the first steps of the Puerto Rico Central Cancer Registry - Geocoding Project (PRCCR-GP). As a pilot project, 87.0% of 12,767 records were successfully geocoded with at least 70% accuracy for four common cancer sites in a five-year period. An interactive reference map was created by PRPB GIS experts to facilitate the geocoding process of rural addresses. PRCCR staff received basic training and a geocoding manual was created.

CHALLENGE
The successful geocoding of residential addresses in the PRCCR database was hindered by the fact that most rural addresses are often reported in terms of distance in kilometers (e.g., Road 18, Km 18.5), or by PO box. In a previous effort to geocode residential addresses using batch geocoding services, we were able to geocode approximately 70% of residential addresses, but many cases were not coded accurately. We reached out to GIS experts at the Puerto Rico Planning Board to determine how to improve geocoding accuracy for residential addresses of cancer cases in Puerto Rico, in particular the rural addresses.

SOLUTION
In 2019, PRCCR began the geocoding pilot project in collaboration with PRPB to geocode 12,767 residential addresses of breast, thyroid, liver, and cervical cancer cases. The PRPB is a state government agency that has a GIS department that acts as a repository of geo data; they are responsible for the implementation of controls needed to maintain the integrity and confidentiality of the GIS in PR (I). PRPB GIS experts were able to successfully geocode 87% of the residential addresses with at least 70% certainty. The following table summarizes geocoding results by level of certainty.
SUMMARY

Inter-state exchanges play a critical role in completing Rhode Island cancer surveillance. However, it is challenging to verify if Rhode Island resident cases were submitted by the out-of-jurisdiction registries in a complete and timely manner. Rhode Island and a neighboring state mutually agreed to a modification in the data exchange schedule. The Rhode Island Cancer Registry (RICR) could gain leverage in monitoring cases from inter-state exchanges in a timely and predictable manner.

CHALLENGE

The RICR currently has interstate data exchange agreements in place, either through the NAACCR Interstate Data Exchange Agreement (with 44 states, as of January 2020, Data Exchange Agreement (naaccr.org) or individual state-to-state agreement (with 1 state).

To fulfill RICR’s responsibility as a sending registry, the RICR conducts interstate data case searches quarterly, in the months of January, April, July, and October. Non-RI resident cases identified through this protocol are sent to corresponding states that participate in the agreements. Through these agreements, the RICR can collect RI resident cases diagnosed and/or treated from registries with signed agreements. Each state transmits data to the RICR, according to its own data abstraction and exchange policy and protocol. Therefore, timeline and frequency when the RICR receives reports from other states are difficult to predict and monitor. Although consensus among the bordering states is quarterly exchange, backlogging often occurs for many reasons, such as registry staff shortage/turnover from the sending state, unexpected software changes/glitches, and other reasons.

SOLUTION

In 2020-2021, the RICR conducted reviews to identify missing and/or reporting delays from several in-state facilities and a neighboring state’s registry (“State A”), over the course of a ten-year (diagnosis) span. We found (1) yearly unduplicated case volume from State A varied (from 515 to 1,753 during 2012-2019), (2) timeliness of State A reported cases, measured by “Date of Case Load (in RICR database)” and “Date of First Contact,” was 400-500 days on average, and (3) frequency of data receipts from State A was not consistent year to year (once-three times a year).

It was a challenging task to verify if Rhode Island resident cases submitted by the out-of-jurisdiction registry were complete and timely. Two registries, RI and State A, met virtually in February 2021, and shared the above findings. Having discussed how to improve data exchange procedures and outcomes, the two registries agreed that the most workable and quick-fix strategy was modification of the data exchange schedule that would help RICR gain leverage in monitoring cases from State A in a timely and predictable manner. State A was willing to transmit RI resident cases monthly to RICR.

RESULTS

Since March 2021, RICR receives State A data every 15th day of the month. Frequency of data receipts changed from one-three times a year in previous years to monthly in 2021. Accordingly, staff workload to review and process State A cases were evenly distributed since March. Impact on completeness and timeliness are being monitored.

SUSTAINING SUCCESS

Inter-state exchanges play a critical role in completing Rhode Island cancer surveillance. Data sourced from out-of-state contributed approximately 10% of all abstract records for cases diagnosed in 2010-2019 (10,600 records per year, on average). Out-of-state reports mainly came from States A, B, C and D; small number of cases (less than 5 per year) were from 27 other states across the nation. Case reporting from State A is particularly significant to the RICR, attributed to RI residents’ physical proximity and accessibility to state-of-the-art cancer centers in State A. For the cases diagnosed in 2010-2019, 900 to 1,000 (unduplicated) records, each year, were State A-sourced cases, accounting for 86% of all out-of-state reports. Besides, 50% of these State A records were not accompanied with other source(s), such as reports from in-state facilities or pathology labs, meaning that a significant number of the RICR case reporting was created from a single source – the State A report. Monitoring and verification of out-of-state reports are critical activities that help RICR submit complete, timely and quality reporting.

REGISTRY CONTACT INFORMATION

401-222-4577
https://health.ri.gov/programs/detail.php?pgm_id=124
SUMMARY
Implementing Meaningful Use (MU; now referred to as "Promoting Interoperability") has been a challenge for many state cancer registries. Working collaboratively with Department of Health informatics staff, as well as the TCR certified tumor registrar staff, the TCR was able to successfully process over 100,000 individual MU reports with a final preparation of 1075 abstracts. Most of these MU cases, 723 in total, were the sole case documenting the cancer for the patient.

CHALLENGE
The total numbers of MU reports received provided a significant challenge to overcome. The TCR has received over the last several years, since beginning MU reporting during the 2017 DX year, almost 2 million individual HL7-CDA files for processing, which consumes a significant fraction of our current storage capacity. Irregularities in MU report formats provided the most significant hurdle to overcome during the processing of cases, which resulted in a significant number of so-called critical errors in the data. The total error percent of incoming reports was about 30% of total reports, so critical errors accounted for about half of all errors in the data. In general, the data is also of low quality, resulting in significant increases in quality assurance activities by CTR staff.

SOLUTION
Partnering with the Tennessee Department of Health’s Office of Informatics & Analytics (OIA) provided significant assistance completing MU data exchange goals. OIA staff were instrumental during the provider onboarding stage, as well as providing support to on-boarded providers during the data submission process. This would have been impossible for the TCR to complete, since the TCR has only one staff member working part-time on MU reporting goals. This partnership also allowed data submitted by on-boarded providers to improve in terms of overall quality.

RESULTS
TCR staff evaluated all submitted cases for the 2018 DX year, which is the most recent year of complete data available from the TCR. SAS was used for the analysis. Briefly, abstract-level MU cases were pulled from the abstract tables in CRS Plus. These abstract-level records were merged with consolidated records pulled from the medical sum tables in CRS Plus. To determine the numbers of MU cases for which no other incoming record was received, the variable “type of reporting source” was used to perform this analysis. As previously stated, the TCR received a total of 1075 abstract-level MU cases during the 2018 DX year. Of these, essentially 307 cases had to be consolidated with an incoming hospital case (type of reporting source = "1"), which were received after the initial MU linkages to the CRS Plus database were performed. After evaluation of all cases by type of reporting source, there were a total of 723 MU cases, for which the MU case was the sole case documenting disease in the individual.

SUSTAINING SUCCESS
Given the intensive nature of MU processing, TCR staff is hoping that the CDC’s Data Modernization Initiative may help to simplify the current MU processing paradigm. Until such time, though, TCR staff intends to continue processing MU cases to improve overall data completeness. Through collaborations and general processing experience, TCR staff believes that MU cases will be able to yield at least 3% of the TCR’s total annual data submission. Currently, for the 2018 DX year, cases documented only by an MU abstract account for about 2% of the TCR’s annual data submission. This is demonstrated by the very rapid rise in the total numbers of abstract-level records produced each year beginning with cases diagnosed during the 2015 DX year, during which the TCR completed only 16 MU abstracts compared to the 1075 abstracts completed for cases diagnosed during the 2018 DX year.

REGISTRY CONTACT INFORMATION
615-741-5548 or 800-547-3558
https://www.tn.gov/health/health-program-areas/tcr.html
SUMMARY
Cancer incidence and mortality data are most often displayed at the national, state, or county level due to privacy concerns, as well as concerns over the reliability of the statistical rates. However, data displayed at such a high level are often of limited use for cancer-related public health efforts at the local level.

CHALLENGE
Until recently, the geographic specificity in cancer incidence data being geocoded at the census tract level was not readily available. Additionally, standardized sub-county level aggregations of census tracts were not developed for ensuring the maximum number of sub-county areas to be displayed with minimal privacy or statistical reliability/stability concerns.

SOLUTION
To address this significant barrier in presenting sub-county level cancer incidence data, the Centers for Disease Control and Prevention’s (CDC’s) National Environmental Public Health Tracking Program (NEPHT) and the CDC’s National Program of Cancer Registries (NPCR) asked for registry volunteers to assist their efforts in working together to address how best to display cancer data at a more local, sub-county level. Texas was one of 21 registries that agreed to participate in a pilot project examining the feasibility of displaying data at the sub-county level.

Registries were grouped into three Regions with Texas participating in Region 3 along with Arizona, California, Idaho, North Dakota, Utah, and Washington. Other regions consisted of Florida, Georgia, New Jersey, North Carolina, Puerto Rico, Rhode Island, South Carolina, and Virginia in Region 1, and Louisiana, Michigan, Minnesota, Missouri, Nebraska, and Wisconsin in Region 2.

Participants in each region examined presenting sub-county level analyses for lung cancer and lung cancer stratified by sex, as well other leading cancer sites, such as prostate cancer, liver and intrahepatic bile duct cancer, colorectal cancers, non-Hodgkin Lymphoma, female breast cancer, and melanoma.

RESULTS
States were provided with the necessary population data from the U.S. Census Bureau by age, sex, and census tract. A SAS statistical software program was provided to calculate rates, as well as proposed spatial aggregations and shape files for maps.

The NEPHT, NPCR, and state registries determined that it was feasible to display an average annual number of cancer cases and incidence rates for prostate, colorectal, non-Hodgkin Lymphoma, female breast, and melanoma cancers. The periods of time ranged from 5 to 10-year periods, and person aggregations were for 5,000 or 20,000 persons, depending on the cancer site.

SUSTAINING SUCCESS
To sustain success, the Texas Cancer Registry is awaiting its departmental Institutional Review Board and Research Executive Steering Committee approval to submit census tract level data to the CDC’s NPCR for use by the NEPHT in presenting sub-county level counts and incidence rates at the local level. The TCR also plans to continue working with CDC on Phase 2 of the pilot project to explore the feasibility of including more rare cancers and smaller populations in the future.

REGISTRY CONTACT INFORMATION:
512-776-3080
http://www.dshs.texas.gov/tcr/home.aspx
**Cancer Survivor Survey through a Central Cancer Registry to Evaluate Control Program Targets for Change**

**SUMMARY**

The 2016 – 2020 Utah Comprehensive Cancer Prevention and Control Plan included several targets for change for cancer survivors. Utah Cancer Registry collaborated with the Utah Comprehensive Cancer Control Program to survey Utah cancer survivors. Results were used to assess needs of this population and to evaluate progress toward targets for change.

**CHALLENGE**

The Utah Comprehensive Cancer Control Program (Cancer Control Program), in coordination with the Utah Cancer Action Network, developed the 2016 – 2020 Utah Comprehensive Cancer Prevention and Control Plan (State Cancer Plan) as a guide for cancer control efforts. Survivorship and Quality of Life was a priority area of focus in this plan. This priority area included nine targets for change addressing the health status, health behaviors, and health care of cancer survivors (Table 1). Most targets for change were aligned to Healthy People 2020 objectives. The State Cancer Plan included an action step of performing a needs assessment for survivors. Whereas the Utah Behavioral Risk Factors Surveillance System (BRFSS) Survey2 collects state-level data about residents’ health and health-related behaviors and includes some cancer survivors among respondents, Utah set out to conduct a survey focused exclusively on the needs of recent cancer survivors to fully assess progress on the targets for change.

**SOLUTION**

The Utah Cancer Registry and the Cancer Control Program collaborated in creating a questionnaire that included items to capture self-reported status on each target for change. Questions from the BRFSS cancer module were included, as well as questions from other standardized instruments. Utah Cancer Registry conducted surveys in 2018, 2019, and 2020. Subjects were population-based samples of cancer survivors diagnosed during 2012-2018. Weighted random sampling was used to enrich for Hispanic survivors and for survivors who were residents of geographic areas with fewer residents having health insurance. Utah Cancer Registry analyzed responses to items pertaining to the targets for change in the State Cancer Plan and prepared a report for the Cancer Control Program. The report was used in evaluation of the 2016 – 2020 State Cancer Plan and to inform goals for the 2021 – 2025 plan.
SUMMARY

The Comprehensive Cancer Control (CCC) and Vermont Cancer Registry (VCR) programs collaborate on designing metrics for evaluating how well the state’s cancer partnership is reducing the burden of cancer among all Vermonters. Various metrics use VCR data; survival has not been included. The 2021-2025 State Cancer Plan will be the first plan to have an objective relating to Vermont cancer survival data.

CHALLENGE

VCR needed to overcome two challenges to realize its goal of calculating and using survival statistics for cancer control evaluation:

- Develop and implement the survival methodology.
- Participate on Vermonters Taking Action Against Cancer (VTAAAC) Steering Committee planning process.

SOLUTION

Step 1. Develop and implement the survival methodology.

We requested access to CINA Analytic File and used that SEER*Stat database1 to analyze Vermont cancer survival statistics (shown in Figure 1).

Figure 1. 5-year relative survival (%), 2009-2015, by Vermont leading cancer sites.

Males | Females
---|---
Prostate | Lung and breast
Colon and Rectum | Skin
Bladder | Skin
Esophagus | Skin
Cervix | Skin
Cancer of Other Sites

Source: Vermont Cancer Registry, Vermont Department of Health, Burlington, Vermont.

Step 2. Participate on Vermonters Taking Action Against Cancer (VTAAAC) Steering Committee planning process.

The Cancer Registry Manager is a longstanding member of the VTAAAC Steering Committee. She helped the CCC Manager with the process of garnering consensus in the cancer control community in drafting all the goal areas, objectives, and strategies. Figure 2 shows the various steps on the plan drafting process. Due to the pandemic, this process was prolonged over one year.

Figure 2. State Cancer Plan Development Process, March 2020.

RESULTS

Objectives in the 2016-2020 Vermont Cancer Plan using VCR data include:

- Prevention: incidence rates of tobacco-associated, obesity-associated, and HPV-associated cancers, and invasive melanoma.
- Screening: colorectal, cervical, breast, and lung cancers diagnosed at an advanced stage among screening eligible population.

In addition to these objectives, the 2025 Vermont Cancer Plan will include:

<table>
<thead>
<tr>
<th>Objective</th>
<th>Baseline (2009-2015)</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase the proportion % of cancer survivors who are living five (5) years or longer after diagnosis.</td>
<td>66%</td>
<td>69%</td>
</tr>
</tbody>
</table>

Check back soon for the new plan on the Cancer Plans and Reports page: https://www.healthvermont.gov/wellness/reports/cancer.

SUSTAINING SUCCESS

VCR staff routinely meet with members of the CCC, Breast & Cervical Cancer Screening, and VTAAAC teams. Vermont’s Cancer Leadership Team uses a multidisciplinary approach to integrate work among programs. This collaboration is key to having VCR’s recommendations for certain metrics, such as cancer survival, be considered for publication in the State Cancer Plan.

REGISTRY CONTACT INFORMATION

802-863-7300
https://www.healthvermont.gov/stats/registries/cancer-registry

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1 SEER*Stat Database: NACCR Incidence Data - CINA Analytic File, 39th Edition, for Expanded Races, 18CSC File With County, Vermont - Survival VT which includes data from NPCR’s National Program of Cancer Registries (NPCR), CCCR’s Provincial and Territorial Registries, and the NCI’s Surveillance, Epidemiology and End Results (SEER) Registries, certified by the North American Association of Central Cancer Registries (NAACCR) as meeting high-quality incidence data standards for the specified time periods, submitted December 2018.
**SUMMARY**

According to the North American Association of Cancer Central Registries (NAACCR) webpage: “Sometimes patients are diagnosed and/or treated in an area that is different from their residence, and agreements must be made between registries to share data.” In the Virgin Islands, it is a common practice among residents to do the annual health check-up in the United States, and it’s even more common to seek health care off-island once diagnosed with a serious illness, especially after the hurricanes that ravaged St. Thomas and St. Croix in 2017. Having the Interstate Data Agreement in place, as well as an agreement with Florida Cancer Data System (FCDS), has allowed us to include new cases in our database and, the submitted data helped complete staging and treatment for cases that were diagnosed in the Territory and whose staging workup and treatment was done off-island.

**CHALLENGE**

The United States Virgin Islands (USVI), an unincorporated United States territory, consists of three main islands, St. Croix, St. Thomas, and St. John, and many other surrounding minor islands. According to the U.S. Census Bureau, as of April 1, 2020, the U.S. Virgin Islands’ population was 82,441, representing a decrease of 18.1% from the 2010 Census population of 106,405. Approximately 82% of the USVI population who are at increased risk for health conditions and are confronting several health challenges including limited access to overall health care services, and specialized care including cancer care. All three islands are designated Medically Underserved Areas (MUAs), i.e., residents have a shortage of personal health services (HHS 2015). There is an average of 1.4 physicians per 1000 in the USVI compared to 2.3 per 1,000 Stateside (range 1.6-3.2) (AAMC State Physician Workforce Data Book 2013).

The Territory has one hospital in each island district (St. Croix, and St. Thomas/St. John), one Federally Qualified Health Center (FQHC) in each island district, private practices, and the Department of Health (DOH) operated clinics on each island. Currently, there are three Hematology oncologists and no Radiation oncologists in the Territory. The Charlotte Kimelman Cancer Center that was operating in St Thomas until 2017, was destroyed by Hurricane Irma and there is no plan to rebuild the cancer center soon.

All these factors, in addition to limitations of health care services in the Territory, force patients, especially cancer patients, to seek treatment off-island where a comprehensive diagnostic workup, staging, and treatment plan can be designed and delivered.

**SOLUTION**

The VICCR is part of the North American Association of Central Cancer Registries (NAACCR) Interstate Data Exchange Agreement. However, the state of Florida, where most Virgin Islanders seek treatment out of the Territory, currently is not part of such an agreement, leaving the VICCR with potentially missed cases. With the collaboration and support of our NPCR Program Consultant, we engaged in communication with the FCDS personnel, with the main purpose of establishing a Data Exchange Agreement between the FCDS and the VICCR.

**RESULTS**

Data providing diagnostic workup, staging, and treatment has been received from 17 states with the State of Florida being the main source. For the diagnosis year 2016, which is our most complete year, 24% of the newly diagnosed cases were diagnosed off-island.

**SUSTAINING SUCCESS**

For established registries in places where patients can get adequate health care, having the Interstate Data Agreement may provide supplemental information that may not affect incidence rates. In our case, it is necessary to maintain these relationships, and these agreements with our peers will allow our registry to collect a significant amount of information to make our data more complete.

**REGISTRY CONTACT INFORMATION**

787-510-7761
SUMMARY

The Virginia Cancer Registry (VCR) took the initiative to invest early and heavily in training and development, to make good use of our preferred data visualization software, Tableau. Through these efforts, VCR transformed the lengthy, paper-copy of the Annual Burden Report to an adaptable, interactive, and user-friendly series of dashboards and partnered with the online civic analytics company, LiveStories, as a better publication distribution vehicle.

CHALLENGE

A rapidly changing world has forced many cancer registries to re-think the way they conduct business, and the VCR is no exception. The fallout of COVID-19 has altered our workflows, disrupted the way we communicate, and made it difficult to reach our internal and external stakeholders. One of the main issues that needed to be addressed, because of all this change, was how to better distribute all the data, statistics, and important information that we, as a team, work so hard to collect, aggregate, and disseminate. The VCR does not simply exist to be a centralized repository for reportable cancer data. The success of our organization as a public health entity is entwined in our ability to provide and ensure maximum accessibility to reliable and informative data. Advancements in presentation and data visualization software, data dashboards, and online civic analytics platforms are specific tools the Virginia Cancer Registry (VCR) can leverage to maximize our accessibility and disseminate useful data to stakeholders, reporting partners, and the public.

One example of how VCR has put these new tools into action is the advancements in publication of our annual Cancer Burden Report. This data-driven report gives an overview of cancer in Virginia with the overall goal to present the latest available cancer incidence, staging, mortality, risk factor, screening, survivorship, and cost data through extensive tables, charts, and maps. As informative as the Burden Report was, it became particularly time and labor intensive to produce. Time spent on contents, citation, formatting, and editorial work alone on the earlier editions resulted in the need to modify production frequency from annually to biennially. Other challenges encountered included the associated costs for mass printing, ease of distribution, lack of interactive format, and limitations on available cancer sites. In addition, the internal agency approval process for mass printing required document review by non-data-driven entities. In one incident, erroneous edits were made to the data tables due to the entity’s misinterpretation and 500 copies of the burden report with inaccurate information were printed and wasted.

SOLUTION

The VCR encourages continued education for their staff to maximize every employee’s potential. To meet the needs of the mentioned challenges, VCR leadership actively sought out new ways to improve data delivery, including providing staff with additional training in Tableau software to ensure the challenges posed were met with viable and sustainable solutions. Selecting a staff member to be the Tableau publisher within the program allowed the Epidemiology team to collaborate on multiple projects using Tableau software. This opened the door to brainstorm other areas within the program that these “transformations of data” could occur. Led by our Senior Epidemiologist, the team now has a series of dashboards designed to be easily updated, re-designed, and interpreted by the reader. The next step involved deciding what data was needed to mirror the former Burden Report’s format and content. This took active collaboration with the Education and Training Coordinator. Though Tableau allows for multiple data sheets to be used simultaneously, it is more streamlined to extract all that you need into individual Incidence and Mortality report files.

RESULTS

By using Tableau and LiveStories, VCR has been able to retire the antiquated printed burden report, and shift to a more streamlined online version. VCR developed a web-based burden report dashboard, complete with interactive charts, tables, and graphs. By adding this to the VCR website, it allows anyone 24/7 access from anywhere in the world! Although the Tableau visualization-based cancer burden report includes many of the same cancer stats as the paper version, it now includes 20 cancer sites stratified by locality, race, and sex. The interactive maps, charts, and tables are more compelling and more accessible to readers. Through LiveStories, VCR can provide pertinent updates and disseminate useful data to stakeholders, reporting partners, and the public, as well as offer helpful tips on dashboard and website navigation and usage. Using a virtual data platform has allowed the registry to reduce the time, labor, and costs of production and dissemination, while maximizing accessibility, availability, and collaborative engagement opportunities.

SUSTAINING SUCCESS

The internal working group’s collaborative efforts were vital to program success in this endeavor, and the Registry’s dedication to embracing innovative processes has been a driving force to this success. Methods are in place to ensure the continued success of the virtual data publications, especially during updates, trouble shooting, and staff transitions. Once the working group decided on a visualization format in Tableau, a hard copy was saved so that future data can be extracted in the same way, and a list file detailing what visualizations are needed for the individual dashboards was created. LiveStories has quickly become a mainstream platform, used by schools, civic organizations, and other government agencies across the country and can be shared on social media sites such as Facebook and Twitter! Please come check out our work via the links provided below. We hope you are as excited and pleased with it, as our VCR team is!

The Virginia Cancer Registry (VCR) took the initiative to invest early and heavily in training and development, to make good use of our preferred data visualization software, Tableau. Through these efforts, VCR transformed the lengthy, paper-copy of the Annual Burden Report to an adaptable, interactive, and user-friendly series of dashboards and partnered with the online civic analytics company, LiveStories, as a better publication distribution vehicle.
SUMMARY
Hereditary cancer syndromes, such as hereditary breast ovarian cancer syndrome (HBOC) and Lynch syndrome (LS), are caused by genetic mutations that confer a high probability for cancer development to those who inherit the mutation. These syndromes significantly increase the risk for several types of cancers among those who inherit the mutation. Additionally, these individuals are often diagnosed with cancer at younger ages than those without the syndromes. Thus, diagnosing hereditary cancer syndromes in these individuals represents a significant public health issue because of the opportunity for prevention and/or early identification and better managing patient care. Unfortunately, these syndromes are also largely undiagnosed – less than 2% of people with Lynch Syndrome are diagnosed, for example (Hampel, 2011). That is why the Screening and Genetics Unit (SGU) and the Washington State Cancer Registry (WSCR) at the Washington State Department of Health (DOH) collaborated and utilized WSCR pathology reports. The criteria established by the National Comprehensive Cancer Network (NCCN) was used to identify the potential hereditary cancer syndrome cases (Daly, 2020; Gupta, 2020). To identify potentially inherited cancer cases, we used the NCCN criteria to select women with breast cancer age 50 or younger, men with breast cancer, women with ovarian cancer, any person with colon cancer age 50 or younger, and women with endometrial cancer age 50 or younger. The collaboration helped the SGU initiate active surveillance for HBOC and LS and increase provider awareness regarding clinical guidelines for genetic testing in patients at risk for HBOC or LS. The SGU was also able to advocate referrals of these cases by notifying the reporting healthcare providers about the potential risk for the patients and where to refer their patients.

CHALLENGE
The main challenge in obtaining cancer cases from the pathology report has been that the path reports do not list a health care provider who would typically be responsible for referring the patient to a genetics counselor. Often the pathologist listed has no relationship with the patient and only examined a tissue sample for biopsy. Sometimes we can get the name of the patient’s Primary Care Physician (PCP) or oncologist from the pathologist but if they do not respond, we are unable to identify and fax an appropriate provider.

SOLUTION
We are trying to overcome the challenge by faxing clinics instead of individual providers when we know they do not see the patient directly to ask for contact information for the appropriate provider.

RESULTS
We used the Electronic Mapping, Reporting, and Coding (eMaRC) Plus tool provided by the Centers for Disease Control and Prevention (CDC) to read the cancer path reports. The WSCR path reports provided the potential hereditary cancer cases with provider and reporting facility information. Providers or clinics received a faxed letter explaining that the patient might benefit from an appointment with a genetic counselor. Often the path reports do not list a health care provider who would typically be responsible for referring the patient to a genetics counselor. A total of 7 patients had already undergone genetic testing for LS/HBOC and/or met with a Genetic Counselor.

REFERENCES

REGISTRY CONTACT INFORMATION
360-236-3669
https://fortress.wa.gov/doh/wscr

SUSTAINING SUCCESS
WSCR plans to provide recent diagnosis year data once the consolidated cancer records from the Fred Hutchinson Cancer Research Center are received. The Cancer Surveillance System (CSS) of the Fred Hutchinson Cancer Research Center provides data on cancer cases from thirteen counties in Western Washington, covering most of the state’s population, including the largest urban center of Seattle. CSS has been in operation since 1974 as a regional registry participant in the Surveillance Epidemiology and End-Results (SEER) Program of the National Cancer Institute. Including these records will expand the scope of the SGU’s work to include cases from across all of Washington State, allowing for greater potential public health impact.
**SUMMARY**

State privacy laws prohibit the West Virginia Cancer Registry (WVCR) from sharing identifiable information from cancer patients with researchers without the patient’s written consent, severely limiting researcher’s access to this potentially valuable pool of respondents. We developed procedures for "blind contact" of cancer patients, allowing researchers access to patients in the registry while maintaining patient confidentiality.

**CHALLENGE**

Laws that protect the privacy of cancer patients in West Virginia are one barrier that limits researchers' ability to access and fully utilize data collected by the WVCR. Signed consent from each patient is required before any information can be released. We sought to develop procedures that would allow researchers to access our database of cancer patients without violating patient confidentiality.

**SOLUTION**

Our solution to this problem was to develop procedures for "blind contact" of patients. The researchers specify the details of the sample they wish to contact and provide WVCR with all the contact materials. The registry then selects the sample of patients meeting those criteria from our database and mails out the research packets directly without releasing any personal information to the researchers. The research materials are returned directly to the researchers by the patients, effectively having each patient provide their own consent by contacting the researchers themselves. Using this method, we can contact individuals in our cancer database without releasing personal information to the researcher.

**RESULTS**

We collaborated with West Virginia University (WVU) Cancer Institute for our first survey project. The survey was sent to individuals diagnosed with cervical cancer between 2000-2020 and had a West Virginia address at the time of diagnosis. The purpose of the survey was to determine if adverse childhood experiences (ACES) were associated with provider relationships and how that may influence cervical cancer diagnosis and health care. Before we began mailing, we compiled a list of cervical cancer survivors in the state that were alive around the time of mailing to avoid sending mail to deceased individuals and their families. This required comparing cancer records to the state's Vital Records and the Social Security Death Index (SSDI). Next, we printed, collated, sealed, and addressed the envelopes. The first set of letters were mailed on July 23rd, followed by the reminder letters three weeks later. WVU Cancer Institute ultimately had an 8.0% response rate, with no negative feedback from survey takers. These procedures allowed the researchers to collect information from a specific cohort of interest that would have been very difficult to recruit by any other means.

**SUSTAINING SUCCESS**

After the success of our first survey project, we discovered that there were facets of the project that worked very well, while others needed adjusting. For instance, having the WVCR handling the address labels and mailing was seamless; the researcher was able to receive survey responses without ever realizing the identities of the survey takers. However, the manual labor that went into printing, collating, and sealing almost 1,200 surveys proved to be very tedious and time-consuming. For future surveys, we plan to continue with printing and affixing mailing labels, but we would highly encourage the researcher to collate and seal the envelopes themselves or through a printing company. Additionally, we found that the reminder letter did not significantly increase the response rate, so we do not plan on using follow-up letters for future projects. Finally, we found it useful to complete a linkage between our mailing list and SSDI/Vital Statistics to avoid sending surveys to deceased individuals. Ultimately, we found that this survey methodology can be expanded to any research requiring patient contact. We provide the patient with the researchers’ contact information, and the patient then initiates contact with the researcher. This will allow additional opportunities to utilize our local cancer data to improve the health and well-being of West Virginians.

**REGISTRY CONTACT INFORMATION**

304-558-4463  
https://dhhr.wv.gov/oeps/cancer/Pages/default.aspx
Historically, case submissions to the Wisconsin Cancer Reporting System (WCRS) from reporting facilities were erratic, leading to spikes in the processing of data, an overuse of resources, and difficulty in the prioritization of more meaningful efforts. In 2021, WCRS implemented changes, including more effective communication and project management, which made case submissions more consistent and reliable with little adverse impact on the central registry and reporting facilities.

Prior to the current V21 data transmission standard, the last major upgrade was V18 in 2018-2019. In 2020, no major version changes occurred, so for the purposes of this discussion, 2019 and 2021 will be compared. In 2019, WCRS was unable to process 12-month data until implementing software upgrades in September. This resulted in subsequent data processing (imports) of 53% of the total abstracts received in 2019 within a span of one month. The delay in processing made tracking data quality indicators and completeness of case ascertainment difficult. This issue was compounded by the fact that software was upgraded after annual call for data activities had been initiated. The subsequent processing of over 25,000 cases post-upgrade presented problems because the number of pending cases was very high and difficult to manage.

The above efforts in improving communication with reporting facilities and practicing better project management resulted in increases in completeness of case ascertainment for 12-month data had been received and processed in August. At the December 2019 Data Submission, 42% of the expected 12-month incidence cases had been received. In comparison, in 2021, estimates for completeness of case ascertainment are higher at both points in time. In August, an estimated total of 73% of expected incidence cases had been received and processed for 12-month data, a 16-fold increase compared to 2019. If current trends continue, completeness of case ascertainment for 12-month data is expected to be between 83% and 87% at the time of submission, double that of 2019.

The strategy for software implementation and communication through continued follow up and training with facilities is clearly effective in creating a steady stream of data with no major spikes or lags month-to-month. Contact with delinquent facilities can also help to determine steps to resolve the issue of delayed submissions. This allows better prediction of workload and prioritization.

Continuation of our efforts for improvement will allow better management of resources and create opportunities for projects to further improve their operations. Leveraging project management strategies used during software upgrades with other operations and quality improvement efforts will be key to continuous improvement. Adopting project management tools and software, increasing documentation, and continuing existing efforts will improve time management, registry operations, and ultimately, data quality.

608-266-6781
https://www.dhs.wisconsin.gov/wcrs/index.htm
SUMMARY
The ability for the Wyoming Cancer Surveillance Program (WCSP) to receive ePath reports from the Utah Cancer Registry (UCR) has increased the number of WCSP cancer cases. Not only were new cases identified by ePath, but ePath provided valuable information for updating already identified Wyoming cancer cases.

CHALLENGE
Improving the WCSP’s ability to capture all Wyoming residents diagnosed with cancer who are diagnosed and or treated in Utah.

SOLUTION
Because of the longstanding collaborative relationship between UCR and the WCSP, UCR understood the WCSP’s dilemma in capturing all Wyoming residents who crossed state boundaries into Utah. Because of this ongoing difficulty for the WCSP, UCR had the ability to remedy the problem with the data exchange of ePath reports.

RESULTS
The largest number of ePath records went to 2 adjacent states: Idaho (n = 1,084) and Wyoming (n = 621). Of the 621 ePath reports (2018 calendar year) received, eighty-nine (89) of those ePath reports were determined to be new cases. Because of Wyoming’s small population, 89 new cases equated to 2.8% of Wyoming’s annual cases that would have been missed had ePath and reports not been received.

SUSTAINING SUCCESS
Currently the data exchange of pathology reports from the University of Utah to the WCSP is easily sustainable. A future goal would be for every State to replicate the efforts and success of UCR’s e-path data exchange.

REGISTRY CONTACT INFORMATION
307-777-3477

CITATION
https://www.ncra-usa.org/Portals/68/JRM%20Summer%202021%20Final.pdf?ver=SfzzaE0R_E_odIp8XOjw4g==

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention