

From Surveillance to Prevention: Leveraging Cancer Registry Infrastructure to Improve Access
to Screening Data

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Abstract

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Increasing cancer screening rates is a public health priority. Currently, cancer screening rates remain below target levels. Primary care providers (PCPs) play a key role in ordering preventive cancer screenings, such as colonoscopies and mammograms, yet many PCPs lack access to complete patient records. A lack of electronic health record (EHR) interoperability means that procedures completed outside the healthcare system are often missing from the EHR. This thesis evaluated whether existing cancer registry infrastructure, such as the Surveillance, Epidemiology, and End Results Program (SEER) could support provider-accessible preventive screening systems through comparison with the Controlled Substance Utilization Review and Evaluation System (CURES), CanScreen5, and the Florida pilot project. Because SEER is structured for de-identified population level data, models such as CURES and CanScreen5 are more legally and structurally feasible in supporting a provider-accessible preventive screening data base. Future pilot programs should focus on a provider-accessible registry or organized cancer screening system.

Introduction

Cancer is the second leading cause of death in the United States.¹ Reducing cancer diagnoses and disparities is a public health priority, with Healthy People 2030 providing measurable cancer screening objectives.² Despite these established guidelines, many individuals remain unscreened or not up to date with recommended preventive services. Being up to date on cancer screenings significantly improves health outcomes by lowering the likelihood of being diagnosed with cancer at a late stage.³

Colorectal Cancer Screening

Colorectal cancer is the second leading cause of cancer deaths in the United States for both men and women combined.⁴ To detect cancer early and prevent late stage diagnosis, the United States Preventive Task Force (USPTF) recommends all adults begin screening for colorectal cancer at age 45.⁵ Healthy People 2030's target for individuals being up to date on colorectal cancer screening is 72.8%.⁶ However, only 61% of adults aged 45-75 are up to date on colorectal cancer screenings.⁷ Additionally, Healthy People 2030 set a target of 7.7 colorectal cancer deaths per 100,000 people, however with a current death rate of 12.7 per 100,000 people, we are likely to fall short of that goal.⁸

There are important disparities with regard to colorectal cancer incidence and mortality; African Americans and Native Americans are more likely to be diagnosed with and die from colon cancer.⁹ Additionally, those with less education, lower income, and live in a rural area are less likely to be up to date with screening.^{9,10}

Breast Cancer Screening

One in eight women will develop breast cancer in their lifetime.¹¹ To detect cancer early and prevent late stage diagnosis, the USPTF recommends biennial screening mammography for

women aged 40-74.¹² However, only 60% of women aged 40-49 and 80% of women aged 50-74 have had a mammogram in the past two years.¹³ Additionally, Healthy People 2030 set a target of 15.3 breast cancer deaths per 100,000 people, however with a current death rate of 18.7 per 100,000 people, we are likely to fall short of that goal.¹⁴ Early detection through mammography is the best way to prevent late-stage diagnosis and increase survival; when detected early and at the localized stage, the five-year survival rate is over 99%.¹¹

There are important disparities with regard to breast cancer diagnosis and screening rates. African American women are 38% more likely to die from breast cancer relative to white women.¹¹ African American women have the lowest survival rate for breast cancer regardless of the stage of diagnosis.¹¹ Additional disparities exist in screening rates; those who are low-income or live in a rural area are less likely to be up to date on screening.¹⁰

Electronic Health Records and Cancer Screening

In the United States, primary care providers (PCPs) play a key role in ordering preventive screenings, including mammograms and colonoscopies. The adoption of electronic health records (EHRs) should have increased the rate of screenings by providing automated reminders to patients and providers through health maintenance modules, which can identify care gaps.¹⁵ However, patient screening records, including mammograms and colonoscopies, are often missing from or not updated across different EHRs.^{4,16}

The adoption of EHRs is a vital part of healthcare delivery. Federal policy, such as the 2009 U.S. Health Information Technology for Economic and Clinical Health (HITECH) Act accelerated the adoption of EHRs by healthcare systems across the United States.¹⁷ As of 2021, 96% of nonfederal acute-care hospitals and 78% of office-based providers use an EHR.¹⁷

However, alongside the advancements that EHRs bring, there are significant challenges to EHR interoperability that affect the optimal impact of cancer screening.

Results such as colonoscopy and mammogram reports are often unavailable to PCPs. Patients often complete these procedures at gastroenterology or radiology practices that do not communicate with other EHR systems, leading to missing records and fragmented communication. As a result, PCPs may unknowingly refer patients for screenings that have already been completed, while specialty clinics spend significant time attempting to retrieve prior records to avoid unnecessary procedures. Despite federal policy efforts, interoperability is the most desired improvement to EHRs reported by providers.¹⁸ In a 2025 national survey, fewer than 15% of PCPs reported experiencing ideal interoperability, defined as often obtaining, finding, and reconciling external data within their EHRs.¹⁸ This administrative burden not only affects clinic workflows¹⁷ but also delays care and adds to inefficiencies in meeting national cancer screening objectives.

In addition to interoperability challenges, EHR health maintenance modules often require manual updating of screening completion dates. Health maintenance modules were designed to track preventive screening services and completion.¹⁵ They can automate schedules for age-appropriate screenings, such as mammograms and colonoscopies, and alert providers during visits that a patient is overdue.⁴ However, failure to manually update these modules can result in inaccurate reminders or incorrectly classify patients as ‘not due’. For example, some EHRs automatically set the colonoscopy interval to ten years. If a patient has abnormal past results, but these results are not in the EHR system, an automatic ten year interval can cause the patient to be overdue for their follow-up screening.⁴ A reliance on manual data entry and non-standardized documentation contributes to inconsistencies in cancer screenings within EHR systems.¹⁸

There are multiple EHR systems available and in use in the United States, such as Epic, Cerner, Meditech, and athenahealth. Because each EHR system uses its own data structure and format, it is difficult for these different systems to “talk” to each other. This lack of interoperability means patient records in one healthcare system’s EHR cannot often be accessed easily, if at all, by another healthcare system using a different EHR.

Federal initiatives, including the HITECH Act and support for regional health information exchanges (HIEs), have aimed to improve interoperability across healthcare systems. However, data suggests that interoperability across healthcare systems remains inadequate.¹⁸

Clinical Consequences

Colonoscopy reports are frequently missing from EHRs, especially when the patient completed the procedure outside the healthcare system.⁴ The lack of interoperability between different EHRs means that records are more likely to be ‘lost’ or inaccessible to providers when the procedure was performed outside of the clinic.⁴ This leads to delayed follow-ups or unnecessary procedures because the provider is not aware of previous screenings. Due to the long follow-up interval, many patients have difficulty remembering exactly when their last colonoscopy was, and research has shown that patients tend to over-report the completion of colonoscopies.⁴

Even if the procedure report is available to the provider, the pathology report is often missing, leading providers to rely on patients’ memory.⁴ However, studies have shown that patients do not accurately recall results, leading to incorrect reports of polyp presence.¹⁹ Even if the patient correctly recalls the date of the previous colonoscopy, missing pathology results make it difficult for the provider to determine when the patient is due for follow-up.⁴ For example, there are three key features of polyps that determine colonoscopy recall time – size, quantity, and

pathology. Only 8% of patients correctly recall all three key features of polyps that is needed to determine the correct follow-up interval.¹⁹

Most radiology sites require prior mammogram images, which enables providers to better detect subtle changes, reduce false positives, and avoid unnecessary follow-ups.²⁰ A lack of prior imaging in the EHR system may result in delayed screenings or less accurate interpretation of the results.

Additionally, poor coordination between healthcare systems, including insufficient information management, leads to delayed follow-up by PCPs after abnormal mammogram results.¹⁶ Previous research has shown that mammograms completed in a different healthcare system than where the PCP is located, such as in an external radiology site, leads to inaccessible mammogram reports within the primary care office.^{21,4}

Different Infrastructure Models

Cancer registries are used to track cancer after diagnosis. Cancer registries are designed for the collection, storage, and management of cancer data and are crucial for cancer surveillance.²² The Surveillance, Epidemiology, and End Results Program (SEER) is the main cancer surveillance registry in the United States, covering nearly 46% of the population's cancer incidence and survival data.^{22,23} SEER is designed for population-level cancer surveillance and research. However, its data are obtained from reports submitted by hospitals and registrars, providing an example of how individual-level health data can be securely collected for public health purposes.

In contrast, systems such as California's Controlled Substance Utilization Review and Evaluation System (CURES) show how state-level registries can manage individual-level health data. While CURES tracks prescription drug use rather than screening procedures, its governance

and data structure offer a potential model for how cancer screening data might be integrated into a state-run system.

Additionally, other countries provide examples of individual-level screening data systems. The CanScreen5 project, developed by the International Agency for Research on Cancer (IARC), supports the collection, use, and storage of individual-level data on breast, cervical, and colorectal cancer screenings.²⁴ Unlike traditional cancer registries, the CanScreen5 project was designed to provide invitation-based screening and follow-up.²⁴

In the United States, the Florida Pilot Project, integrated screening data into routine cancer surveillance systems.²⁵ More specifically, this project explored the feasibility of incorporating breast and cervical cancer screening data into state cancer registries.²⁵

Policy Question

How could existing cancer registries, such as SEER, better support a provider-accessible, preventive screening data system to improve cancer screening?

Scope

This study limits its scope to colonoscopy and mammography to maintain focus on more universal screenings that are likely to be varied across healthcare systems.

Methods

A policy analysis, which is a synthesis of multiple data sources to evaluate policy options²⁶, was conducted using SEER as a case study to explore how existing data infrastructures could be leveraged to support and improve access to preventive cancer screenings. Multiple data sources were used including SEER's publicly available documentation on governance, data flow processes, and reporting standards. SEER's Data Collection Storage and Management guidelines describe data structure, submission protocols, and quality standards, which was used to assess

data collection standards. Confidentiality, user agreement, and accessing data documents were analyzed to determine the legal feasibility of leveraging SEER data infrastructure to support cancer screening systems.

A thematic analysis²⁷ was used to compare key domains across different models, such as CURES, CanScreen5, and the Florida Pilot Project. Governance, data flow, provider accessibility, and reporting structure were analyzed to determine the feasibility of a cancer screening data system. These domains were used to compare the strengths and limitations of different models.

CURES²⁸ was selected as a comparison model as it provides an example of a provider-accessible database that is used throughout California healthcare systems. This state-run database provides an example of a system that supports individual-level health data and has already been adopted into clinical workflows. CanScreen5 and the Florida Pilot Project were identified through review of cancer screening literature. CanScreen5²⁴ provides an example of organized cancer screening at the international level, whereas the Florida Pilot Project²⁵ demonstrates an example within the United States at integrating state cancer registries with screening data.

Lastly, a feasibility analysis was conducted to evaluate the legal, structural, and governance considerations of adapting existing models to a preventive cancer screening system. Comparative findings from SEER, CURES, CanScreen5, and the Florida pilot project were used to assess the strengths and limitations of provider-accessible cancer screening infrastructure.

SEER

Purpose

There are two types of cancer registries: population-based and hospital-based. Population-based registries, such as SEER, record all cancer cases within a defined population

for public health purposes.²⁹ More specifically, SEER is designed to track patterns, monitor trends, assist in cancer control efforts, and advance research.²⁹

Hospital-based cancer registries maintain data on all patients diagnosed or treated for cancer within a specific healthcare facility.²⁹ These registries are designed to improve patient care, administrative processes, clinical research, and professional education.²⁹

Data Collection and Reporting Structure

Individual hospitals report cancer cases to a state registry, as all 50 states mandate the reporting of cancer data under state law.³⁰ Every year, the state cancer registries electronically submit cancer incidence data to SEER or the Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR).^{31,23} Data reported to SEER includes patient demographics, primary tumor site, tumor morphology and stage at diagnosis, first course of treatment, and follow-up.²³ SEER data does not include individual data nor data from raw EHR reports. Instead, the data that is initially pulled from the hospital medical record is standardized using the North American Association of Central Cancer Registries (NAACR) data standards.³⁰

Confidentiality Protections

To access SEER data, an individual must have permission from a designated authority, as well as acknowledge and sign the data use agreements and data limitations documents.^{32,33} The Data Use Agreement prohibits the linkage of SEER data with another database at the individual level.³⁴ Other important prohibitions of SEER data include, re-identification of individuals, identifying data sources, identifying geographic regions, and releasing data to others.³³

Structural Features Relevant to Prevention

SEER data is updated annually which supports cancer surveillance, but limits real-time use for providers.²³ Without individual-level data, SEER's infrastructure does not allow providers to access identifiable patient data. SEER's data structure is designed to protect confidentiality while allowing access to data for cancer surveillance, differentiating it from a system designed for cancer prevention and screening.

Comparative Models

Purpose

CURES is a web-based system that allows authorized providers and pharmacists to access individual-level prescription information. CURES was designed with public health in mind and is aimed at reducing prescription drug abuse.²⁸ CanScreen5 is an example of a global cancer screening registry that supports individual level screening data. The aim of this screening registry model is to report the performance of cervical, breast, and colorectal cancer screening programs.²⁴ The Florida Pilot project linked breast and cervical cancer screening data with matched cancer cases in the state cancer registry, which aimed to enhance cancer surveillance infrastructure.²⁵

Governance

CURES is run by the California's Department of Justice and is an example of a provider accessible data base that stores individual-level patient information while remaining in compliance with both state and federal laws.²⁸ In comparison, CanScreen5 and the Florida Pilot Project are governed by public health institutions. CanScreen5 operated through national or regional screening systems with many programs operating under government-mandated screening policies.²⁴ The Florida Pilot Project worked jointly with the state cancer registry, the state health department, and local healthcare systems.²⁵

Data Collection and Reporting Structure

CURES tracks individuals who are prescribed Schedule II to Schedule V controlled substances in California.²⁸ Patient level information that is available on CURES includes first and last name, date of birth, gender, address, prescription name, payment method, and pharmacy name.²⁸ Data are electronically reported to CURES by licensed pharmacies through standardized reporting systems. CanScreen5 data mainly comes from the Ministry of Health in each country that participated in the program. Similar to SEER, the data was collected according to set criteria and indicators and underwent quality validation.²⁴ CanScreen5 stored individual-level cancer screening data for breast, cervical, and colorectal cancer screening programs.²⁴ The Florida Pilot Project received individual-level patient data by linking healthcare systems' EHR to the state cancer registry.²⁵

Structural Features Relevant to Prevention

These models contain features that support cancer prevention. CURES permits all healthcare providers that are licensed to prescribe, order, administer, furnish, or dispense schedule II through V controlled substances to access the database.²⁸ CanScreen5 supports invitation-based screening and tracking of individuals with abnormal screening results, which helps ensure adherence to follow-up.²⁴ Through the linkage of EHRs and the state cancer registry, the Florida Pilot Project enhanced cancer prevention data collection.²⁵

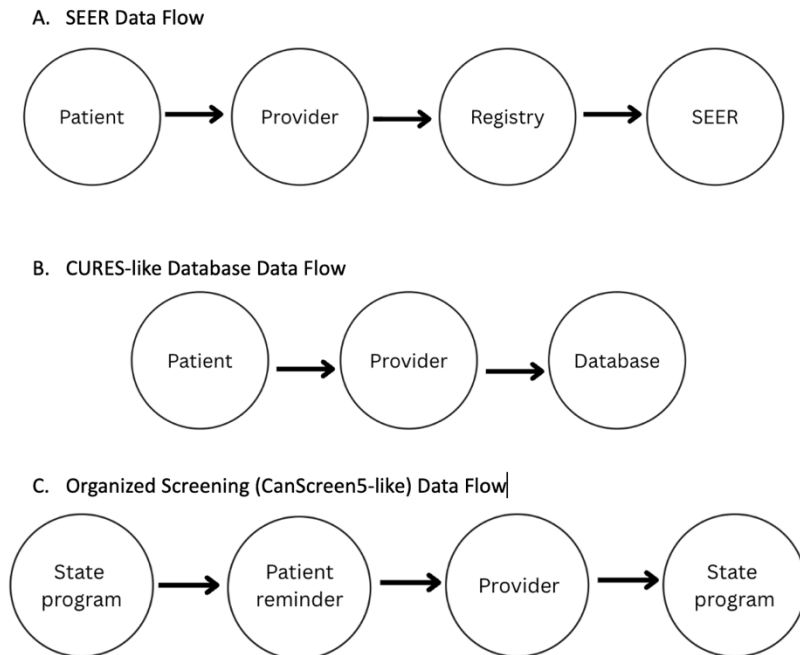


Figure 1. Comparison of data flow across cancer registries and screening models.

(A) SEER data flow demonstrates population-level, de-identified reporting from providers to state and national registries without provider access.

(B) CURES-like database illustrates provider-accessible, individual-level data with mandated reporting.

(C) Organized screening model represents a state-administered system with patient-level tracking, invitation, and follow-up.

Feasibility Analysis

To evaluate the feasibility of the comparative models, legal, structural, and governance considerations were analyzed. Legal feasibility evaluated whether SEER and the comparative models could legally support a preventive cancer screening data base. Structural and governance considerations evaluated data flow and data ownership of each model.

Legal feasibility

SEER is currently structured for de-identified population-level cancer surveillance. As SEER is currently governed, cancer registry data is only allowed to be accessed for research purposes related to cancer surveillance. However, state-level cancer registries, as demonstrated

in the Florida Pilot Project²⁵, can legally link identifiable screening data with cancer registry data under public health law.

A provider-accessible cancer screening database, however, may be more legally aligned with a structure similar to CURES. CURES allows providers to access to individual level patient data while remaining in compliance with federal and state law. HIPAA permits the collection and use of identifiable health information within authorized registry systems, as long as appropriate safeguards are in place.³⁵ Additionally, HIPAA allows the disclosure of protected health information when required by law.³⁵ Under the California Health and Safety Code, California law requires controlled substances to be reported, and authorizes providers to access the database.²⁸

Organized cancer screening programs, such as the CanScreen5 project, operate through public health agencies that collect identifiable screening data in order to track patient participation and follow-up. In the United States, public health agencies are allowed to collect identifiable health information for disease surveillance and prevention.³⁵ Under the HIPAA Privacy Rule, covered entities may disclose protected health information to public health agencies without patient authorization when the data are used for prevention or monitoring.³⁵ Therefore, designing a state-level screening registry to track preventive cancer screenings and issue patient reminders could legally operate under existing public health laws.

Structural feasibility

A data base that aims to link state cancer registries with EHRs, such as seen in the Florida Pilot project, would face several key barriers. As highlighted by the Florida Pilot project, difference in EHR systems, data formats, and documentation practices makes linking EHRs with state cancer registries challenging. Additionally, research shows that screening data is

consistently missing from EHRs.⁴ This suggests that approaches that rely on linking registries with EHRs would encounter many barriers.

A provider-accessible registry similar to the CURES system would require a reporting pathway for screening and pathology reports. CURES requires pharmacies to submit records within one day of the controlled substance being dispensed.³⁶ Relying on manual submission by providers and laboratories for cancer screenings could increase administrative burden, especially for providers. Additionally, if providers and laboratories fail to upload results, the system would have incomplete data, similar to what we are seeing now with EHRs.

An organized cancer screening program similar to CanScreen5 would shift responsibility from providers to public health agencies. While this would require the establishment of administrative infrastructure that is capable of identifying screen-eligible individuals and managing screening invitations and follow-up, it would reduce the reliance on EHR systems and manual documentation.

Governance considerations

Implementation of a screening registry would require clear specific governance on oversight, reporting mandates, and accessibility. Existing systems, such as SEER, CURES, and CanScreen5, illustrate several different governance structures. SEER operates under federal public health authority with state mandates requiring reporting. An organized cancer screening database similar to CanScreen5 could be coordinated through state public health agencies. California's CURES database is administered at the state level by the Department of Justice with reporting mandated by state law.

There would also need to be established rules regarding data ownership and access. A screening registry system would need to explicitly state who is responsible for maintaining the

database and who is authorized to access the information. Both SEER and CURES restrict access to authorized users. Because CURES restricts access to authorized providers and pharmacists, this system demonstrates how provider access can be managed through state authentication.

Discussion and Conclusion

Synthesis and Findings

Under current law and governance infrastructure, SEER cannot be directly adapted for a provider accessible screening database. As discussed in previous sections, SEER is structured for de-identified, population-level cancer surveillance, with strict data use agreements that prohibit re-identification of data. However, SEER's infrastructure demonstrates the feasibility of large-scale, standardized data collection, highlighting the potential for centralized cancer screening systems.

Based on the comparative models and feasibility analysis, two alternative approaches emerged as legally and structurally feasible. First, a provider-accessible registry model, similar to California's CURES system, demonstrates how identifiable patient information can be securely collected and accessed by authorized providers under state authority. Second, organized screening models, such as the CanScreen5 project, demonstrate how cancer screening programs can be managed by public health agencies to track screening participation and follow-up.

Recommendations for future screening infrastructure

A provider-accessible registry, similar to California's CURES database, is legally feasible and structurally possible and offers one potential option for addressing the lack of EHR interoperability and missing cancer screening reports. However, there are important limitations to note, such as provider burden and adding another system to provider workflows. Though a provider-accessible database could potentially reduce the number of missing screening reports,

studies show that providers express frustration when having to access multiple systems to retrieve patient data.¹⁷ Additionally, uploading procedure and pathology reports would likely fall on the clinical staff that performs the procedures. Although this is similar to how reports are entered into EHRs now, especially when reports are retrieved from outside facilities, a database similar to CURES would not ease the administrative burden of uploading records.

If participation in the database is voluntary, it is unlikely to fix the issue of missing cancer screening data. Due to provider workload and administrative burden, many providers may not consistently upload screening reports to an optional external database. Therefore, a state mandate requiring the reporting of preventive cancer screening procedures would be necessary, similar to the reporting requirements established under California's CURES program. This type of mandate could be justified under public health authority, particularly given disparities in cancer screening rates and the prevalence of late-stage cancer diagnoses.

A second option to address EHR fragmentation and missing cancer screening reports is to develop a state-level organized screening system, similar to the CanScreen5 model. Currently, the United States operates under an opportunistic screening model, which is when screening is initiated by patient request or by providers during an office visit.²⁴ An organized screening system combines a population-based approach to cancer screening, but focuses on screening instead of surveillance. This type of system would reduce reliance on fragmented EHRs and would reduce provider burden. Additionally, organized screening systems have been shown to increase screening rates and reduce health disparities.²⁴ This is especially important given that cancer screening uptake in the United States remains below target rates.³⁷ Additionally, roughly 60% of colon cancer³⁸ and 30% of breast cancer³⁹ is diagnosed at a late stage.

An organized screening system would require policy implementation at the state level. This system would require the establishment of a state-administered public health program that is responsible for identifying screen-eligible individuals, issuing screening reminders, and tracking follow-up. This would require policies and funding from the state legislature to support program infrastructure.

From a legal perspective, such a system would fall within established public health authority and would not conflict with HIPAA, as population-based registries and public health reporting systems, such as state vaccine registries, already exist under these laws. While data input would still require integration from healthcare providers and laboratories, this responsibility would fall under public health agencies instead of individual providers. As a result, a state-level organized screening system would reduce provider burden while improving the completeness of cancer screening data.

Conclusion

Missing cancer screening reports and a lack of EHR interoperability create significant barriers to meeting national cancer screening guidelines, particularly for procedures such as colonoscopy and mammography. As this analysis demonstrates, existing cancer registries such as SEER are not structured to support provider-accessible screening data due to their de-identified, surveillance-focused governance. Additionally, approaches that rely on linking screening data from EHR systems to registry infrastructure would be insufficient, as screening data is not consistently documented in EHRs.

However, alternative systems offer feasible pathways forward. A provider-accessible registry, similar to CURES, could support cancer screening data if accompanied by mandated reporting requirements. Alternatively, organized screening systems implemented at the state level

may provide a more comprehensive system by shifting responsibility from providers to public health agencies.

Given these findings, future efforts should focus on the development and evaluation of state-level pilot programs to test the feasibility of these systems. Advancing preventive screening infrastructure is crucial to improving screening rates, reducing late-stage cancer diagnoses, and addressing cancer disparities.

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