

## CancerLinQ Frequently Asked Questions

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## **Background Information**

### **What is CancerLinQ?**

CancerLinQ™ is a groundbreaking health information technology platform that aims to rapidly improve the quality of cancer care. It is managed by CancerLinQ LLC, a wholly owned non-profit subsidiary of the American Society of Clinical Oncology (ASCO) established for the development and operation of CancerLinQ™. The CancerLinQ platform assembles vast amounts of usable, searchable, real-world cancer information into a powerful database that provides doctors with immediate feedback to help improve and personalize care for people with cancer. The data collected by CancerLinQ is used to provide reports, services, and other tools designed to support providers’ quality assessment and improvement, care coordination, case management, and other health care operations activities.

### **What is ASCO?**

The American Society of Clinical Oncology, Inc. (ASCO), a 501(c)(3) charitable organization, is the world’s leading organization representing physicians who care for people with cancer. ASCO’s mission is to conquer cancer through research, education, and promotion of the highest quality patient care. CancerLinQ™ will aid this mission by giving oncology professionals the ability to learn from every patient to accelerate progress against cancer and will provide patients and physicians with more comprehensive information to make decisions about cancer prognosis and treatment.

### **How is CancerLinQ™ funded?**

CancerLinQ™ is currently funded via two avenues: ASCO and its philanthropic funding arm, the Conquer Cancer Foundation, a division of ASCO. The long-term goal is for CancerLinQ™ to be a self-sustaining enterprise.

## Privacy and Regulatory Compliance

### **Is CancerLinQ™ HIPAA compliant?**

Yes, CancerLinQ™ is a Business Associate under the Health Insurance Portability and Accountability Act (HIPAA). CancerLinQ™ has a dedicated Privacy and Security Officer, HIPAA Policies and Procedures, and HIPAA training for all personnel with access to protected health information (PHI). CancerLinQ™ performs a regular HIPAA security assessment.

### **Does CancerLinQ™ meet state privacy standards?**

Because CancerLinQ™ complies with HIPAA, it meets all state privacy standards that are equivalent or less stringent than HIPAA. A few states have privacy laws that are more stringent than HIPAA in certain areas, and this is something for each practice to review and decide before participating. CancerLinQ™ will work with practices to address state compliance questions so practices can participate in CancerLinQ wherever possible.

### **Does CancerLinQ™ data travel outside of the United States?**

The HANA cloud servers are in Virginia and California. CancerLinQ™ data is not stored overseas. A limited number of CancerLinQ support resources outside of the United States may remotely access the system to provide technical support; however, they do not locally download PHI.

## Data Storage and Security

### **How is data security assured?**

CancerLinQ™ benefits from the SAP HANA Enterprise Cloud's rigorous data security, which includes end-to-end encryption, frequent testing, anti-virus and network security software, as well as thorough administrative security protocols and procedures. Additional information is provided in the CancerLinQ Privacy and Security Program Overview document.

### **Does CancerLinQ™ have cyber insurance?**

Yes, CancerLinQ has cyber liability coverage with a limit up to \$15,000,000.

### **Who is responsible for breaches of the CancerLinQ™ system?**

CancerLinQ™, SAP, and their subcontractors are all directly responsible as Business Associates under HIPAA. The practice is also responsible as a Covered Entity under HIPAA, but the Participation Agreement between CancerLinQ LLC and the practice states that CancerLinQ LLC will indemnify the practice for breaches that are not caused by the practice.

### **Is CancerLinQ™ data encrypted?**

Yes, CancerLinQ employs 256-bit encryption for PHI in motion and at rest.

### **Does CancerLinQ™ de-identify data?**

Yes, PHI in CancerLinQ is de-identified using the Expert Determination Method under HIPAA. The de-identification is done by trained CancerLinQ informaticists using validated software from Privacy Analytics.

## Data Collection and Storage

### **Does CancerLinQ™ collect Protected Health Information (PHI)?**

Yes, CancerLinQ collects fully-identifiable patient information. This is necessary for the quality reporting and analytics that is provided to the practice.

### **What data elements are collected?**

CancerLinQ™ collects relevant data in the electronic medical record (EMR) of cancer patients, rather than particular data elements. This is necessary for the powerful data mining that supports quality improvement tools within the system. In the future, CancerLinQ™ may collect additional data types including genomic information, practice management, third party data sets, (e.g. SEER data), and others in order to enhance current data exploration capabilities.

**Where is the data stored?**

CancerLinQ™ data is stored in a CancerLinQ-specific instance of SAP's HANA Enterprise Cloud.

**Can CancerLinQ collect unstructured data?**

Yes, CancerLinQ™ collects unstructured data and uses Natural Language Processing (NLP) technologies to process it into structured data fields.

**How often is data collected?**

CancerLinQ™ initially collects all historical data, and then updated data from most practices on a daily basis. The frequency varies depending on the source systems.

**Does CancerLinQ™ collect provider-level information?**

Yes, provider-level information is collected from the EMR and other practice management systems. This information is kept confidential within CancerLinQ™. Provider-level information is never disclosed without the practice's prior approval.

**Does CancerLinQ™ collect financial information?**

Yes, financial information is collected if it appears in the practice management system. This information is kept confidential and is never disclosed unless directed by the practice.

**Does CancerLinQ™ collect genomic information?**

CancerLinQ collects genomic testing reports if they are included in the EMR. At this time, CancerLinQ does not collect full genomic sequencing files.

## **Data Governance and Access**

**Who has access to my practice's data in CancerLinQ™?**

Each practice decides which of its physicians and other personnel will have access to the practice's PHI within the CancerLinQ™ platform. Select, trained informaticists at CancerLinQ LLC have access to PHI, as do certain technical support personnel from CancerLinQ LLC and its technology partner, SAP. Others have access only to aggregate, de-identified CancerLinQ™ data, based on the [CancerLinQ Data Governance Policies](#).

**Is CancerLinQ™ a research activity?**

No, CancerLinQ™ is a quality improvement activity and is part of a practice's health care operations. A national IRB has reviewed the CancerLinQ™ program and determined that participating in CancerLinQ™ is not a research activity.

**Will CancerLinQ™ data ever be used for research?**

Fully identifiable data in CancerLinQ™ will not be used for research. Aggregate, de-identified information will eventually be available for research queries that meet the data governance standards.

**Is CancerLinQ™ data sold?**

Practices' PHI in CancerLinQ™ is never sold. Data that has been aggregated and de-identified may be used to produce reports and other products that are sold by CancerLinQ™ to sustain the program.

**Is my practice's data separated from other practice's data?**

Yes. CancerLinQ™ logically segregates all individually identifiable data by practice, and practices are only able to access their own patient data. De-identified data is aggregated among practices; identifiable data is firewalled from de-identified data at all times.

**Does CancerLinQ™ add or change the data in the EMR?**

No. CancerLinQ™ does not "write" to the EMR; it only receives data from the EMR.

**What processes are in place to ensure appropriate data governance?**

CancerLinQ™ employs robust [data governance policies](#) and processes in order to ensure appropriate data use and access. Additionally, CancerLinQ™ is advised by a [committee](#) of data governance industry experts and vanguard

practice physicians who set appropriate limits for data use and approve any provision of de-identified data to 3<sup>rd</sup> parties for research or industry purposes.

## **Patient Data**

### **Do patients consent to CancerLinQ™ participation?**

CancerLinQ does not require practices to obtain patient consent. Because CancerLinQ™ is part of health care operations, individual patient consent is not required under HIPAA. Rather, CancerLinQ™ uses a patient opt-out method. All patients receive information about their doctor's participation in CancerLinQ™, and may opt out. Affirmative consent may be required under a few states' privacy laws, but this may be covered through a general consent already gathered by the practice.

### **How does a patient opt-out of CancerLinQ™?**

A patient opts out of CancerLinQ™ by informing their physician of their desire to opt out. An authorized user at the practice then opts the patient out via the CancerLinQ™ platform.

### **How does patient opt-out work for historic data in the EMR?**

If a current patient opts out, his or her historical PHI will be deleted from CancerLinQ™. Information about former patients may be disclosed to CancerLinQ™ as part of health care operations without providing such patients an opt-out. The practice has the discretion to provide notice to former patients regarding opt-out.

### **What happens to a patient's data after he/she opts out?**

If a patient's opt-out request is entered in the CancerLinQ™ system by the practice, a CancerLinQ LLC team member will delete PHI relating to the patient. However, some minimal PHI may be retained in order to prevent collection of PHI about the patient in the future. Information that has already been de-identified will remain in CancerLinQ's de-identified data sets.

## **Practice Participation**

### **Is there a fee to participate in CancerLinQ™?**

CancerLinQ LLC does not charge a fee to providers, practices, or patients in order to participate in CancerLinQ™. In addition, CancerLinQ LLC currently waives the initial onboarding fee, as well as user fees for 5 years. To the extent necessary, certain limited costs may be incurred by the practice in terms of dedicated personnel hours, along with the acquisition of hardware and software resources to support a connection to CancerLinQ™.

### **What is required in order to implement CancerLinQ™?**

It is necessary for a participating practice to utilize an EMR system (CancerLinQ™ can connect with any EMR system). Additionally, individual participation in CancerLinQ™ is not possible at this time, meaning a practice must choose to participate rather than an individual clinician. CancerLinQ™ strives to ensure that implementation has minimal impact on participating practices. The implementation period takes approximately 4-6 months. The expected time commitment for participating practices during that period is 1-2 hours per week via telephone.

### **Can my practice discontinue using CancerLinQ™ at any time?**

Yes, practices are at liberty to discontinue use of CancerLinQ™ at any time with 90 days' notice.

### **How do I obtain more information about participating in CancerLinQ™?**

CancerLinQ LLC is always happy to provide information or a live demonstration of the product. Please utilize the contact form found [here](#) and a representative will contact you promptly.

## **Partnerships**

### **What is the relationship between CancerLinQ LLC and SAP?**

SAP is the world's largest provider of enterprise application software. SAP has a proven track record of success partnering with the healthcare sector. In January 2015, ASCO announced a [strategic technology collaboration](#)

between CancerLinQ LLC and SAP America to build CancerLinQ™. SAP provides the technology and platform, and CancerLinQ provides the oncology expertise, leveraging the more than 40,000 members of ASCO.

**What is the relationship between CancerLinQ LLC and Jitterbit?**

CancerLinQ LLC has teamed with Jitterbit to ensure that CancerLinQ can access, acquire and analyze any type of data from a variety of source systems, CancerLinQ LLC chose the Jitterbit Healthcare Interoperability Platform to bring together and transform data from all of these sources. Together, CancerLinQ LLC and Jitterbit developed an intelligent way to accurately process and transform healthcare data from any source to a single common format that can be ingested into the CancerLinQ™ platform.

**What is the relationship between CancerLinQ LLC and Privacy Analytics?**

CancerLinQ LLC utilizes Privacy Analytics' PARAT CORE software to statistically de-identify patient records.

**With which other organizations is CancerLinQ partnering?**

CancerLinQ LLC has partnered with Cancer Informatics for Cancer Centers CI4CC, a nonprofit organization that provides the leading national forum for academically focused research from informatics scientists, as well as for engagement of senior cancer informatics and technology leaders at academic cancer centers around the world and the 70 U.S. NCI-funded cancer centers. The collaboration establishes an informatics advisory council for CancerLinQ™ comprised of leading experts from cancer centers across the nation and places a CancerLinQ LLC representative on a CI4CC Leadership Board. The collaboration facilitates cross-filtration and cross-participation in a variety of avenues, including key forums, engagement in programmatic development, and alignment in strategic opportunities. Discussions with a number of other organizations are underway.

## **CancerLinQ™ Functionality**

**How can CancerLinQ™ benefit my practice?**

CancerLinQ™ can assist practices in exploring their own data through a variety of reports, as well as through direct access to patient-level records viewed longitudinally. CancerLinQ™ also brings the power of big data to the bedside, allowing physicians to query de-identified data in real time to support clinical decision making.

**What functionality can CancerLinQ™ provide?**

CancerLinQ™ provides real-time access to practice data at the patient level, as well as access to the de-identified database, allowing physicians to compare the care they provide to a larger cohort of patients like theirs; hypothesis generation and ad-hoc data exploration is also supported. Additionally, physicians and practices can view real-time compliance with Quality of Oncology Practice Initiative (QOPI®) e-measures and see patients who still need action to ensure that quality metrics are met.

**Can CancerLinQ™ help my practice with quality measurement?**

CancerLinQ™ can provide real-time compliance with ASCO's QOPI® measures, allowing physicians to ensure that they are meeting validated quality metrics. Data is extracted from the EMR automatically, eliminating the need for manual chart abstraction.

**What is the relationship between CancerLinQ™ and QOPI®?**

The Quality Oncology Practice Initiative (QOPI®) is a quality improvement initiative from ASCO. CancerLinQ LLC and ASCO's QOPI team work closely together to ensure that QOPI® e-measures are available within CancerLinQ™.

**Can CancerLinQ™ display 3<sup>rd</sup> party measures?**

Not at this time. As CancerLinQ™ develops, compliance reporting or full support of 3<sup>rd</sup> party measures may be possible.

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For additional information, please see the CancerLinQ™ [website](#)