

OVERVIEW

The Challenge:

Give oncologists crucial access to usable, searchable, real-world cancer information while protecting patient privacy.

The Solution:

A proven, HIPAA-compliant methodology to assess risk and de-identify patient data. Through Privacy Analytics' methodology and software, CancerLinQ™ will be able to unlock and make available large volumes of aggregated cancer patient data that resides in unconnected clinical and practice management systems.

The Benefit:

Unlocking previously inaccessible data supports providing real-time quality feedback to providers and allows physicians to compare their actual care against guidelines and with their peers, uncover previously unseen patterns and ultimately gain new insights to improve treatment and outcomes.

CancerLinQ: Enabling Access to Real-World Cancer Information to Derive Clinically Meaningful Insights that Support Quality Improvement and Hypothesis Generation

Oncologists and other health professionals understand that improving how we approach cancer care requires better knowledge. Greater knowledge can only be accomplished through quality — and quantity — of data. But how do we get these greater volumes of quality data and still protect patient privacy?

Gaining Access and De-identifying Cancer Data for Secondary Use

CancerLinQ LLC, a wholly owned nonprofit of the American Society of Clinical Oncology (ASCO), chose to use Privacy Analytics' de-identification methodology and tools to support CancerLinQ™, a rapid learning healthcare system that will help oncology professionals aggregate and analyze data on cancer patients to improve care. Through securely de-identifying patient data from practices of all sizes and geographic locations across the United States, healthcare practitioners will be able to advance cancer treatment and care.

ASCO is dedicated to supporting the improvement of cancer care and more than 35,000 professionals from all specialties in oncology are members in this society. ASCO developed CancerLinQ as part of its mission to support researchers and practitioners in oncology.

Currently, it is estimated that over 97% of information on cancer patients typically sits in unconnected data centers and servers, preventing it from being shared or analyzed. Clinical trials currently provide oncologists and researchers with the main source of information for advancing care and treatments. However, only 3% of cancer patients participate in these trials, which do not capture populations that need more specialized care such as the elderly, or those with rare diseases.

In order to allow timely access and analysis of high volumes of cancer patient data, an automated software system that protects patient privacy is required. Privacy Analytics — the leading provider of software that safeguards and enables personal health data for secondary purposes —

not only provided the technology that would enable the data for research and analytics, but also trained ASCO CancerLinQ employees in de-identification methodologies.

How It Works

CancerLinQ will allow health practices, care centers and hospitals across the U.S. to upload their health information to the CancerLinQ system. This real world information can provide detailed and current information to participating practices to analyze for the improvement of cancer care. The data will capture many different types of cancers and conditions, enabling a more representative sample for practitioners compared to typical clinical trial studies. The system is powered by the SAP HANA® platform, which will aggregate the data with other sources of information such as clinical guides and physicians' notes, and enable participating practices to query the information.

Before the data can be used, protected health information (PHI) must be de-identified in order to protect patient privacy.

Privacy Analytics' software gives a consistent, scalable and repeatable approach to de-identifying health data. Highly-trained CancerLinQ staff serve as experts and are responsible for utilizing Privacy Analytics' software and methodologies to apply anonymization techniques and run risk measurements. CancerLinQ utilizes the software to perform a risk assessment of the data based on its context for intended use and automatically de-identify the data. The trained staff review the de-identified data to ensure the smallest level of risk is achieved before transferring the data into

CancerLinQ's de-identified databases. In addition to accessing identifiable data on its own patients, a participating practice will be able to access the aggregated de-identified information through CancerLinQ.

Real World Application: Understanding Cancer When Little is Known

Research and literature on treatments are not always readily available for oncologists faced with treating a patient with specialized needs, such as dealing with a rare form of cancer or when the treatment has not been used for that particular form of cancer. While a doctor will design the best treatment plan based on the information available, sometimes the patient – and doctor – want a second opinion.

However, there may not be a qualified expert nearby or readily accessible to quickly receive the requested feedback. The ability to search de-identified information on similar patients by logging into CancerLinQ enables the doctor to confirm their decision or adjust the plan based on how other patients have reacted to treatment in similar situations.

Real World Application: Enabling More Effective Research Efforts

Researchers often faced limited access to data to support their research as well as arduous approval processes. By enabling the ability to access de-identified information, researchers can see patterns in cancer and cancer treatments, as well as develop hypotheses for further research.

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Real World Application: Improving Care Plan Performance

A practitioner using CancerLinQ to evaluate the care plan for their patient may be alerted to specific side effects of treatments and suggest referring the patient to a specialist who can further discuss those effects. A medical practice can review how well they are adhering to clinical guidelines compared to the national average. The practice can then take steps to improve performance and track their progress.

CancerLinQ provides real-time quality performance indicators based on widely accepted quality measures in oncology. Practices can monitor their adherence to quality performance indicators in real time and see a list of patients within an actionable time frame. With this granular information readily available, the practice can easily identify those patients that may benefit from clinical intervention.

Through Privacy Analytics' methodology and software, CancerLinQ provides practitioners and researchers with needed access to real-world cancer information, while protecting patient privacy, in order to uncover previously unseen patterns and gain insights to improve cancer treatment and care.