



## **CancerLinQ™ Data Governance Approach**

### ***Introduction***

Preserving patient trust through responsible data use is one of CancerLinQ's highest priorities. CancerLinQ is committed to:

- Transparency about collection, use, and disclosure of each patient's data through routine information sharing and education.
- Rigorous policies and procedures that govern how CancerLinQ data will be used and accessed.

### ***Background***

The American Society of Clinical Oncology (ASCO), a 501(c)(3) charitable organization, is the world's leading organization representing physicians who care for people with cancer. ASCO believes that the ability to learn from every patient will accelerate progress against cancer and will provide patients and physicians with more comprehensive information to make decisions about cancer prognosis and treatment. CancerLinQ LLC is a wholly owned non-profit subsidiary of ASCO established for the development and operation of CancerLinQ.

CancerLinQ is a groundbreaking health information technology platform that aims to rapidly improve the quality of cancer care. CancerLinQ 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 will be 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. In all of its operations, CancerLinQ is guided by a commitment to ethical and responsible data collection and use.

### ***CancerLinQ Data Governance***

CancerLinQ has formed a Data Governance Oversight Committee to guide the responsible and ethical use of data. The Data Governance Oversight Committee consists of a panel of oncologists and others with expertise and experience in implementing data governance safeguards in a variety of clinical settings.

This committee is responsible for:

- Reviewing and advising on policies and standard operating procedures for evaluating researcher requests to use secondary de-identified and limited data sets
- Reviewing and advising on policies and procedures for the evaluation of business proposals to analyze or access de-identified data for business purposes
- Devoting ongoing attention to changes in the scientific, technological, legal, and ethical norms that form the basis of CancerLinQ's policies and operational decisions.

This expert panel directs the efforts of CancerLinQ data governance staff dedicated to the



handling of data in a manner that preserves patient trust and is in compliance with all federal and state guidelines, such as HIPAA.

CancerLinQ makes its key data governance policies available publicly at [www.CancerLinQ.org](http://www.CancerLinQ.org). In addition, CancerLinQ has [published](#) background information on its regulatory framework, and will continue to share updates and lessons from its policies and experience, as they become available.