

## CancerLinQ<sup>®</sup> 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 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 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.

### CancerLinQ Data Governance

CancerLinQ's data governance approach was set from 2015 through 2019 by the Data Governance Oversight Committee, a panel of oncologists and others with experience in implementing data governance safeguards in a variety of clinical settings.

The Data Governance Oversight Committee helped develop CancerLinQ's policies and procedures relative to the responsible and ethical use of data. Its work included developing guidance on evaluating researcher requests for access to de-identified and limited data sets, as well as policies and procedures for evaluating proposals to analyze or access de-identified information for business purposes. The Committee was sunset in 2019 and responsibility for data governance has since been imparted to CancerLinQ staff, but CancerLinQ continues to rely

on the Committee's work in its approach to data in a manner that both preserves patient trust and that is in compliance with all federal and state guidelines. In all of its operations, CancerLinQ is guided by a commitment to ethical and responsible data collection and use.

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 its use of data, and will continue to share updates and lessons from its policies and experience, as they become available.