CancerLinQ™ Privacy and Security

Introduction
Preserving the trust of patients is one of CancerLinQ’s highest priorities and is essential to its success. CancerLinQ is committed to:

- Transparency about collection, use, and disclosure of each patient’s data through stakeholder engagement, communication and education.
- Robust data security controls to preserve the privacy of those patients whose data are included in CancerLinQ.
- A simple “opt-out” procedure for patients who choose not to have their information included in CancerLinQ.

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.

Transparency about CancerLinQ
CancerLinQ collects patient data from oncology providers whose practices or sites voluntarily participate in CancerLinQ. CancerLinQ requires all participating providers to inform their patients of their participation in CancerLinQ. Patients have the option to opt out of CancerLinQ by informing their physicians of their choice (see below).

CancerLinQ makes its key data governance policies available publicly at www.CancerLinQ.org. These policies explain the ways in which CancerLinQ does and does not use patient data.

CancerLinQ’s Privacy and Security Safeguards
CancerLinQ relies on patient participation to improve the quality of cancer care, so we take the security of patient information very seriously. CancerLinQ maintains patient privacy and data security every step of the way, and meets legal, regulatory, and technical standards governing the
use of patient health information.

CancerLinQ’s activities are regulated by and comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which sets enforceable standards governing the collection, use, disclosure, and protection of patient data for all healthcare activities involving identifiable patient information.

CancerLinQ will never disclose identifiable patient data to anyone other than the patients’ doctors or medical practices.

In addition to a patient’s own physician or medical practice, a small number of select, trained personnel from CancerLinQ and its technology team will be able to see the patient’s identifiable information. Other access will only be granted if required by law, or with the patient’s permission.

Data security is integrated into all facets of CancerLinQ. CancerLinQ’s computer network is protected from unauthorized access, its software is defended against misuse by highly sensitive protection and detection software, and its servers are housed in a state-of-the-art data center with industry-leading physical and technical security measures.

**CancerLinQ’s Opt-Out Approach**

For patients who do not want their data included in CancerLinQ, an option to opt out is offered.

When a patient decides to opt out, that patient’s identifiable health information will not be used by CancerLinQ. Very limited information is retained to ensure that no new data about that patient enters CancerLinQ in future. Any anonymous data already in the system will remain.

Opting out is easy for patients. Upon deciding not to share data with CancerLinQ, the patient asks his or her oncology care provider for a CancerLinQ opt-out form. The form is also available at [www.CancerLinQ.org](http://www.CancerLinQ.org). The patient completes the form and gives it to his or her oncology provider, who informs CancerLinQ.