



## Participation Policies for CancerLinQ™ Subscribers

### I. Introduction

CancerLinQ is committed to conquering cancer through appropriate, secure and ethical usage of health information entrusted to the CancerLinQ system. The ability to learn from every patient will accelerate progress against cancer and will give patients and physicians more comprehensive information to make decisions about cancer prognosis and treatment.

CancerLinQ is a learning health system designed to monitor, coordinate, and improve the quality of care provided to cancer patients. Once collected for these Health Care Operations purposes, CancerLinQ data is expected to also have utility in other secondary applications, such as updating and developing quality benchmarks and clinical guidelines, hypothesis generation, research, and provision of reports.

### II. Glossary of Terms Used

**Consumer:** An individual or entity that enters into an agreement with CancerLinQ to receive one or more reports.

**De-Identified Data:** Refers to Health Information: (a) that has been redacted or otherwise revised to exclude all identifiers specified in 45 CFR § 164.514(b)(2) and with respect to which no actual knowledge exists that the information could be used alone or in combination with other information to identify any individual who is a subject of the information; or (b) that an appropriately qualified professional has determined does not constitute Individually Identifiable Health Information in accordance with 45 CFR § 164.514(b)(1).

**Electronic Health Record (EHR):** Longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. Includes, but is not limited to, information about patient demographics, progress notes, diagnoses, medications, vital signs, past medical history, immunizations, laboratory data, and pathology and radiology reports.

**Health Care Operations:** Any one or more of the activities set forth in 45 C.F.R. § 164.501, including but not limited to quality assessment and improvement, outcomes evaluation, case management and care coordination, business planning and development, and business management and general administrative activities.

**Individually Identifiable Health Information:** Information created or received by a health care provider, health plan, employer, or health care clearinghouse that relates to the past, present, or future physical or mental health or condition of an individual, the provision of health care to an individual, or the past, present, or future payment for the provision of health care to an individual. Additionally, the information must either identify the individual; or there is a reasonable basis to believe the information could be used to identify the individual. 45 CFR § 160.103.

**Licensed Marks:** A trademarked image or logo that the Subscriber has obtained permission to utilize or display.

**Limited Data Set:** Protected health information that excludes the following direct identifiers of the individual, or of relatives, employers, or household members of the individual: (i) Names; (ii) Postal address information, other than town or city, State, and zip code; (iii) Telephone numbers; (iv) Fax numbers; (v) Electronic mail addresses; (vi) Social security numbers; (vii) Medical record numbers; (viii) Health plan beneficiary numbers; (ix) Account numbers; (x) Certificate/license numbers; (xi) Vehicle identifiers and serial numbers, including license plate numbers; (xii) Device identifiers and serial numbers; (xiii) Web Universal Resource Locators (URLs); (xiv) Internet Protocol (IP) address numbers; (xv) Biometric identifiers, including finger and voice prints; and (xvi) Full face photographic images and any comparable images. Disclosure of a limited data set may only be for the purposes of research, public health, or health care operations, and must be accompanied by a fully executed data use agreement. 45 C.F.R. § 164.514(e).

**Protected Health Information (PHI):** The subset of Individually Identifiable Health Information that is: (i) transmitted by Electronic Media; (ii) maintained in Electronic Media; or (iii) transmitted or maintained in any other form or medium. Protected Health Information excludes Individually Identifiable Health Information: (i) in education records covered by the Family Educational Rights and Privacy Act, as amended, 20 U.S.C. § 1232g; (ii) in records described at 20 U.S.C. § 1232g(a)(4)(B)(iv); (iii) in employment records held by a Covered Entity in its role as Employer; and (iv) regarding a person who has been deceased for more than 50 years.

**Redacted Data:** Refers to the De-Identified Data and Limited Data Set data, collectively, in CancerLinQ.

**Research:** A systematic investigation, including development, testing, and evaluation of a therapeutic intervention, designed to develop or contribute to generalizable knowledge. Research includes development of research projects or preparation for research.

**Report:** A document or dashboard that provides information and analyses gleaned from review or analysis of CancerLinQ data. CancerLinQ will offer a family of reports, to include Quality Reports, Practice Management Reports, Public Health Reports, Market Reports, and others.

**Primary Account User:** A User at each practice whose responsibility it is to manage all Users within the practice, including but not limited to setting up new User accounts,

monitoring User activity, and communicating with CancerLinQ when necessary for technical issues and questions.

**Quality Report:** A report provided to Subscribers by CancerLinQ in connection with the Health Care Operations quality assessment and improvement services for which Subscriber has engaged CancerLinQ, including any customized reports and dashboards.

**Subscriber:** An entity that enters into a Participation Agreement and Business Associate Agreement with CancerLinQ in order to provide data to CancerLinQ and receive Health Care Operations services from CancerLinQ.

**User:** An individual who is assigned log-in credentials to access services from CancerLinQ. A Subscriber or Consumer account may have one or more Users associated with it.

**User Login:** A set of unique credentials that indicates an individual User.

### **III. General**

- A. All CancerLinQ Subscribers must sign a Participation Agreement, including a Business Associate Agreement. The agreements must be signed by a representative of the organization with appropriate legal authority for the Subscriber organization.
- B. At least one principal, employee, or member of the Subscriber entity must be a full member of ASCO at all times during the Subscriber's participation in CancerLinQ.
- C. CancerLinQ Subscribers must comply with all applicable laws and all CancerLinQ policies and procedures.
- D. Subscriber will not attempt to gain unauthorized access to CancerLinQ systems or data. Access to CancerLinQ will be provided by CancerLinQ or the Subscriber's Primary Account User.
- E. Subscriber will not attempt to reverse engineer, translate, or alter any of the CancerLinQ services or portal.
- F. Subscriber must not attempt to re-identify any patients about whom they receive Redacted Data or reports derived from CancerLinQ data sets.
- G. Subscriber will not attempt to discover or alter source code.
- H. Subscriber will take reasonable security measures to protect the CancerLinQ system. This includes maintaining virus protection on all devices used to connect to CancerLinQ. Virus protection software must be updated regularly and in accordance with the publisher's update prompts.

- I. CancerLinQ reserves the right to publicly identify Subscriber as a participant in CancerLinQ.
- J. Subscriber may identify themselves as participants in CancerLinQ.
- K. CancerLinQ Subscribers and Users are strictly prohibited from stating or implying that participation in CancerLinQ implies an endorsement from CancerLinQ or the American Society of Clinical Oncology (ASCO).

#### **IV. CancerLinQ Subscriber System Access and Account Management**

- A. Subscriber must provide CancerLinQ with current and accurate information regarding the location(s) in which Subscriber maintains a place of business (i.e. legal entity name, practice d/b/a name, address(es) of practice location(s), address(es) of clinic site(s), etc...) as well as the identities and contact information of the responsible person(s) for the organization. Any changes must be communicated to CancerLinQ within 30 calendar days.
- B. Subscriber will designate at least one User as a Primary Account User who will be responsible for the control of the account access privileges for the Subscriber. Subscribers must notify CancerLinQ of any changes to the Primary Account User as soon as possible, and no more than 5 business days after a change occurs.
- C. Subscriber, through the Primary Account User, will designate a number of User Logins for their practice location. CancerLinQ will determine the number of User Logins for each practice.
- D. Subscriber, through the Primary Account User, is responsible for maintaining accurate and appropriate login rights and permissions for Users in the Subscribing Practice.
- E. Subscriber will not grant User Login credentials, User privileges or other access to CancerLinQ to anyone who is not a principal or employee of the Subscriber and legally bound by the terms of the Participation Agreement and these Policies.
- F. CancerLinQ practices may contribute their data to other programs if they so choose. Similarly, participants in other data programs may be Subscribers to CancerLinQ.
- G. User Login credentials may not be shared under any circumstances.
- H. If a User leaves the Subscribing Practice, Primary Account Users are required to deactivate the associated User Login as soon as possible, but no later than 5 business days after the User leaves.

- I. CancerLinQ reserves the right to monitor access to and usage of the CancerLinQ system by Subscribers and associated Users, including monitoring User access to the system, use of tools within the system, and interactions with data within the system.
- J. CancerLinQ reserves the right to deactivate User Logins or modify privileges of User accounts for unauthorized or inappropriate User activities, including, but not limited to, violation of the Participation Agreement and/or failure to comply with CancerLinQ policies or procedures.

## **V. Data Policies**

### **Data Collection from CancerLinQ Subscriber**

- A. Subscriber should notify CancerLinQ about any suspected or actual data quality or integrity issues in its Electronic Health Record (EHR) or practice management system within 3 business days.
- B. Subscriber must transmit a minimum dataset to CancerLinQ in order to obtain benefits from the system; data requested include but are not limited to patient history, demographic information such as address and birthdate, and treatment plans if available. Subscriber is encouraged to transmit all available data to CancerLinQ. If Subscriber chooses not to transmit all data to CancerLinQ, CancerLinQ may not be able to, or may choose not to, provide all desired services and functionality. CancerLinQ may terminate the Participation Agreement if it is determined that the data submitted by the Subscriber is not sufficient to provide necessary services.
- C. Subscriber will work with CancerLinQ to develop and execute a CancerLinQ implementation plan. Subscribers are encouraged to transmit historical EHR and practice data to CancerLinQ, followed by prospectively acquired data, as stated in the CancerLinQ Participation Agreement.
- D. CancerLinQ does not constitute a system of record. CancerLinQ is not responsible for providing backups or copies of the data that was submitted by a Subscriber.
- E. Subscriber must make reasonable efforts to ensure that the Data is free of all viruses or malware which could harm CancerLinQ hardware or software.

### **Data Use**

- A. Subscriber is asked to notify the CancerLinQ Helpdesk within 5 business days if they believe there are any quality issues with the reports that they receive from the CancerLinQ system.

- B. To use CancerLinQ for research, Subscriber must follow, as appropriate, their internal Institutional Review Board (IRB) process, obtain consent from patients if required, and receive written approval from CancerLinQ.
- C. Subscriber will have access to Reports from CancerLinQ as a part of their subscription. Additional custom Reports may be requested by a Subscriber. Requests must be made following CancerLinQ's established procedures. CancerLinQ reserves the right to approve/disapprove requests.
- D. Subscriber must not use any CancerLinQ information received from a custom Report for a purpose not initially specified in the approved Report proposal or later requested from CancerLinQ.
- E. Subscriber may not share custom Reports with anyone outside of their organization, except for purposes related to financial/legal advising or insurance reimbursement, without permission from CancerLinQ.
- F. Subscriber must not attempt to identify any other Subscribers or Users whose information is included in CancerLinQ Reports.
- G. If CancerLinQ Data or Reports are shared externally, the following guidelines must be strictly adhered to:
  - 1. Reports may not be used to suggest an endorsement or accreditation by ASCO or CancerLinQ.
  - 2. Subscribers may not advertise their quality or achievements compared to those of other practices (such as declaring a practice "better" or "best") based on CancerLinQ reports.
  - 3. No disclaimers or legal notices may be removed or obscured from the Reports.
  - 4. Report Benchmarks and Subscriber Performance Reports may not be altered in any fashion.
- H. Subscriber may not publicly present information about CancerLinQ or based on Reports generated by CancerLinQ without informing CancerLinQ prior to presentation.
- I. Subscriber may not share custom Reports with anyone outside of their organization without written permission from CancerLinQ. However, sharing of such Reports to provide evidence of quality improvement is permitted without written permission from CancerLinQ.

### **Data Accountability & Ownership**

- A. Subscriber retains ownership of their data and reserves the right to transmit data to CancerLinQ at their discretion, although failure to transmit a minimum dataset may result in termination of the Participation Agreement if it is determined that the data submitted by the Subscriber is not sufficient to provide necessary services.

- B. Once data has been submitted to CancerLinQ, CancerLinQ retains the intellectual property rights in the organization of the data and any analytics or Reports produced by CancerLinQ.
- C. Custom Reports, including the display of content contained in such Reports, is the intellectual property of CancerLinQ and may not be sold, reproduced, or shared without approval by CancerLinQ.

### **Data Availability, Retention & Disposal**

- A. CancerLinQ will make every effort to ensure that data remains available within the system with limited outages. CancerLinQ will communicate with Subscriber if an outage is planned for system maintenance.
- B. CancerLinQ will retain Subscriber data indefinitely unless otherwise negotiated with Subscriber.
- C. Upon termination, CancerLinQ will continue to secure Subscriber data in accordance with HIPAA, HITECH, and applicable state law. Subscriber data that remains in the system will remain de-identified, aggregated, and used to produce Reports.
- D. CancerLinQ will not dispose of data unless mandated by legal requirements.

### **VI. CancerLinQ Subscriber Privacy & Notification**

- A. Subscribers are required to notify their current patients regarding the Subscriber's participation in CancerLinQ and the opportunity to opt out of having their data included in the system.
- B. Subscribers are required to offer their current patients an opportunity to opt out of having their data included in CancerLinQ. If a patient notifies the Subscriber that they would like to opt-out, the Subscriber's Primary Account User can opt out patients directly through CancerLinQ.
- C. Subscribers are required to notify patients that once they opt out of CancerLinQ their identifiable personal health information is destroyed except for limited personal information required to ensure that no additional patient data is ingested into CancerLinQ. De-identified patient information will be retained in the CancerLinQ system even if a patient chooses to no longer have their data contributed to CancerLinQ because de-identification removes the link between data and a specific individual.
- D. CancerLinQ will supply practices with communication materials regarding notification of participation and the opportunity to opt out. Subscribers may communicate these topics to their patients in any one or more of the following ways:
  - 1. Inclusion in the Subscriber's Notice of Privacy Practices;
  - 2. Notification displayed within Subscriber's waiting room or exam room;

3. Materials available in Subscriber's waiting room or exam rooms;
  4. Information on the Subscriber's website;
  5. Letter to Subscriber's patients;
  6. Information in Subscriber's patient newsletter;
  7. Information provided verbally once to a patient with instructions as to where to find more information; or
  8. In any other way that fits into the Subscriber's existing workflow or practices.
- E. CancerLinQ will provide functionality to enable Primary Account Users to opt out a patient within their CancerLinQ portal along with appropriate training materials.
- F. To the extent that a practice would like to notify patients who no longer receive treatment at their facility regarding opt out options, CancerLinQ will provide support and assistance.
- G. Subscribers are the primary points of contact for patient questions regarding opt out. If a patient contacts CancerLinQ directly, CancerLinQ will direct the patient to speak with his/her practice.
- H. Subscribers will notify CancerLinQ of any technical issues encountered in processing opt out requests in CancerLinQ.

## **VII. Enforcement**

Consequences for failure to comply with these policies will be determined by CancerLinQ, in its sole discretion, on a case by case basis. Failure to comply may result in sanctions up to, and including, termination of Subscriber and its Users from participation in CancerLinQ. Subscriber will be provided an opportunity to appeal any such consequences.

### **Application:**

*Applies to CancerLinQ LLC*

### **History:**

*Adopted by CancerLinQ LLC Board of Governors May 2015*