



American Society of Clinical Oncology

Information Sharing Policy of American Society of Clinical Oncology

(June 2, 2017)

I. Introduction

The American Society of Clinical Oncology (the “Society”) and its Affiliates (collectively “ASCO”) are committed to conquering cancer through research and education that enables and supports prevention and the delivery of high quality cancer care. ASCO believes that the appropriate, secure, and ethical use of information generated by, collected by and entrusted to ASCO can accelerate progress against cancer. ASCO intends to further its charitable purposes of disseminating oncology information, facilitating collaboration among those involved in oncology, and promoting high quality cancer care by sharing ASCO Information with researchers and other stakeholders both internal and external to ASCO. This policy describes the general principles and processes for how ASCO will share its information.

II. General Principles of ASCO Information Sharing

ASCO upholds the ethical principles of stewardship, protection, transparency, and accountability to guide policies and decisions about sharing information. ASCO may share information with individuals and entities that promise to use it in a manner that will advance the charitable, educational and scientific goals of ASCO and in keeping with ASCO’s standards for data protection, privacy and security.

In the process of managing and sharing information, ASCO is guided by the following principles:

- ASCO’s policies for information sharing will be transparent. Mechanisms for requesting ASCO Information will be clearly described in policies and procedures.
- ASCO will adhere to its existing legal, contractual, and policy obligations when sharing information.
- ASCO will protect the privacy of patients, members, donors, volunteers, attendees and others per ASCO policies and agreements.
- ASCO will consider the interests of ASCO, the needs of ASCO members, external researchers, patients, and other stakeholders in the cancer community when sharing information.
- ASCO will promote access to information for projects that address the needs of patients with cancer, including marginalized populations and communities.
- ASCO will promote authenticity, quality, reliability and integrity of information and analyses.
- ASCO will promote fair access and efficiency in the use and sharing of ASCO Information within the bounds of this Policy.
- ASCO will not grant requests for exclusive access or rights to ASCO Information.
- ASCO will promote timely sharing of results from projects informed by the use of ASCO Information.

ASCO will make reasonable efforts to evaluate all compliant requests. ASCO retains sole discretion as to whether or not to fulfill requests for which information is available and of sufficient quality. ASCO does not guarantee fulfillment of any specific requests.

III. Application

This Policy applies to the Society and its Affiliates, including the Conquer Cancer Foundation (CCF) the Institute for Clinical Excellence, and CancerLinQ unless specific terms or the context dictate otherwise. This Policy also applies to ASCO journals and publications. For purposes of this Policy, the term “ASCO” refers to all of these entities and publications, collectively and as applicable. ASCO addresses information sharing through written policies and a range of procedures consistent with this Policy. Specific policies and procedures for individual entities or programs (“Program-Specific Policies”) may be adopted by ASCO from time to time.

IV. Information Requests

Any individual or entity with a legitimate interest in ASCO Information (“Requestor”) may submit a request to ASCO, using the provided Request Form. ASCO has the right to charge an application fee for information requests.

Where access procedures are defined in a Program-Specific policy, requests for ASCO information will follow the Program-Specific policy. For general requests for ASCO Information, Requestors will complete a Request Form and provide all required information. Required information includes but may not be limited to:

- a. Completed Request Form
- b. Project Description to include summary and objectives of project, including methodology, statistical analysis plan, and publication plans
- c. IRB approval if necessary
- d. Qualifications of project team
- e. Funding source for project
- f. Format of data requested including specific data elements, data definitions, format for data delivery and requested timeline
- g. Any other relevant information as determined by ASCO.

V. Evaluation and Decisions

Requests will be evaluated by the ASCO Information Sharing Committee (“Committee”). The Committee at its sole discretion may call upon subject matter expert reviewers who can advise on the specifics of a Request or project. The Committee has the responsibility and authority to evaluate requests, assess the feasibility of providing ASCO Information for the request and approving or denying requests.

VI. Evaluation Criteria

The Committee will evaluate requests in a reasonable timeframe consistent with the principles described in Section II of this Policy. All approved requests must be consistent with ASCO’s

charitable mission. The Committee will evaluate Requests based on the following factors, and additional factors to be determined by ASCO from time to time:

- a. The proposed use of ASCO Information is consistent with ASCO's charitable mission
- b. ASCO has capacity to produce the requested ASCO Information with reasonable expenditure and allocation of resources
- c. The Requestor and team is, in the Committee's opinion, qualified to carry out the proposed analysis or project
- d. The requested ASCO Information is appropriate for the project and of sufficient quality to achieve the project objectives
- e. The Requestor has acceptable publication or other dissemination plans in place
- f. The Requestor can accept and carry out ASCO's terms of agreement and legal obligations including privacy and security requirements
- g. The request is consistent with any applicable Conflict of Interest policies
- h. The request is otherwise consistent with ASCO Information Sharing principles
- i. Fulfilment of the request is in the best interest of ASCO.

VII. General Conditions of a Data Use Agreement

Approved Requestors will be required to complete a Data Use Agreement with the following general terms:

- a. Agree to use the data only for the approved research project. If the Requestor or entity later wishes to use the data in a new project, a new project proposal must be submitted.
- b. Requestors must agree to keep the level of confidentiality required by ASCO, which may differ for different types of information. They must promise not to try to re-identify individuals, institutions or practices if such data is included, alone or in combination with other sources of data. The data may only be shared within the team conducting the analysis project described in the Application.
- c. Applicable regulatory requirements must be met including IRB approval for the proposed project, if required. A copy of any approvals must be provided to ASCO.
- d. ASCO makes no representations and extends no warranties of any kind, either expressed or implied about its information. There are no expressed or implied warranties of merchantability or fitness for a particular purpose, or that the use of the information will not infringe any patent, copyright, trademark, or other proprietary rights. No indemnification for any loss, claim, damage, or liability will be intended or provided.
- e. ASCO reserves the right to assess fees for the provision of ASCO Information. Fees are intended to cover the administrative costs to ASCO of creating information, storing the information, formatting the information, curating the information, analyzing the information (if requested) and evaluating requests to use the information.
- f. ASCO will use reasonable efforts to provide access to a copy of the data to the extent required by a journal, funding source, or regulatory body and if ASCO is given adequate notice of the requirement.

- g. ASCO may request that copies of all abstracts/manuscripts arising from the project must be sent to ASCO for review prior to submission for meeting presentation or submission for publication.
- h. ASCO may impose other conditions on the use or transfer of ASCO Information in keeping with its policies.

VIII. Violations of this Policy

Violations of this Policy or any terms of an applicable Data Use Agreement may result in appropriate legal action in addition to referral to ASCO Member Discipline and Author Conduct Policies. Requestors found to be in violation of this Policy may be barred from future use of ASCO Information and other ASCO resources .

Glossary of terms

Affiliates: All entities controlled by ASCO including its subsidiaries, and affiliated organizations and programs including CCF, CancerLinQ, QCP and QOPI.

ASCO Information/ Data: Information and data received, held, or generated by ASCO. The terms “data” and “information” may be used interchangeably in this Policy.

ASCO Information Sharing Committee: The ASCO Information Sharing Committee is an internal committee of Senior staff to be appointed by the CEO.

Data Access/Use Agreement: A written agreement(s) signed by ASCO and the Requestor that sets out the permitted uses of ASCO Information/Data and other responsibilities of Requestors. A Data Access Agreement may be part of a larger agreement between a Requestor and ASCO. Where necessary, a Data Access Agreement will be a HIPAA-compliant Data Use Agreement.

Program-Specific Policies: Policies covering access and use of information pertinent to specific ASCO programs. Some Program-Specific policies include:

- a. CancerLinQ Discovery Data Access Policy
- b. TAPUR Data Sharing Policy
- c. QOPI Data Sharing Policy [in development]
- d. ASCO Licensing Standards
- e. Membership Data Policy [in development]
- f. Privacy Policies of ASCO’s family of websites Terms and Conditions and Privacy Policy
- g. Other policies developed by ASCO

Publication: An abstract, manuscript, slide set, poster, filing, or publishable report based on ASCO Information.

Requestor: Individual or entity requesting ASCO Information.

Application:

Applies to ASCO and its affiliates

History:

Adopted by the ASCO Board of Directors on June 2, 2017