

Policy Name: Authorized Group Representation	Policy Number: 14.1
Section: Public Relations – 14	Date Revised: January 1, 2018

14 Public relations

14.1 Authorized group representation

No one other than the group chair, or the authorized representative of the chair, may represent the Alliance in any manner.

Policy Name: Public Service	Policy Number: 14.2
Section: Public Relations – 14	Date Revised: January 1, 2018

14.2 Public service

The Alliance receives major support from the National Cancer Institute (NCI), Division of Cancer Treatment and Diagnosis (DCTD), Cancer Therapy Evaluation Program (CTEP). The goal of this national program is to seek improved methods of cancer therapy, a goal shared by the Alliance. The Alliance represents a bridge between the NCI and cancer patients throughout the country who receive new methods of treatment devised by Alliance investigators and approved by the NCI. In addition, the Alliance depends upon the scientific and financial resources provided by academic medical institutions and community sites throughout the country. The group is committed to conduct its science in a spirit of open inquiry, to critically evaluate promising new ideas and technology, and to take measures to minimize the risks of these new treatments to study participants. The institutions that participate in Alliance studies must agree to furnish study-related data concerning participants who have consented to be enrolled in Alliance studies, regardless of the level of institutional funding, and to undergo audits that evaluate and help to insure the integrity of the data collected. In turn, the Alliance provides these medical centers with the opportunity to see their ideas evaluated in definitive national trials and to provide novel therapies to their patients.

The Alliance also receives support from the NCI's Division of Cancer Prevention (DCP) and Division of Cancer Control and Population Sciences (DCCPS). Using these resources, the Alliance pursues studies to reduce the incidence and prevalence of clinically significant cancers, to alleviate the symptoms of cancer and the toxicities of cancer treatment, and to improve the delivery of cancer care in community and academic practices, with special emphasis on issues affecting minority, underserved, and elderly patient groups.

Thus, the Alliance serves three constituencies:

1. The public whose taxes support Alliance, in part
2. The research participants who agree to take part in Alliance-sponsored clinical and cancer control research
3. The academic institutions and community sites that support our many scientists, physicians, and staff

Policy Name: Dissemination of Information to the General Public	Policy Number: 14.3
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14.3 Dissemination of information to the general public

It is the responsibility of the Alliance Office of the Group Chair and each member of the Alliance to furnish accurate information concerning the Alliance and its research programs to the general public.

Questions from the public fall into several categories and are answered according to category.

- **Questions about new treatments:** These questions are usually referred to an executive officer or a protocol coordinator. If the Alliance has a relevant protocol that is open to accrual, it is appropriate to describe it and refer patients to an appropriate Alliance institution. If the question comes from a geographic location not served by Alliance, it should be indicated that there are other network groups that may also have studies that are appropriate, and that information concerning all NCI-sponsored clinical trials in cancer may be obtained from several websites (see the Alliance website (<http://www.allianceforclinicaltrialsinoncology.org>) under the ‘Resources’ heading).
- **Questions of a medical nature about a specific patient:** The Alliance personnel do not furnish medical advice. For answers to questions of this nature, individuals are referred to the patient's physician.
- **Requests from patients or physicians for copies of Alliance protocols and forms:** Alliance protocols are considered confidential documents and are generally not provided to the public. A non-Alliance physician may receive a copy of an Alliance protocol upon request and after approval by the principal investigator of the Alliance Central Protocol Operations Program (CPOP) or the group chair. The request must be made in writing and the intended use of the protocol must be clearly stated.
- **Inquiries concerning gifts to support cancer research:** Questions should be referred to the Alliance for Clinical Trials in Oncology Foundation.
- **Questions about the Alliance history, structure, and membership:** Refer to the Alliance communications specialist, chief administrative officer (CAO), or refer to the Contact us section of the [Alliance website](#).
- **Questions about Alliance research results:** The Alliance works closely with the NCI, industry partners, member institutions and patient advocacy groups to disseminate information regarding the activation, progress, results and findings of its research. All requests should be referred to the Alliance communications specialist.

Requests for access to the Alliance website: The Alliance website contains sections available to the general public as well as sections that are accessible only to Alliance members or others who have been granted access. The Alliance periodically receives requests for access to the password-protected section of the website. Such requests should be submitted in writing to the CAO and should explain the purpose of the request in detail. The CAO authorizes access if the request is deemed appropriate. In most cases, access is time-limited.

- **All other questions:** Refer to the Alliance communications specialist.

Policy Name: Confidentiality of Patient Information	Policy Number: 14.4
Section: Public Relations – 14	Date Revised: January 1, 2018

14.4 Confidentiality of patient information

The Alliance has instituted procedures designed to protect the privacy of its clinical trial participants. Although there are some limits to non-disclosure of information to federal regulatory agencies, the Alliance intends to protect the privacy of its clinical trial participants to the limit allowed by the law. The Alliance consent form describes the steps taken in this regard. Alliance information systems are HIPAA compliant and Alliance has received a Certificate of Confidentiality from the NIH to protect information about specimens or data obtained from participants in Alliance studies.

Information about Alliance clinical trials may also be provided to pharmaceutical companies, foundations and others that support the work of the group. In all instances the Alliance takes steps to protect the privacy of the study participant. Patient identifiers (including but not limited to patient name, social security number, address and phone number) are not released. Alliance reports and publications do not present information that would allow the identification of its study participants.