

APPENDIX 6

**CONFIDENTIALITY OF CANCER INFORMATION SERVICE COMMUNICATIONS
(POLICY #6)**

Confidentiality

Confidentiality is a value that maintains respect for the privacy and dignity of those who use a variety of medically related services. The promise of confidentiality permits a relationship of trust between those being served and those providing service. Individuals seeking cancer information frequently entrust detailed personal information to the Cancer Information Service (CIS) to receive information tailored to their specific needs. All who contact the CIS, including cancer patients and their families, have the right to expect that CIS staff will respect the confidentiality of their communications.

Confidentiality extends to the following:

- Identities of those who use CIS services.
- Identities of patients who are the subject of CIS communications.
- Identities of physicians who are mentioned in CIS communications.

Confidentiality requirements extend to all CIS staff, including CIS program staff at the National Cancer Institute (NCI). If it is necessary to share identifying information with other CIS offices or NCI to provide quality service, it is not considered a breach of confidentiality.

Anonymity

Although confidentiality protects identifying information disclosed by CIS clients, CIS staff also respects the wishes of clients who choose to remain anonymous. Staff provide all services possible to meet the needs of clients while respecting client anonymity.

Destruction of Identifying Information

Once service is completed, including any follow-up calls or contacts, identifying information about CIS clients is destroyed. CIS systems automatically purge identifying information on a set schedule. CIS contractors who keep identifying information to complete follow-up calls or contacts destroy these records in accordance with CIS procedures.

The CIS keeps contact information on clients of CIS services for longer periods only with the informed consent of the clients. This is done to continue providing requested assistance: e.g., call backs to smokers requesting proactive service or to conduct Office of Management and Budget-authorized data collection for evaluation purposes.

Legitimate Exceptions to Confidentiality

In some instances, situations arise that supersede a promise of confidentiality. These situations require obtaining immediate assistance for individuals who are a danger to themselves or others or those who may be victims of abuse. Reporting suspected abusive behavior or threats of suicide in good faith supersedes requirements of confidentiality. See [Procedure CC-5, Handling Difficult Contacts](#).

Research Activities and Confidentiality

The conduct of research studies within the CIS may require the collection and storage

of identifying data in addition to that collected in normal CIS operations. Data are collected after obtaining required consent based on the parameters of the research project and in accordance with requirements of Institutional Review Boards and the NCI. CIS clients who participate in research studies must have confidence that data obtained will not be used for other than the stated research purposes or be stored in a way that would compromise confidentiality. The CIS does not share research data with those who are not parties to the studies. The timeframe for keeping research data is determined according to the scope and purpose of individual studies. See [Policy 9, Data Collection in the Cancer Information Service Program](#), and [CIS Initial Training Program Module 8: Data Collection](#).

Source: National Cancer Institute Operations Manual
Cancer Information Service Policy 6: Confidentiality of Cancer Information Service Communications

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