

## **APPENDIX 7**

**CONFIDENTIALITY OF CANCER INFORMATION SERVICE (CIS)**

**COMMUNICATIONS (POLICY 3)**

## **Confidentiality of Communications**

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### **Confidentiality**

Confidentiality maintains respect for the privacy 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 National Cancer Institute (NCI) Contact Center (CC) staff so that information can be tailored to their specific needs. CC staff respect the privacy of all people who contact the Center.

Confidentiality extends to the following:

- Identities of those who use CC services.
- Identities of patients who are the subject of CC communication.
- Identities of physicians who are mentioned in CC communication.

Confidentiality requirements extend to all CC staff, including CC program staff at NCI. If it is necessary to share client information with NCI to provide quality service or with researchers for studies authorized by NCI to which clients have consented, it is not considered a breach of confidentiality.

### **Anonymity**

Although confidentiality protects client information, CC staff also respect the wishes of clients who wish to remain anonymous. Staff provide all services possible to meet the needs of clients while respecting client anonymity.

### **Destruction of Identifying Information**

Personally identifiable information will be destroyed or de-identified within 90 days of contact. Exceptions include: Contacts used for quality assurance and training purposes, callbacks, and research studies for which clients have given informed consent. Once service is completed, including any follow-up calls or contacts, identifying information of CC clients is destroyed. CC systems automatically purge identifying information on a set schedule. If information is kept by the CC to complete follow-up calls or contacts, these records are destroyed following completion of the inquiries.

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The CC keeps client contact information for longer periods only with the informed consent of the client. This is done to continue providing requested assistance: e.g., to call clients back when an inquiry requires additional research, to conduct NCI-approved health communications research projects, or to conduct Office of Management and Budget-authorized data collection for evaluation purposes.

### Research Activities

The conduct of health communications research studies within the CC may require the collection and storage of identifying information. Data are collected after obtaining required consent based on the parameters of the research project and in accordance with requirements of Institutional Review Boards (IRB) and NCI. CC 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 CC does not share research data with those who are not parties to the studies. The timeframe for keeping research data is determined by the scope and purpose of individual research studies. See *Policy 6, Data Collection in the NCI Contact Center, and Initial Training Program Module 8: Data Collection*.

### Legitimate Exceptions to Confidentiality

In some instances, situations arise that supersede a promise of client confidentiality. These situations may include individuals who are a danger to themselves or others or individuals who indicate that they are victims of abuse. CC staff should obtain immediate assistance from a Supervisor and report suspected abusive behavior or threats of suicide following *Procedure OP-11, Handling Difficult Contacts*.

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