

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES . PUBLIC HEALTH SERVICE . Centers for Disease Control

CDC
Staff Manual
on
CONFIDENTIALITY

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES Public Health Service Centers for Disease Control Atlanta, Georgia 30333

Contents

1.	Introduction	1
2	Background	5
576	2.1 Section 308(d) of the Public Health Service Act	
	2.2 Privacy Act of 1974	
	2.3 Federal Law Governing Federal Employees' Behavior	
	2.4 Freedom of Information Act	
3.	Individual Employee's Responsibilities	—— е
4.	Assurances of Confidentiality	
	4.1 Policy Implementation	
	4.2 Procedures	
	4.3 Responsibilities	
	4.4 Repository of Assurances	12
5.	Treatment of Requests for Information	13
6.	Physical Protection of Records	14
	6.1 Policy	14
7.	Authorized Disclosures	15
	7.1 Disclosure to the Parent Locator Service	15
	7.2 Disclosures Permitted by Section 308(d) of the	
	Public Health Service Act	
	7.3 Disclosures Within the Department	16
	7.4 Transfers of Data to Other Departments of the	
	Federal Government	17
	7.5 Cooperative Arrangements	
	7.6 Governing Principles	18
В.	Automatic Data Processing Systems Security	18
	8.1 General	18
	8.2 Physical Security	19
	8.3 Data Security	19
	8.4 Reference	20

9. Avoidina	inadvertent Disclosures in Published Data.	_ 20
9.1 Prob		20
	es of Disclosure.	21
	clai Guidelines for Avoiding Disclosure	22
		. 23
	vating a Disclosure Problem	. 23
9.5 Mea	sures to Avoid Disclosure	. 23
Appendix A.	Requirements Relating to Confidentiality and	
	Privacy in Data Collection Contracts	26
1.		25
11.		25
iu.	Policy	26
IV.	Dissemination	33
Appendix B	Requirements Relating to Confidentiality and	
ripportain o.	Privacy in Data Processing Contracts	35
1		35
	Part and a second	35
	Background.	35
in.		
IV.	Dissemination .	3/
Appendix C.	Nondisclosure Agreement (CDC 0.979)	39
Appendix D.	Request for Authorization to Give Assurance	
	of Confidentiality (CDC 0.970)	41

CENTERS FOR DISEASE CONTROL STAFF MANUAL ON CONFIDENTIALITY

1. INTRODUCTION

The Centers for Disease Control (CDC) collects, compiles, and publishes a large volume of personal, medical, apidemiological, and statistical data. The success of CDC's operations depends in part on the sensitivity and voluntary cooperation of its employees to protect the confidentiality of these data. This manual is for your reference and provides information, rules, and regulations governing confidentiality protection.

The following definitions will be dealt with in this manual:

Confidential information is any information about an identifiable fiving person or establishment, when the person or establishment providing the data or described in it has not given consent to CDC to make that information public, and CDC assured confidentiality when the information was provided.

A confidential record is a record containing confidential information about an individual or establishment.

Consent to the publication, other release, or other use of information must be obtained when information is collected. The respondent is clearly informed about the uses to be made of data he is asked to supply. If the respondent then supplies the requested data, CDC staff interprets this to mean that the respondent agrees to those intended uses he has been told about. CDC can then make such uses of the data as have been described to the respondent, but no other uses of the data may be made.

How is consent obtained from an establishment? The answer to this question depends partly upon whether the request for information is made in a personal interview or by mail.

If the request for information is made in person by a staff member or agent of CDC, the contact person first inquires as to who is authorized to provide the requested data on behalf of the establishment. When such authorized person is informed of the uses to be made of the data, and then supplies the data, CDC staff interprets this to mean that the establishment has given consent to the uses of data as specified.

When data are sought from an establishment by mail, the request may be addressed to the establishment itself, to the manager of the establishment, or to some other person who, as CDC has previously

ascertained, is authorized to provide requested data on behalf of the establishment. The letter transmitting the request explains the uses to be made of the data. When CDC staff then receives the requested data from the establishment, it is interpreted to mean that the establishment has by implication consented to those uses of which it has been informed.

The statement of assurances is that set of information given to any individual or establishment asked to provide information to CDC. It must include as a minimum:

- 1. The legal authorization(s) for soliciting the data:
- 2. The purposes and uses for which the data are being collected;
- 3. The voluntary or mandatory nature of the response;
- 4. The consequences to the respondent for failing to provide any part of the requested data, and when confidentiality has been authorized:
- 5. A guarantee that CDC will protect the data against other uses. (With the exception of several regulatory and grant requirements, CDC's direct requests for data are all voluntary, and there are no effects upon the establishment or individual for failing to respond.)

The statement of assurances may be contained in a letter or brochure handed or mailed to a respondent so that he receives it before providing the information. It also may be included, usually in abbreviated form, on the survey schedule or questionnaire itself. The statement is included in any contract drawn up to obtain information about individuals or establishments. The statement may be given orally to a respondent, but it also must be provided in written form to be retained by the respondent. The sole exception to this requirement is that if a self-administered questionnaire is used, the statement may be made part of the questionnaire, and no separate copy need be given to the respondent.

The assurance of confidentiality is to be found in the statement of assurances. The assurance of confidentiality includes those parts of the statement which relate directly to the promise of confidentiality; these are:

- An explanation of the purposes for which the information is being collected:
- 2. A description of the uses to be made of the information; and
- A guarantee that CDC will neither make nor permit others to make any other uses of the information.

This assurance of confidentiality, then, constitutes the guarantee given to the data supplier that CDC will limit its uses of the data to those specified in writing to the respondent and that CDC will actively protect the information from any other uses.

2. BACKGROUND

Since its inception, CDC has worked diligently to maintain the confidentiality of its records. All necessary and appropriate steps must be taken to assure that CDC's record for protecting confidentiality will continue.

While it is a matter of principle for CDC to maintain the confidentiality of records, a set of laws exists which requires and/or permits CDC to do so.

2.1 Section 308(d) of the Public Health Service Act (42 U.S.C. 242m)

This section provides the basic legal requirements for protecting CDC's records. It reads in part:

No information, if an establishment or person supplying the information or described in it is identifiable, obtained in the course of activities undertaken or supported under Section 304, 305, 306, 307, or 309 may be used for any purpose other than the purpose for which it was supplied unless such establishment or person has consented (as determined under regulations of the Secretary) to its use for such other purpose; and (1) in the case of information obtained in the course of health statistical scrivities under Section 304 or 308, such information may not be published or released in other form if the particular establishment or person supplying the information or described in it is identifiable unless such establishment or person has consented (as determined under regulations of the Secretary) to its publication or release in other form

The following authorities under Title III of the Public Health Service Act, as amended, were delegated by the Director, National Center for Health Statistics (NCHS), to the Director, CDC, as they pertain to the functional responsibilities assigned to CDC:

Section 304 of the Public Health Service Act (42 U.S.C. 242b), as amended—General Authority Respecting Research, Evaluations, and Demonstrations in Health Statistics, Health Services and Health Care Technology authorizes CDC to collect information through health statistical or epidemiological activities, where such activities of CDC are not duplicative of other activities of the Department, and when the Director, CDC, determines that the authority to give assurances of confidentiality based upon Section 308(d) is necessary for the successful conduct of these statistical and epidemiological activities.

Section 306 of the Public Health Service Act (42 U.S.C. 242k), as smended—NCHS authorizes CDC to collect information through health