



The Legal Basis of Public Health

An Individual or Group Study Course in Ten Modules

Module 2

Data Collection and Surveillance

SS0002



CDC
CENTERS FOR DISEASE CONTROL
AND PREVENTION

The Legal Basis of Public Health

SS0002 - Module 2, Data Collection and Surveillance

Continuing Nursing Education (CNE)

This activity for **2.6 contact hours** is provided by The Centers for Disease Control and Prevention (CDC), which is accredited as a provider of continuing education in nursing by the American Nurses Credentialing Center's Commission on Accreditation.

Continuing Education Units (CEU)

The Centers for Disease Control and Prevention (CDC) awards **.2 Continuing Education Unit (CEU)**. The CDC is an Authorized CEU Sponsor of the International Association for Continuing Education and Training.

The Legal Basis of Public Health

Authors

Babette Neuberger, JD, MPH
Associate Dean for Academic Affairs
University of Illinois-Chicago
School of Public Health

Tom Christoffel, JD
Professor of Public Health (retired)
Consultant and Writer
Boulder, Colorado

Course Design

Babette Neuberger, JD, MPH
Associate Dean for Academic Affairs
University of Illinois-Chicago
School of Public Health

Catherine B. Shoemaker, MEd
Senior Instructional Designer
Division of Media and Training, PHPPO
Centers for Disease Control and Prevention
Public Health Training Network

Writing and Design Consultant

Sharon Cramer Bell, Ed.M
Publications Consultant
Decatur, Georgia

Content Reviewer

Verla Neslund, JD
Deputy Legal Advisor to CDC and ATSDR
Centers for Disease Control and Prevention
Agency for Toxic Substances and Disease Registry

Supported by

The Centers for Disease Control and Prevention
The Association of Schools of Public Health

Cooperative Agreement U36-CCU 300430-14

Provided through

Public Health Training Network
<http://www.cdc.gov/phtn>

About the Authors

Babette Neuberger is a faculty member and the Associate Dean for Academic Affairs at the University of Illinois at Chicago School of Public Health. She holds a law degree and masters of public health degree, and specializes in the field of environmental and occupational health law and policy. Professor Neuberger teaches courses on public health law, the political process, negotiations, environmental and public health policy. She was an environmental enforcement attorney with the United States Environmental Protection Agency and has taught numerous training courses for environmental health staff at the state and federal level. Professor Neuberger is a member of the Illinois Bar.

Tom Christoffel is a lawyer by training, with particular interest in the use of law to protect the public from injury. He has been an educator for most of his career, including twenty years on the faculty of the University of Illinois at Chicago School of Public Health. He has developed and taught courses on public health law, injury prevention, government regulation, health care politics, policy analysis, and related subjects. He currently holds adjunct faculty appointments at the UIC School of Public Health, the Johns Hopkins University School of Hygiene and Public Health, and the University of Colorado School of Medicine. Professor Christoffel's books include *Health and the Law: A Handbook for Health Professionals*, *Protecting the Public: Legal Issues in Injury Prevention* (with Stephen P. Teret) and *Injury Prevention and Public Health: Practical Knowledge, Skills, and Strategies* (with Susan Scavo Gallagher). He is also the author of numerous book chapters and journal articles on law, public health, injury prevention, evaluation methodology, medical peer review, and other topics. Professor Christoffel is a Trustee of the Civil Justice Foundation, a member of the Editorial Board of the Journal of Public Health Policy, and a member of the Massachusetts Bar. He is currently a consultant and freelance writer in Boulder, Colorado.

Course Contents

This course consists of the following ten modules and a Coordinator Guide, which includes suggestions for using the course materials.

SS0001	Module 1, Introduction
SS0002	Module 2, Data Collection and Surveillance
SS0003	Module 3, Service Delivery
SS0004	Module 4, Licensing
SS0005	Module 5, Inspections
SS0006	Module 6, Enforcement
SS0007	Module 7, Policy Development
SS0008	Module 8, Negotiation
SS0009	Module 9, Communication
SS0010	Module 10, Responsibility and Liability

Table of contents

About this module	1
Overview	1
Module components	1
Goals	1
Learning objectives	2
Authority	3
Authority to collect information	3
Authority to compel disclosure	5
Specific diseases and conditions	5
Certain businesses	10
Inspections	11
Subpoenas	11
General requirements	12
Public access to agency records	17
Public access: a broad but not absolute right	17
When federal and state confidentiality laws conflict	19
Interpreting laws protecting specific categories of information	21
Confidentiality must be protected	23
Medical records and confidentiality	24
Maintaining confidentiality in the era of managed care	25
Proper consent	26
Medical emergencies	26
What kinds of records should be shared with a managed care entity?	27
Releasing individual case level data to researchers	27
Business information	29
Issues concerning HIV and AIDS	30
Reporting requirements	30
Legal protection of confidentiality	31
Liability for breach of confidentiality	32
Contact tracing or partner notification	33
Testing for HIV	34
Quarantine and isolation of HIV-infected persons	35
Application and summary	37
Self-check review	40
References	43
Group exercises	44
Evaluation and Test for Module 2	46

About this module

Collection and dissemination of information is a core function of public health agencies

Overview

The first core function of public health is assessment—that is, the collection of information. The Committee for the Study of the Future of Public Health recommended “that every public health agency regularly and systematically collect, assemble, analyze, and make available information on the health of the community, including statistics on health status, community health needs, and epidemiologic and other studies of health problems.”

To implement this recommendation public health professionals must collect data on a wide array of matters, including many that may be personally or commercially sensitive.

Module components

This Data Collection and Surveillance module consists of the following components:

- Text and self-study exercises to be completed individually or discussed with members of your learning group.
- A self-check review, found at the end of the text, will help you assess your understanding of the material.
- Group exercises to undertake with your learning community, found at the end of the text.

Goals

This module is intended to help you as a public health professional:

1. Make maximum use of permissible public health legal authority to collect data for surveillance and for protection of the public’s health.
2. Do what is necessary to balance the need to protect confidentiality of information while adhering to the public’s right to access public health information.

Learning objectives

At the end of this module, you should be able to:

1. Identify how federal legislation affects your agency's authority to collect information and carry out surveillance activities.
2. Identify how the statutes, regulations, and local ordinances of your particular state and local government affect your agency's authority to collect information and carry out surveillance activities.
3. Distinguish between information that must be held confidential and information that must be or could be made available to the public.
4. Describe appropriate procedures for collecting, releasing, and withholding information.



Start by networking...

Because laws and regulations vary from state to state, you need access to much more information than this module provides if you are to understand the legal basis for the activities of your agency. Networking with knowledgeable people is one way to get this information.

In addition to those you have already listed, we have entered additional categories of persons who may be able to help you with Module Two.

State Health Department Freedom of Information Act officer

Federal agency Freedom of Information Act officer

Authority

Authority to collect information

Agencies have broad authority to collect information.

As a public health professional who is committed to serving and protecting the public, you need to know about any possible threats to the public's health, as well as about the current health status and health needs of the public. This information is used for professional purposes only, not for exploitation or personal gain, or to satisfy curiosity or titillate.

The collection of public health information has evolved steadily over the years. Vital records have been kept since early colonial America. In the late 19th century, recording communicable disease was authorized by law, and more recently, in the 1960s, child abuse reporting became a requirement for public health officials.

Under the police power, state and local public health agencies generally have **broad authority** to obtain this type of information. In fact, the courts have generally interpreted the authority of state governments and their subdivisions to protect the health and safety of the public as giving public health officials broad surveillance and data collection authority.

Landmark case on reporting drug prescriptions

In a leading case in this area, *Whalen v. Roe*, 429 U.S. 589 (1977), the U.S. Supreme Court held that under the Constitution, New York could require that Schedule II drug prescriptions be reported to the state. Schedule II drugs are those that have a high potential for abuse, but also have an accepted medical use. They include opiates and amphetamines. Physicians and patients challenging the law claimed that mandatory disclosure of the name of a patient receiving Schedule II drugs violated the patient's right of privacy and interfered with the doctor's right to prescribe treatment for his patient solely on the basis of medical considerations.

In upholding the New York law, the Court made the following points:

The need for information often overrides certain privacy concerns.

- Disclosure of privileged medical information to doctors, to hospital personnel, to insurance companies, and to public health agencies is often an essential element of modern medical practice, even when the disclosure may reflect unfavorably on the character of the patient. Familiar examples include statutory requirements relating to sexually transmitted disease, child abuse, injuries caused by deadly weapons, and certification of fetal death.

- Requiring disclosures to state agencies, even when such disclosures may reflect unfavorably on a person's character, does not automatically amount to an impermissible invasion of privacy.
- The Schedule II drug prescription reporting requirement was reasonably related to the state's legitimate interest in protecting the public's health; it was accessible to public health agencies; and its confidentiality was being adequately protected.

Clearly, *Whalen* and related cases provide strong support for the authority of public health agencies to carry out their assessment function.

Authority may extend to local agencies

This authority is not necessarily limited to the state public health agency. Often the surveillance and data collection authority is specifically delegated from the state to the local health departments. Also, the health care delivery system, especially hospitals, provides a considerable amount of information, usually as aggregate data with no personal identification.



Bringing it home...

What kind of data does your agency collect?

How is the data stored? Where is it stored?

Who has access to the data?

What is done with the data?

Authority to compel disclosure

From a social policy point of view, full access by health departments to information they need to monitor and protect the public's health is both justified and necessary. In most instances, such information will be voluntarily reported or provided upon request. But sometimes a simple request is not enough. In such instances, disclosure must be compelled; a health department must take legal action through the courts.

Authority to compel disclosure is in specific statutes.

Although the authority to compel the disclosure of public health information is well established, it is not general or unlimited. Instead it is provided for in *specific statutes* that spell out the steps that a health department must take to compel the release of information. When these steps are followed, courts tend to support and assist rather than restrict the legitimate assessment efforts of public health agencies.

Four categories of authority

Statutory authority for compelling disclosure usually falls into one of four categories:

- *Specific diseases and conditions.* Statutes that specify reporting requirements for specific diseases and conditions
- *Certain businesses.* Statutes that specify what records must be kept and reported to the health department by certain businesses
- *Inspections.* Statutes that give a public health agency authority to conduct inspections.
- *Subpoenas.* Statutes that give a public health agency authority to request subpoenas and seek enforcement of them

Each of these categories is discussed in detail below.

Specific diseases and conditions

Requirements vary by state.

State laws define an agency's authority and state reporting requirements and practices. These laws vary from state to state. In some states, the relevant reporting statutes specify diseases and conditions that must be reported to the state or local health department. In other states, the reporting statutes allow the state health department itself to determine what diseases and conditions must be reported. For example, the Illinois Department of Public Health Act gives the Department of Public Health broad authority to "investigate the causes of dangerously contagious or infectious diseases, ...and [to] take means to restrict and suppress same."

Example of state-established requirements

Pursuant to this broad grant of authority, the Illinois Department of Public Health adopted regulations requiring the following Class 1 diseases be reported by telephone as soon as possible:

- anthrax
- cholera
- diarrhea of the newborn
- diphtheria
- food borne illness
- measles
- meningitis
- meningococemia
- plague
- poliomyelitis
- human rabies
- smallpox
- typhoid fever
- typhus

Vital statistics

All states have authority to collect information on births and deaths—vital records and vital statistics—although much of that information may be provided voluntarily. Such records have been kept since early colonial America.

State and local health departments have traditionally collected information on communicable diseases, which they voluntarily share with the federal Centers for Disease Control and Prevention. But not all states have specific authority to collect general information on health (i.e., blood pressure), either directly or from other data sources such as hospitals and clinics.

Communicable diseases

When the National Association of County and City Health Officials (NACCHO) collected information on the activities of local health departments in 1992 and 1993, it found that 82 percent of all local health departments were involved in communicable disease epidemiology and surveillance, and 42 percent were involved in disease data collection and analysis. The chart on page 8 gives information on the number of health departments that performed various data collection functions in 1992-1993.

Sexually transmitted diseases

The collection of information on cases of sexually transmitted diseases is a special instance. State laws regarding these diseases have traditionally provided a mechanism for collecting information on contacts of the index case and have authorized contact tracing.

For example, the Illinois Sexually Transmissible Disease Control Act stipulates that “the Department [of Public Health] shall adopt rules authorizing interviews ...[of] all persons infected with a sexually transmissible disease and all persons the Department reasonably believes may be infected ...for the purpose of investigating the source and spread of the disease and for the purpose of ordering a person to submit to examination and treatment as necessary for the protection of the public health and safety...”

Pursuant to this authority, the Illinois Department of Public Health adopted regulations that require state, county, city, and other health officers to:

- Ascertain the existence of and investigate all cases of a number of sexually transmitted diseases within their jurisdictions.
- Identify, examine, and treat, if necessary, contacts of such STD cases.
- Examine persons who are suspected of being infected with STDs and who might infect others, and detain them if necessary in a hospital or other facility until test results have been received.
- Report results of positive examinations to the health department if the examination is performed by a physician.

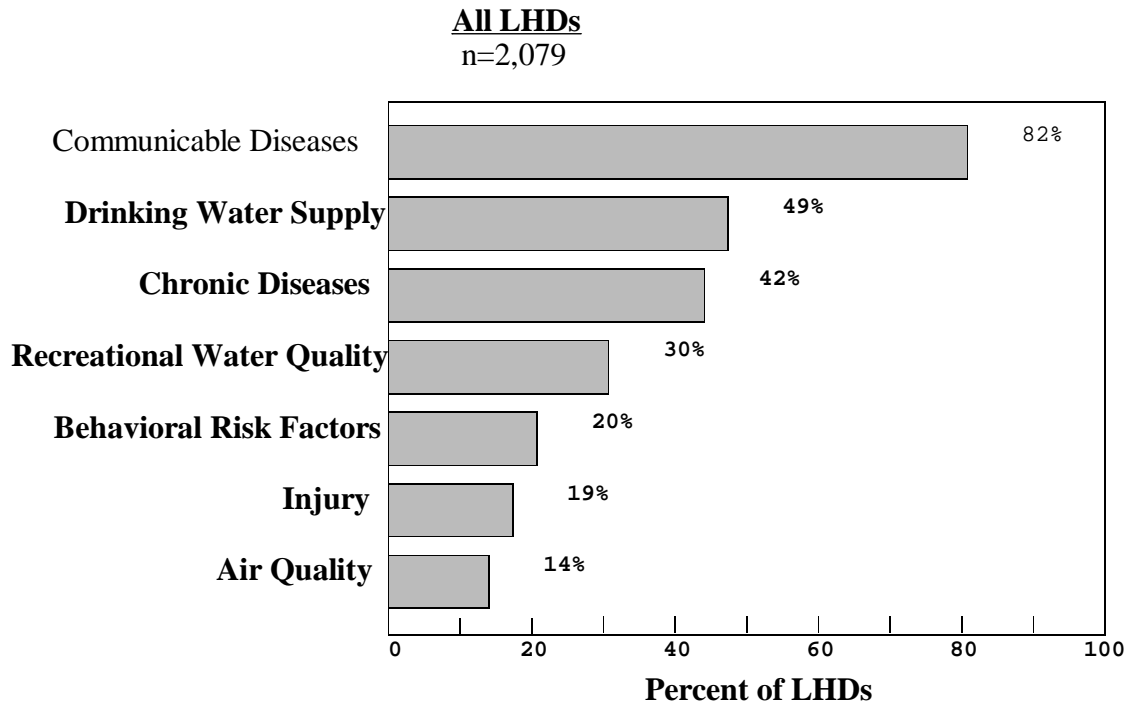


What do you think...

Home testing kits for HIV/AIDS are becoming available and may soon be widely used. What are the reporting implications for the private laboratories who do the tests?

Do you think regulations should require them to report their results?

U.S. Local Health Departments That Maintain Surveillance Data by Selected Category 1992-1993



By Population of Jurisdiction

	0 to 24,999 n=915	25,000 to 49,999 n=453	50,000 to 99,999 n=296	100,000 to 499,999 n=296	500,000+ n=73
Communicable Diseases	76%	84%	85%	90%	95%
Drinking Water Supply	44%	48%	53%	58%	67%
Chronic Diseases	36%	45%	46%	46%	60%
Recreational Water Quality	24%	30%	33%	38%	60%
Behavioral Risk Factors	15%	21%	24%	25%	37%
Injury	15%	18%	21%	21%	47%
Air Quality	10%	11%	13%	21%	45%

n = number of respondents

¹National Association of County and City Health Officials, 67

What you should know for your state

If you collect information on sexually transmitted diseases, you should be completely familiar with your state's statutes and regulations because this is such a sensitive area and because the states vary so widely in their requirements and grants of authority. In particular, you should know whether you can do any of the following:

- Compile and maintain a register of names of index cases.
- Ask index cases to disclose the names and addresses of their sexual and drug-sharing partners. (No state authorizes compulsory disclosure.)
- Contact disclosed "contacts."
- Tell contacts who gave their names.

Registries

Most states have laws that authorize the creation of registries for various diseases or injuries, such as cancer registries or brain injury registries. Such laws authorize the state health department to receive and maintain information on all cases of registry diseases or injuries.

Other types of reports

A variety of other types of reports may also be required by statute, such as reports of the results of pre-marital testing and reports of drug screening tests.



What do you think?

How is information in cancer and brain injury registries used? Is it worthwhile maintaining such registries?

Is premarital testing still required in your state? Is it useful information? Why or why not?

Who must report The categories of persons who are required to report diseases or conditions vary from state to state. All states require health care professionals to report certain types of injuries (such as bullet and knife wounds) and certain communicable diseases.

State laws also require non-professionals to report. In Illinois, for example, health department regulations state that:

It shall be the duty of every physician, dentist, other practitioner, attendant, nurse, laboratory, parent, householder, school authority, or any other person having knowledge of a known or suspected case or carrier of communicable disease or communicable disease death, to report promptly such case, suspected case, carrier or death by telephone or in writing to the local health authority in whose jurisdiction the patient resides, and to cooperate in any case investigation conducted by health officials.

Seeking prosecution A health department can seek prosecution of (and civil or criminal sanctions can be imposed on) persons who fail to provide information that the department is legally authorized to collect from them. Although health departments rarely prosecute for non-compliance, the possibility of prosecution can encourage voluntary cooperation with reporting requirements, and voluntary compliance is clearly preferable.

Certain businesses

Businesses required to report Specific and detailed public health record-keeping may be required of some businesses, such as food-handling establishments, health care facilities, pharmacies, milk distributors, and handlers of hazardous substances. The power to require such record-keeping is often contained in licensing laws, which may specify that particular categories of records be maintained and available for inspection by the state or local health department. Such requirements may extend to self-inspection reports.

Sanctions for non-compliance Although a health department may have the legal authority to use civil or criminal sanctions against persons or businesses that do not comply with record-keeping or reporting requirements, it should resort to these only in extreme cases of refusal, if at all. Public health assessment programs, like any administrative program, function best if voluntary cooperation can be routinely obtained. Tying record-keeping and reporting requirements to licensing laws provides a strong incentive for license holders to "voluntarily" comply, because loss of a business license is a very severe sanction indeed.

Inspections

Information is collected during inspections.

Laws relating to public health surveillance and data collection overlap with laws relating to public health inspections, because health agencies are authorized not only to inspect premises and collect physical and biochemical evidence, but also to collect information from record books, logs, and self-inspection documents. Professor Bernard Schwartz notes that "inspection is *the* indispensable law-enforcement device in the urban community. Without inspections, there is no practical way to determine whether undesirable housing conditions or other violations of the standards prescribed exist."¹

Subpoenas

Definition of subpoena

A subpoena is a legal document, enforceable through court order, that requires the recipient to offer evidence in a court of law. A *subpoena duces tecum* is a type of subpoena that requires the recipient to produce records, books, and documents. The steps involved in obtaining a subpoena, along with an example of an actual subpoena, appear in Module 5, Inspections.

Some public health agencies may, themselves, have the power to subpoena witnesses and documents. Others may need to apply to a court to obtain or enforce a subpoena. Grad notes that:

Some agencies have their own subpoena powers; others must apply to a court.

If the order to produce the information is lawful (that is, the information sought is within the scope of an authorized investigation), the health officer will encounter little or no difficulty enforcing such a subpoena, even if the person or entity to whom it is addressed asserts that compliance may involve self-incrimination. If the organization to whom the subpoena is addressed is a corporation, partnership, or other legal entity, rather than an individual who is an agent of the business entity, it may not claim Fifth Amendment protection, because the privilege against self-incrimination can be claimed only by natural persons.² But even if the subpoena is addressed to an individual, the Fifth Amendment protection will not apply, because the courts have held that business and other records required to be kept by law are not private papers, but assume the characteristics of public or quasi-public documents.³

¹ Gellhorn, 531

² The law recognizes two kinds of "persons": natural and artificial. A natural person is a human being. An artificial person is a corporation, partnership, or other legally created entity.

³ Grad, 270-271

Authority to subpoena records is well-established

The authority of government to compel persons to produce their books and records is broad and well-settled. In a series of opinions dating back to the 1940s, the United States Supreme Court has determined that in traditional areas of governmental regulatory activity, such as public health protection, the courts should seek to aid, not restrict, information collection efforts of governmental entities. Similarly, the federal Administrative Procedure Act states that the courts "shall sustain the subpoena or similar process or demand to the extent that it is found to be in accordance with law." Nevertheless, the power to compel disclosures is not absolute.

General requirements

Courts balance public and private needs.

The courts weigh the needs of public health agencies to collect information against the interests of individual citizens in keeping highly personal information private. To balance the two, the courts have required that agencies collect only information that is relevant to public health protection.



See Group exercise 2.1 at the end of the module.

Requests for information must be specific and relevant.

Agency requests for information must be specific and definite in order to meet due process fairness requirements. Demands that are unduly vague or unreasonably burdensome will not be upheld by the courts. Relevance is not a difficult test to meet. As long as public health authorities can offer a plausible rationale for needing certain information, the courts are unlikely to second-guess them.

Gellhorn and Byse explain that ". . . the issue of relevance is to be determined on the basis of *possibilities*. The courts are not prone to speculate about whether the materials sought by an administrative subpoena will *in fact* prove to be useful in a suitably identified and lawful investigation. They inquire only into whether the materials *might possibly be useful*."⁴

⁴ Gellhorn, 564-565

Prohibited practices As Frank Grad puts it, "The courts know that the requirement of relevance must be liberally construed, because it is generally impossible to predict the full importance of information sought in advance of obtaining it."⁵

Still, relevancy is not a meaningless requirement. In particular, two practices are prohibited:

- Agencies may not go on blind fishing expeditions, seeking information with no conceivable benefit to public health protection.
- Agencies may not collect extraneous information (such as whether an individual is an illegal alien) or place it in a database.

Compelling disclosure, in summary

Follow laws and regulations

When you are compelling disclosure of information related to specific diseases and conditions, certain businesses, inspections or subpoenas, you need only stay within the specific provisions of your state statutes, regulations and local ordinances. As long as you seek information that might possibly be useful to accomplish the agency's lawful objectives and the demands are not unduly vague or burdensome, the courts will support your information collection efforts.



See Group exercise 2.2 at the end of the module.

⁵ Grad, 272



Bringing it home...

An agency's authority to compel the disclosure of information typically falls within the following four broadly drawn statutory categories: specific diseases and conditions, certain businesses, inspections and subpoenas. For each category think about the following questions:

Specific diseases and conditions:

Which diseases or conditions must be reported to your agency?

By whom?

How are the reporting requirements enforced?

What do you think is the compliance rate for reporting STDs?

Other communicable diseases?

Why maintain a disease registry?

Think of a specific intervention or interventions that your agency has implemented in response to surveillance data?

Certain businesses:

What kind of businesses have reporting requirements in your state?

How are the reporting requirements enforced?

Do businesses within your jurisdiction file self-monitoring reports?

How does your agency ensure the accuracy of self-monitoring reports?

Do you know whether your agency has sought to penalize a company (either civilly or criminally) for failing to comply with reporting requirements? For filing false reports?

Think of a specific intervention or interventions that your agency has implemented in response to business reports.

Inspections:

In which agency programs are you or your colleagues authorized to collect data as part of the agency's inspection function?

Identify three problems you have encountered with data collection during an inspection.

Some examples of issues raised by other inspectors:

- Voluminous records to inspect
- Incomplete records
- Records not maintained at inspection site
- Not sure which records may be inspected or copied
- Difficulty organizing, maintaining and recording records collected during an inspection.

How might these problems be prevented in the future?

Subpoenas:

Does your agency have the power to issue a subpoena for witnesses? For documents? In which programs?

To your knowledge has this authority been used?

What, if any, value is the subpoena authority to your program?

Have you ever encountered difficulty in obtaining records or other information from an individual or entity?

Would the exercise of subpoena power have helped in that situation?



Public access to agency records

Public access: a broad but not absolute right

Public access vs. confidentiality

Passage of freedom of information legislation has made it necessary for public health officials to pay greater attention to balancing the right of the public to gain access to public records with their own responsibility to maintain confidentiality of sensitive information. Determining the proper balance between releasing and withholding information can be complicated and will depend on the specific wording of state statutes or regulations, as well as on court interpretation of regulatory language.

Freedom of information legislation

The federal Freedom of Information Act (FOIA) was enacted as a 1966 amendment to the federal Administrative Procedure Act. Under the FOIA any person can obtain copies of any records of a federal agency upon request unless the agency has already published the information for sale or the information is exempt. The person requesting the information need not disclose the reasons for making the FOIA request.

Exempt materials

Exempted material includes personnel rules and policies, trade secrets, commercial or financial information obtained from a person, privileged or confidential information, certain inter-agency or intra-agency memoranda and letters, personnel and medical files, and law enforcement investigatory files.

Drafts of documents are usually exempt from disclosure to encourage free exchange of ideas.

Public Access to “Draft” Documents

Health officials frequently ask whether “draft documents” are “public records” and whether they are exempt from disclosure. According to guidance from the U.S. Department of Justice, draft documents are exempt from disclosure under Exemption 5 of the federal FOIA. Exemption 5 is quite broad, covering agency records that are “pre-decisional” to an agency’s decision and part of the agency’s “deliberative process.” The purpose of the exemption is to encourage the free and uninhibited exchange of opinions, ideas, and points of view while an agency is formulating its decision. Because draft documents embody pre-decisional thought and facilitate deliberation, according to the U.S. Department of Justice “virtually all draft documents” are technically exempt. And, case law indicates that the exemption remains even after the decision making process has concluded; that is, the exemption potentially lasts forever. (The only exception is where information is subsequently incorporated into the final document.)

In 1993, U.S. Attorney General Janet Reno established new standards of government openness. Under the standard, even where a draft document may technically be exempt from disclosure, federal agencies are urged to release the document unless the agency reasonably foresees that disclosure would harm the agency’s deliberative process.⁶

State laws and agency policy guiding public access to draft documents may vary from the federal law and policy. Health officials should determine the policy of their department. And, generally speaking, to avoid problems, it is good practice for agency officials to destroy drafts of documents when they are no longer needed or useful.

Most states have their own public disclosure laws for state and local information.

The federal FOIA does *not* apply to information of state and local governments and thus does not affect state and local health departments directly. However, many states either already had their own public disclosure acts or enacted them in response to the federal FOIA. These usually closely parallel the federal law. In addition, where state and local health departments collect information pursuant to federally funded or delegated programs, federal laws **will** apply.

⁶ See U.S. Department of Justice, Office of Information and Privacy Guidance, FOIA UPDATE, 1993 [http://www.usdoj.gov/oip/foia_updates/Vol_XV_2/page3.txt].

When federal and state confidentiality laws conflict

On occasion State laws may conflict with federal confidentiality and public access requirements. Which law should a state or local agency follow? The general rules are described in a memorandum prepared by the U.S. Department of Health and Human Services (DHHS), Substance Abuse and Mental Health Services Administration (SAMHSA).

State laws may not override and must yield to federal regulations.

State confidentiality laws may be more restrictive than but may not override the federal regulations.

Example: Before a federally funded state treatment program discloses a patient's HIV status, the patient must not only sign a consent form that is proper under the Federal Alcohol and Other Drug (AOD) Confidentiality Law, but agency personnel must also determine whether the state imposes any additional requirements for disclosing HIV-related information (e.g., a special HIV consent form).

Where state law is not stricter and conflicts with the federal regulations, state law must yield.

Example: If state law mandates that a program notify parents about certain conduct by minor patients, but the federal regulations absolutely prohibit such disclosure, the program cannot make the disclosure; the federal law controls.

Note, however, there is usually a way to disclose properly under the federal law, for example, by obtaining patient consent or a court order that meets the federal requirements. Accordingly, there is rarely an irreconcilable conflict with state law.

States must develop confidentiality laws and procedures when federal funds or programs are involved.

States receiving federal block grant funds to deliver AOD services are required by federal law to develop confidentiality regulations which are equivalent to the federal rules. [See 45 C.F.R. Part 96.132(e)]. Other federal block grant programs have similar rules.⁷

⁷ See Publication No. (SMA) 96-3083 Printed 1996. Publication prepared under contract number 270-93-0004 from the Substance Abuse and Mental Health Services Administration (SAMHSA). Gayle Saunders, of CSAT, served as the Government project officer, U.S. Department of Health and Human Services (DHHS), at <http://www.treatment.org/TAPS/TAP18/TAP18.html>.

For federally delegated programs, the handling of confidential material is often determined in advance pursuant to an agreement between the federal agency and the state. For example, in delegating the federal Clean Air Act Permit Program to the state, the U.S. Environmental Protection Agency (USEPA) and the Illinois Environmental Protection Agency (Illinois EPA) agreed to the following procedures for handling confidential information:

- When sharing any information that is claimed to be confidential, the Illinois EPA or the USEPA must clearly mark the material as such and will separate it from material that is not claimed to be confidential.
- If an information source prohibits either the Illinois EPA or the USEPA from providing requested information to the other agency because of a claim of confidentiality, the agency holding the information must instruct the source to provide the information directly to the agency requesting the information.
- Any information subject to a claim of confidentiality must be handled and treated according to the laws governing the agency holding such information. For information within USEPA's possession, federal rules apply; similarly, the Illinois EPA looks to state law for guidance.⁸

To avoid confusion when potentially sensitive information is shared among federal and state or local agencies, it is helpful to reach agreement on each agency's expectations concerning confidentiality and public access to the records before the documents are transferred.

State public disclosure approaches

State public disclosure laws vary, but all grant public health agencies the power to allow certain records to be inspected regardless of need, forbid the inspection of others, and allow access to some records with conditions. State laws generally take one of three approaches:

- Some states allow inspection of all "public records." Confidentiality in these states is preserved by classifying sensitive records as "non-public." Even so, an agency may deny access to a public record if releasing the information would be harmful to the agency's performance of its duties.
- Some states use common law to determine which records are open to public inspections. A member of the public may petition to the court for access to records and the court may allow access if the petitioner can show a good reason for seeing them.

⁸ See <http://www.epa.gov/reg50air/permits/il-ia.htm>.

- Some states use specific laws to establish which records are *not* open to general inspection.

Interpreting laws protecting specific categories of information

Two opposing interpretations

Laws that protect specific categories of public health information, such as sexually transmitted diseases, can be interpreted in two ways. Some courts have held that all records similar to those already protected by law are equally entitled to protection. An opposite interpretation is that by specifically protecting the confidentiality of information on diseases A, B or C, the legislature is implicitly accepting the more public nature of information on diseases X, Y and Z.

The latter was the view of the highest court of New York State when a county health commissioner sought to resist a subpoena to produce information on whether certain individuals were typhoid carriers. The court noted that:

Although the information may have come to the Commissioner from a physician in private practice, the transmittal from that physician to the public officer was in obedience to the express command of Section 25 of the Public Health Law. An intention that these records as to communicable diseases should not be kept confidential is found in the history of this same section 25.

Since 1909 it has provided as to one such disease (tuberculosis) that the report “shall not be divulged or made public.” In 1939 the Legislature amended the section by naming three other diseases, not including typhoid fever, as to which the reports should be kept secret.... It seems to follow that similar reports as to other communicable diseases are not so privileged.



Stop and think...

Agency “records” include electronic records.⁹

Freedom of information legislation covers not only records maintained in “hard copy” but also electronically-recorded data. While agency officials are generally aware that electronically-maintained databases are covered by public access statutes, many health officials overlook e-mail. This is a mistake. E-mail messages which pertain to, or which were written or received in the course of transacting official business may also be considered “public records” under state law.

Does your state’s “public disclosure” law cover electronically-recorded data, including e-mail?

Even if not specifically mentioned, agency policy may interpret the law as granting the public access to electronically-recorded data, including e-mail “records.” Does yours?

Does your agency have a “records retention policy” which covers e-mail?

⁹ For a detailed discussion of this topic, see B. J. Thompson, “E-Mail: Even if You Don’t Have it Yet, Your City Probably Needs Two Policies For It,” © 1996 [<http://www.bjt-law.com/e-mail2.htm>]

Ways to narrow requests for information

Practice Tip: The Overly Broad Request

Occasionally agencies receive requests for access to public records which are phrased very broadly. Sometimes a broad request is motivated by a desire to gain access to the most complete documentation of a subject within the agency's possession. More often a broad request is made because the requestor lacks information about how an agency is organized and/or how the agency maintains its records. In such cases, it is usually possible to negotiate the terms of the request with the person seeking the information. A discussion with the requesting party about the type of information he or she is seeking, the purpose of the request, and how the agency is organized, will help the person re-formulate a demand which more aptly serves his or her needs, while lessening the agency's burden.

Confidentiality must be protected

Members of the general public, including the news media, may argue that all information collected by an agency is public information, accessible to all. Third parties may argue that they have a special need for certain types of information for independent research studies or to assist them in private litigation. However you and your agency are obligated to maintain confidentiality where required to do so by law, notwithstanding arguments of the public.

Law establishes what to keep confidential

Information that must be reported to public health authorities as required by law is not necessarily privileged or confidential information. Public health-related laws and federal and state public disclosure acts determine what information is to be kept confidential. For instance, information on alcohol and drug treatment is confidential under federal law. Information on sexually transmitted disease is universally closed.

Authority to collect information may be tied to confidentiality requirements.

In some instances, legislatures and/or courts have specifically tied authority to collect health-related information to the understanding that confidentiality will be protected. This was an important factor in the U.S. Supreme Court's decision in *Whalen v. Roe*, 429 U.S. 589 (1977), that upheld data collection requirements for Schedule II drug prescriptions. If challenged, you must be able to show that your agency uses specific procedures designed to assure the integrity and confidentiality of the information collection process.

Protection of information varies by state. Some states make all records of reportable diseases confidential, while others do not. Even where not specifically mentioned, information may fit one of several categories of material that are exempt from disclosure under a state's Freedom of Information Act. For example, Illinois law provides that "all information and records held by the Department [of Public Health] and its authorized representatives relating to known or suspected cases of sexually transmissible diseases shall be strictly confidential and exempt from inspection and copying under the Freedom of Information Act."

Federal Privacy Act The federal Privacy Act of 1974 affords protection from reckless release of government information on individuals, but its practical impact is quite limited.

- It applies only to information that can be retrieved "by the name of the individual or by some identifying number, symbol, or other identifying particular assigned to the individual."
- It does not apply to the release of information when required for statistical research, law enforcement or the protection of the health or safety of third parties.
- It can be superseded by the Freedom of Information Act.

Individuals states may have their own version of the federal Privacy Act.

Medical records and confidentiality

Individually identifiable information cannot be released except when authorized by the individual or to protect public health.

Public health agencies routinely gather medical records of individuals or receive such information pursuant to state reporting requirements. Virtually all states have statutes prohibiting the release of individual medical records where the person is identified, except in narrowly defined circumstances. "Personal identifying information" has been defined by states to include name, date of birth, address and telephone number. [See Colorado Revised Statutes (C.R.S.), Chapter 25.] State law typically provides for penalties (including criminal sanctions) against officials who wrongfully release such information. Colorado law prohibits the release of medical records even where the identifier has been removed, if the person could be identified by other information contained in the record; for example, if the record describes a uniquely identifiable individual who resides in a sparsely populated county. [See Title 25, C.R.S. 25-1-107, 25-1-122.]

Disclosing individual case level data, with personal identifiers, is generally permitted only where:

- There is proper written authorization of the individual.
- The release is necessary “for the treatment, control, investigation, and prevention of diseases and conditions dangerous to the public health, except that every effort should be made to limit disclosure of personal identifying information to the minimal amount necessary to accomplish the public health purpose.” [See C.R.S. 25-4-1404(1)(b).]

Notwithstanding the clear legal prohibition against releasing medical records containing patient identifiers, in practice it has become increasingly more difficult to comply. While not an exhaustive examination of the issue, the following discussion will shed light on some of the complexities involved with maintaining confidentiality.

Maintaining confidentiality in the era of managed care

Managed care complicates confidentiality issues

The proliferation of managed care plans across the country raises new issues of confidentiality for state and local health agencies. For example, agencies that provide alcohol and other drug treatment services either directly or through contractual arrangement are frequently pressed to share client information with the individual’s managed care plan. Some managed care plans require client information from treatment programs to perform "gate-keeping" functions, such as pre-approving treatment plans and monitoring admissions and lengths of stay. Other managed care programs, such as health maintenance organizations, may provide addiction treatment services directly or through their network providers, and thus require client information to coordinate care as well as to perform gate-keeping functions. Finally, managed care plans may require information to document that the patient's treatment is reimbursable.

Under what circumstances may public health agencies share confidential medical information with managed care plans? The answer to this question is complex and will depend on the specific details of the agency program. Health officials are cautioned to thoroughly acquaint themselves with applicable rules and policies before sharing confidential records. The following general principles should be considered.

Proper consent

Consent must be written and understood

Records may be shared if the agency has obtained the proper consent. In determining whether an individual has given proper consent, an agency should ask:

- Has the individual read, understood and signed a valid written consent form?
- Does the consent form conform to applicable state and federal confidentiality regulations?
- Does the consent form include a notice prohibiting re-disclosure of the individual's information?

Re-disclosure of information

If the managed care plan intends to re-disclose information, then the consent form must be written to reflect the intended re-disclosure. This will ensure that the individual is truly making an informed decision about whether to consent.

Medical emergencies

Confidential information on individuals can be released only to those who directly treat medical emergencies.

Public health agencies are generally authorized to release otherwise confidential information to meet a bona fide "medical emergency" affecting the individual or any other person.

For example, the federal SAMHSA regulations permit addiction treatment providers (including health agencies) to "disclose patient-identifying information to medical personnel who have a need for information about a patient for the purpose of treating a condition which poses an immediate threat to the health of any individual and which requires immediate medical intervention." This means patient identifying information **can** be released to a managed care plan that provides direct health care services **and** the client's condition poses an immediate threat to his or her health or that of others and requires immediate medical intervention.

Conversely, if the managed care provider is merely acting as a third-party payer and not a medical service provider, and wishes to see patient records to preauthorize or pay for treatment, the plan is not entitled to receive information from an alcohol and other drug treatment program under the "medical emergency" exception. It must obtain the patient's consent.

What kinds of records should be shared with a managed care entity?

Managed care and insurance computer networks often share data.

Managed care entities often request vast amounts of information about individuals, sometimes seeking the client's entire file. SAMHSA guidance warns that sharing information with managed care plans and insurance carriers creates significant dangers to patient privacy. Many managed care plans, especially those that are part of private insurance companies, routinely share information through vast computerized networks, thus compromising the security of the data.

Limit the amount of information to a specific purpose

Therefore, when disclosing information to managed care entities, health officials should attempt to negotiate a limited disclosure: sharing only that information necessary to meet the intended purpose. For example, where a managed care plan is seeking information to authorize reimbursement, the agency should communicate only the minimum amount of information required to show that the patient has received treatment and that such treatment is reimbursable.¹⁰

Releasing individual case level data to researchers

Another potentially challenging situation arises when individual researchers request data for purposes of investigative study. Researchers requesting computerized data sets with personal identifying information should be required to demonstrate the necessity for obtaining the data. The policy adopted by the Colorado Department of Public Health and Environment recommends that agency officials:¹¹

Procedures for releasing data for research purposes

- Obtain a copy of the protocol from the researcher.
- Make a judgment as to whether the protocol provides sufficient rationale for release, i.e., the release is "necessary for treatment, control, investigation, or prevention of diseases or conditions dangerous to the public health."
- Write a short memo to the file, if the data is to be released, documenting the decision and the rationale.

¹⁰ For a detailed discussion of this issue, see Publication No. (SMA) 96-3083 Printed 1996, Appendix B-Managed Care and Client confidentiality at [<http://www.treatment.org/TAPS/TAP18/TAP18.html>]. The publication was prepared under contract number 270-93-0004 from the Substance Abuse and Mental Health Services Administration (SAMHSA), U.S. Department of Health and Human Services. Gayle Saunders of CSAT served as the Government project officer.

¹¹ State of Colorado, Policy on Release of Disease Surveillance Data, March 1994/ Updated February 1995.

- Require the researcher to sign a confidentiality agreement which describes the procedures for protecting confidentiality of the records, and identifies all persons who will have access to the confidential information.

Release of
aggregate data does
not violate
confidentiality

Clearly, public health officials are less likely to violate confidentiality if data is released in the aggregate with personal identifiers removed.



Stop and think...

What are your agency's policies on releasing medical records to managed care plans?

To individual researchers?

Do your state or local rules follow the guidelines described in the preceding paragraphs? If not, how do they differ?

What is your agency's policy on responding to court subpoenas for individual medical records? How can you find out?

Business information

Trade secrets and other confidential business information must be protected.

Public health officials also collect sensitive business information which would hurt a company's competitive advantage if disclosed. Such information may include process, formulation, sales, and production data—information a company would not routinely share with outsiders. Under federal law, and by state law in most jurisdictions, public officials are required to protect trade secrets and confidential business information of regulated companies if requested by the companies. The courts have held that reports and files generated from confidential data must also be treated as confidential.

You can use measures such as the following to protect the confidentiality of data:

- Limit the number of copies made of the data
- Share the information with only a limited number of other persons within the agency
- Maintain a log showing everyone who has had access to the data

Because you must take such extraordinary measures to protect confidential business information, you should collect it only if absolutely necessary to fulfill your agency's function. If possible, it is better to avoid collecting such information.

Summary

Agency staff need to know policies

With certain exceptions, public records are open to public inspection. You must therefore be familiar with your state's laws and regulations concerning confidentiality and public access to records. Information should never be released without a careful and specific review of all circumstances. Granting access to records as a matter of routine without careful consideration or handling requests for access at a clerical level may result in a serious breach of confidentiality. All public health agency staff with contact with the public must be aware of the need for confidentiality and must understand who is responsible for deciding what information may be released to whom.



See Group exercise 2.3 at the end of the module.

Issues concerning HIV and AIDS

The need to collect sensitive data on HIV infection and AIDS has drawn attention to the issues of authority and confidentiality in public health. Because many legal questions have been raised in connection with these issues, we will discuss them in detail.

Reporting requirements

State laws vary

All states require the reporting of AIDS cases and positive HIV test results. Their laws vary widely, however, in terms of:

- Whether the identity of persons needs to be disclosed
- Which positive diagnoses must be reported, that is, how certain the diagnosis must be
- Who must report
- What personal information must be reported
- How to protect personal information
- What penalties will be imposed for breaches in confidentiality
- Whether contacts are to be traced and notified

Right to privacy vs. right to be forewarned

Health authorities must carefully balance the privacy rights of individuals who are positive for HIV against the rights of others to be forewarned of their potential exposure to the HIV virus. Those with a special need to be forewarned may include health care and emergency care providers, sexual and drug-using partners, school districts, crime victims, prison and mental health institutions, and coroners and funeral directors.

Reasons to maintain confidentiality The need to maintain confidentiality has as much to do with the pragmatic need to encourage voluntary cooperation with testing and contact tracing programs as with the individual's constitutional right of privacy. The practical need to maintain confidentiality was heightened because the initial locus of the disease among the homosexual and drug-using communities caused a social stigma for anyone with the disease. Disclosure of information has led to discrimination in housing, employment, and insurance as well as to loss of friends, family and community support.

Legal protection of confidentiality

States provide different levels of legal protection

No state statute provides complete confidentiality protection for HIV-positive individuals. The states vary in how they balance the rights of the individual and the needs of others to know of a person's HIV status. You need to know what your state's laws provide. For example, you should be able to answer the following questions:

- Can you release HIV-related records under a court order or subpoena?
- If you have released records under a subpoena, what is the status of the records with regard to further disclosure?
- Can you disclose information to contacts of HIV-positive individuals?
- What types of information are protected? For example, do your state laws prohibit disclosure of *any* information that could reveal the HIV-related status of an individual, such as a prescription for AZT, or do the laws protect only some specified information, such as the HIV test results?
- Do your state's laws allow limited disclosure and, if so, who is allowed access to restricted information?



Bringing it home...

What is your state's law regarding reporting of AIDS cases and positive HIV results?

How do statutes in your state balance individual rights with society's need to know?

How many of the questions on the preceding page can you answer?

Where can you find the answers if you don't know?

Liability for breach of confidentiality

To ensure confidentiality, many states have imposed criminal or civil liability for improperly disclosing HIV information.

Criminal liability

At least nine states have made it a criminal offense to improperly disclose some type of HIV information, most commonly HIV testing information. In all of these, the disclosure must have been an intentional violation of confidentiality requirements. In most states an improper disclosure of HIV information is punishable as a misdemeanor, but Michigan treats such a disclosure by government employees as a "felony punishable by imprisonment of not more than three years, a fine of not more than \$5,000, or both."

Civil liability

At least eleven states have created private rights of action for breach of confidentiality requirements. Under their provisions, individuals who have been harmed by the disclosure of confidential information concerning HIV testing, HIV status, etc., may sue the offending party. If the offender is found liable, the harmed individual is entitled to collect monetary damages.

Most of these statutes have limited a private right of action to situations where the information is intentionally released. However, at least six states allow an individual to recover actual damages even where the information was disclosed through negligence.

The lesson in all of this is to maintain confidentiality. The subject of liability is discussed further in Module 10, Responsibility and Liability.

Contact tracing or partner notification

Maintaining confidentiality ensures voluntary cooperation

Tracing contacts of an HIV-infected index case and counseling them is one way a health department seeks to prevent further spread of the disease. Index cases, however, are not required to disclose the names and addresses of their sexual and drug-using partners. They do so voluntarily, and a contact tracing program will not be successful if index cases do not cooperate. To ensure their cooperation, a contact tracing program must maintain confidentiality.

Legal issues regarding disclosure, notification and warning

The following are some of the legal issues that may arise under a contact tracing program:

- **Authority to compel disclosure of contacts.** Currently no state has authority to compel disclosure of contacts.
- **Authority to notify without the diagnosed person's consent.** A few states, including California, Texas and New York, allow contact notification without the express consent of the diagnosed person. Maryland and Oregon require physicians or state officials to notify persons known to be at risk, if the patient refuses to tell them voluntarily.
- **Duty to warn.** Even when public health officials are legally authorized to disclose HIV/AIDS information to a spouse or known sexual or needle-sharing partner, they are not required by law to do so.

Testing for HIV

Federal grants are available to support anonymous testing programs. As of 1990, 42 states had some form of anonymous testing or a combination of anonymous and confidential testing programs. Eight states had only confidential testing.

Reporting requirements under confidential testing

In some states, the law specifies how confidentiality is to be maintained; in others, it merely requires that reporting be “kept confidential.” The following are some of the methods states use to protect the confidentiality of the test results:

- Results are reported using a code that hides the person’s name.
- Results are reported only in the aggregate (total HIV tests conducted and the results of the tests).
- Individual names are coded in local case files, but not in state files. This method is used in Michigan, the only state that makes a breach of confidentiality a felony offense. Local health departments in Michigan are prohibited from maintaining lists of individuals who are tested, but may keep coded names in their files.
- Collection of information is limited to what is truly necessary to protect the public’s health.

Compulsory testing is subject to 4th Amendment standards

The United States Supreme Court has held that mandatory blood testing is a search and seizure that must comply with the standards of reasonableness imposed by the Fourth Amendment to the United States Constitution. Thus, one U.S. Court of Appeals struck down a policy that required certain employees of a health services agency to be tested for the AIDS virus and hepatitis B. The court determined that the risk of disease transmission from the employees to the health agency's mentally retarded clients was minuscule and could not justify requiring employees to submit to the testing [*Glover v. Eastern Nebraska Community Office of Retardation*, 867 F.2d 461 (8th Cir. 1989)].

Instances where compulsory testing was upheld

However, mandatory blood testing has been upheld in other contexts. The following are some of these:

- Testing of prison inmates for sexually transmitted diseases, including HIV

- Testing of prisoners convicted of sex crimes, prostitution or intravenous drug use. (The courts have differed on how they handled testing in this context; in some jurisdictions courts have ordered testing, while in others the requests of prosecutors has been denied. Criminal courts in both Georgia and Florida have agreed to reduced sentences for convicted prostitutes who allowed themselves to be tested for HIV.)
- Testing of immigrants and applicants to the military, Job Corps, and Foreign Service (a federal requirement)
- Testing of blood and tissue donors (required in all states)

Quarantine and isolation of HIV-infected persons

Decision to quarantine based on behavior, not status

The power to quarantine people who have communicable diseases is provided for by statute in every state and by federal law. To apply this authority to people infected with HIV, we must distinguish between quarantine based on a person's **status** and quarantine based on a person's **behavior**.

Isolating HIV-infected individuals on the basis of their HIV status is generally unreasonable for the following reasons:

- A large number of people are infected.
- There is no cure.
- The virus is not spread through casual contact.
- The period of infection is indefinite, which would require an indefinite period of quarantine.

The following, however, are some instances in which quarantine has been upheld:

- In New York, the quarantine of HIV-infected prisoners
- The quarantine of HIV-infected female prostitutes in California, Nevada, and Florida
- The isolation of persons who persist in activities likely to transmit HIV in Illinois and Colorado

Quarantine as least restrictive alternative or measure of last resort

Generally, a state must show that isolation is the least restrictive alternative or the measure of last resort, which means that other less intrusive measures for controlling the spread of infection have failed or are likely to fail.

Application and summary

Have a protocol Your agency may already have or should develop and follow a protocol for collecting, storing and releasing information. This protocol should be carefully reviewed by the agency's legal counsel and by the agency's director. It should include specific provisions for alcohol and drug treatment information, sexually transmitted disease information, and HIV/AIDS information. Obviously, it must adhere to all relevant state and federal legal requirements. It must also specify how to handle information maintained in the following:

- Birth and death records
- Health inspection reports
- Self-reporting records obtained under licensure or other public health authority

Computerized databases

Confidentiality issues with electronic storage of data

One area of increasing importance is the storage of sensitive information in computerized databases. Although one can mask the identity of individuals when storing individual case data electronically, there is always a risk of unauthorized access.

What makes electronic data vulnerable

The following are some of the factors that make it difficult to maintain the security of electronic records:

- Computer systems can be accessed through multiple terminals.
- Many agency microcomputers are linked into computer networks.
- Stored information is often kept in a computer data base longer than necessary, because it is more expensive to remove than to store.

Ways to protect confidentiality of electronic data

To prevent unauthorized disclosure of confidentiality, your agency should develop a written security policy and ensure that all staff members have read it. The following are some of the ways that confidentiality of electronic data can be protected:

- Prevent unauthorized physical access to computer rooms
- Store sensitive reports and disks and hard-drives containing confidential data in secure areas and limit access
- Assign computer users access levels according to their data needs
- Design the computer system to prevent access to sensitive data by people who do not need it as a part of their job
- Design the computer system to identify and record all accidental or intentional attempts to gain unauthorized access to confidential databases

Summary

Summary of main principles

The following are the main principles discussed in this module:

1. Public health agencies and their designated staff members have broad authority to obtain information needed to protect the public's health.
2. Legal rules—both specific and general—control how public health information is collected, maintained, and disseminated.
3. The need to conduct surveillance and collect sensitive data on HIV infection and AIDS has drawn attention to the issues of authority and confidentiality in public health.



Review of terminology...

You may find it useful to check your understanding of legal terms discussed in this module by defining them in your own words. Add to this list if you wish.

Authority to compel disclosure

Civil liability

Criminal liability

Freedom of Information Act

Natural person

Personal identifying information

Privacy Act

Right to be forewarned

Subpoena

Self-check review

Check your understanding of the preceding material by answering the questions below. Circle the letter of the correct response.

1. Which of the following is required for an agency to compel disclosure of information legally?
 - A. The information is relevant to a legitimate state interest in protecting the public's health.
 - B. The information is not of a private nature.
 - C. Confidentiality will be protected.
 - D. All of the above
 - E. A and C, above

2. Which of the following is not legally required of a public health agency exercising its subpoena authority?
 - A. The subpoena must be issued in pursuit of an authorized objective.
 - B. The agency must demonstrate that the evidence sought will in fact prove that a public health risk occurred.
 - C. The evidence sought must be germane to a lawful subject of inquiry.
 - D. The demand for documents and records must not be unduly vague or unreasonable burdensome.

3. Which of the following is true of contact tracing programs for HIV transmission?
 - A. Contact tracing programs have legal authority to compel disclosure of contacts.
 - B. It is appropriate to ask about the immigration status of contacts.
 - C. Contact tracing programs are voluntary and depend on the cooperation of index cases.
 - D. They require index cases to disclose the names and addresses of drug-using partners.

4. The legal litmus test for determining whether materials may be collected as part of a routine investigation is:
 - A. The materials might possibly be useful as part of a lawful investigation.
 - B. The materials will be useful as part of a lawful investigation.
 - C. There is probable cause to believe that the material will reveal a violation of statute or regulation.
 - D. The materials sought will be useful, beyond a reasonable doubt, as part of a lawful investigation.

5. A restaurant patron in Sioux City, Iowa contracted bacillary dysentery (shigellosis), a form of food poisoning generally associated with poor sanitary conditions. The sick customer demanded access to the health agency's records identify by name, address, and phone number the restaurant's employees and their medical test results for the shigella organism. The requested information should be:
 - A. Disclosed under the federal Freedom of Information Act (FOIA)
 - B. Withheld under the exception to the federal FOIA preventing the disclosure of personnel and medical files
 - C. Turned over to the customer because of the public's interest in knowing this health risk
 - D. Withheld if it is deemed confidential by local or state law

6. Which of the following statements about testing for HIV is *not* true?
 - A. States vary in how they maintain confidentiality of test results.
 - B. Mandatory blood testing is allowed for prison inmates; immigrants; blood and tissue donors; and applicants to the military, Job Corps, and Foreign Service.
 - C. All states have made it a criminal offense to improperly disclose HIV test results.
 - D. The majority of states provide for some form of anonymous testing or a combination of anonymous and confidential testing programs.

7. Under federal law, public health officials are required to protect trade secrets and confidential business information, that is, information that would hurt a company's competitive advantage if disclosed. Which of the following would not be considered confidential business information?
- A. employee injury records
 - B. process information
 - C. sales records
 - D. production data

Answers:

1.D, 2.B, 3.C, 4.A, 5.D, 6.C, 7.A

References

Gellhorn, W. & Byse, D. *Administrative Law Cases and Comments*, Foundation Press, 1974.

Grad, F.P. *The Public Health Law Manual*, 2nd ed. Washington, D.C.: American Public Health Association, 1990.

National Association of County and City Health Officials (NACCHO). *1992-93 National Profile of Local Health Departments, National Surveillance Series*. Washington, D.C.: NACCHO, 1995.

Internet Sites:

B. J. Thompson, "E-Mail: Even if You Don't Have it Yet, Your City Probably Needs Two Policies For It," © 1996 [<http://www.bjt-law.com/e-mail2.htm>]

Illinois EPA, [<http://www.epa.gov/reg5oair/permits/il-ia.htm>]

Managed Care and Client Confidentiality.

[<http://www.treatment.org/TAPS/TAP18/TAP18.html>].

Substance Abuse and Mental Health Services Administration (SAMHSA). Publication No. (SMA) 96-3083 Printed 1996. [<http://www.treatment.org/TAPS/TAP18/TAP18.html>.]

U.S. Department of Justice, Office of Information and Privacy Guidance, FOIA UPDATE, 1993 [http://www.usdoj.gov/oip/foia_updates/Vol_XV_2/page3.txt].

Group exercises

The goal of these exercises is to become familiar with the statutes and regulations that address data collection in your state and community. If you are in a group, your group leader will provide guidance. If you are studying individually, it may be necessary for you to ask others in your health department for assistance in answering the questions.

Exercise 2.1 Authority to Collect Information

What authority is there for data collection and surveillance in your agency?

If you are not familiar with the relevant state statutes on data collection, obtain copies and review them.

Have you or your agency experienced difficulty in securing compliance from those required to provide information to your public health agency? If so, what was done? What else might have been done?

Exercise 2.2 Access to Information

What information can you share within your agency?
Who within your agency can you share it with?
Within your level of government?

How do you refuse requests (by the media, plaintiffs, others)?
How do you deny access if a criminal investigation is going on, but you don't want to divulge the fact that this is the reason for not disclosing the requested information? (This issue is discussed in greater detail in Module 9, "Communicating about enforcement-sensitive situations.")

On the federal level, anything blacked out must be described; what is your state's requirement (if any) regarding deletions from released material?

Exercise 2.3 Protecting Confidentiality

Under your state's laws, what are the confidentiality requirements for data collection and surveillance?

Are you familiar with the relevant state statutes? Regulations? Do you have copies?

What confidentiality policies exist within your agency? If they are written, obtain a copy and review them.

Have you experienced difficulty in dealing with confidentiality issues? Explain.

To register for continuing education credit and to evaluate this module

Registering for Continuing Education Credit

To receive credit for this module you must submit course enrollment forms and the answers to the **Evaluation and Test** (located on the following pages) to CDC. There are several ways to complete this registration process:

Complete the forms online.

- U Go to the PHTN website www.cdc.gov/phtn and complete the registration and evaluation online. Directions will be given at the website.

Complete the forms on paper. There are two ways to obtain the forms from CDC. (If you plan to study additional modules, you may want to request enrollment materials for those modules also at this time.)

- U Request the enrollment materials online by going to the following URL at the PHTN website <http://www.cdc.gov/phtn/legal-basis/req-form.htm> and completing the online request form. After the online form is submitted, an enrollment packet will be mailed to you with instructions.
- U Request the enrollment materials by calling **1-800-41-TRAIN** (1-800-418-7246). At the prompts, press 1, then 3. Please clearly speak your name, mailing address, daytime phone number, and the correct module name and number. The enrollment materials will be mailed to you with instructions.

If you are unable to register online, you will have to wait several weeks until your course enrollment materials arrive in the mail. If this is the case, you might want to complete the Evaluation and Test immediately after you finish the module by marking your answers directly on the following pages (or make a photocopy) and then, when the enrollment materials arrive, transfer your answers to the answer sheet included with the materials.

Evaluating the Module

If you are registering for continuing education credit, you will be asked to complete an evaluation as part of that process.

If you are not interested in receiving continuing education credit, we ask that you please take time to evaluate the module. Follow the procedure specified above for getting continuing education credit, but indicate in the first question on the **Evaluation and Test** that you do not wish to receive continuing education credit. Although this is not required, your opinion of the module is important to us. By letting us know if this module was effective for you, we can improve future editions, as well as other PHTN courses.

Evaluation and Test
The Legal Basis of Public Health
Module 2, Data Collection and Surveillance
COURSE #SS0002

Objectives for *Module 2, Data Collection and Surveillance*:

- g Identify how federal legislation affects your agency's authority to collect information and carry out surveillance activities.
- g Identify how the statutes, regulations, and local ordinances of your particular state and local government affect your agency's authority to collect information and carry out surveillance activities.
- g Distinguish between information that must be held confidential and information that must be or could be made available to the public.
- g Describe appropriate procedures for collecting, releasing, and withholding information.

NPlease use the red *CDC Answer Sheet* included in the enrollment materials to complete the following questions.

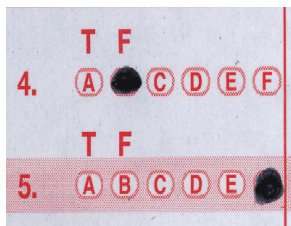
Tell us about yourself...

- 1. What type of continuing education credit do you wish to receive?**
 - A. (CME) *Not Available for this Course*
 - B. Continuing Nursing Education (CNE)
 - C. Continuing Education Units (CEU)
 - D. do not want continuing education credit

- 2. Have you previously completed *Module 1, Introduction*?
(Completion of *Module 1* is required before taking any of the other modules.)**
 - A. yes
 - B. no
 - C. I have just completed ***Module 1, Introduction***.

- 3. Are you a**
 - A. Nurse
 - B. Physician
 - C. None of the above

Please note: Question 5 is a continuation of question 4. Please answer each question, but choose only **ONE** occupation. Your answer to one of these questions will be **F. None of the above**. For example, a Health Educator would answer as follows:



- 4. Which of the following best describes your current occupation?**
- A. Epidemiologist
 - B. Health Educator
 - C. Laboratorian
 - D. Pharmacist
 - E. Physician Assistant
 - F. None of the above
- 5. Which of the following best describes your current occupation?**
- A. Field Inspector (nursing homes, restaurants, etc.)
 - B. Manager/Supervisor
 - C. Environmental Health Worker/Sanitarian
 - D. Lawyer/Attorney
 - E. Other public health professional
 - F. None of the above
- 6. Which of the following best describes the organization in which you work?**
- A. Academic
 - B. Private health care setting
 - C. Federal government
 - D. State government
 - E. Local government
 - F. Other organization

Tell us about the module...

- 7. How did you first learn about this module**
- A. State publication (or other state-sponsored communication)
 - B. MMWR
 - C. CDC website (not including PHTN website)
 - D. PHTN source (PHTN website, catalog, e-mail, or fax announcement)
 - E. Colleague
 - F. Other

- 8. How did you obtain this module?**
- A. Purchased from the Public Health Foundation
 - B. Downloaded from the PHTN website
 - C. Borrowed or copied materials from someone else
 - D. Other
- 9. What was the most important factor in your decision to obtain this module?**
- A. Content
 - B. Continuing education credit
 - C. Request from supervisor
 - D. Previous participation in PHTN training(s)
 - E. Ability to take the course at my convenience
 - F. Other
- 10. I completed this module**
- A. As an individual learner
 - B. As part of a learning group that organized itself
 - C. As part of a learning group that was organized by someone outside of the group
- 11. My completion of this module included interaction(s) with an expert(s) (or reasonably experienced person) on the topic?**
- A. Yes
 - B. No
- 12. My interaction(s) with the expert(s) on this topic could be described as follows**
- A. I had no interactions with an expert
 - B. One or more sessions organized by someone outside of the group
 - C. One or more sessions organized by someone within my group
 - D. One or more informal consultations that I initiated on my own
- 13. How long did it take you to complete this module?**
- A. 1 - 2 hours
 - B. 3 - 4 hours
 - C. 5 hours or more
- 14. How many of the ten modules comprising the *Legal Basis of Public Health* have you completed?**
- A. 1 or 2 modules
 - B. 3 to 5 modules
 - C. 6 to 9 modules
 - D. All 10 modules

15. **How many of the ten modules comprising *The Legal Basis of Public Health* do you plan to complete?**
A. 1 or 2 modules
B. 3 to 5 modules
C. 6 to 9 modules
D. All 10 modules
16. **Please rate your level of knowledge prior to completing this module.**
A. Had a great deal of knowledge about the content
B. Had a fair amount of knowledge about the content
C. Had limited knowledge about the content
D. Had no prior knowledge about the content
E. No opinion
17. **Please estimate your knowledge gain due to completing this module.**
A. Gained a great deal of knowledge about the content
B. Gained a fair amount of knowledge about the content
C. Gained a limited amount of knowledge about the content
D. Did not gain any knowledge about the content
E. No opinion
18. **If this module is further evaluated through the use of focus groups or other methods (e.g., follow up questionnaires) would you be willing to participate?**
A. Yes
B. No

Please use the scale below to rate your level of agreement with the following statements about this module.

- A. **Agree**
B. **No opinion**
C. **Disagree**
D. **Not applicable**

19. **The objectives were relevant to the purpose of the course.**
20. **I would recommend this module to my colleagues.**
21. **I believe completing this module will enhance my professional effectiveness.**
22. **The content in this module was appropriate for my training needs.**
23. **Reading the text on my own was an effective way for me to learn this content.**

24. The self-study questions contributed to my understanding of the content.
25. The group exercises contributed to my understanding of the content.
26. The Coordinator Guide contributed to my ability to have a learning experience appropriate to my (or my group's) needs.
27. Downloading the materials from the PHTN website was user-friendly.
28. Ordering the materials through the Public Health Foundation was user-friendly.
29. Ordering the materials through the 1-800-41-TRAIN phone number was user-friendly.
30. I am confident I can identify how federal legislation affects my agency's authority to collect information and carry out surveillance activities.
31. I am confident I can identify how the statutes, regulations, and local ordinances of my state and local government affect my agency's authority to collect information and carry out surveillance activities.
32. I am confident I can distinguish between information that must be held confidential and information that must be or could be made available to the public.
33. I am confident that I can describe appropriate procedures for collecting, releasing, and withholding information.