

ASTHO, NACCHO and AHCJ Guidance on the Release of Information
Concerning Deaths, Epidemics or Emerging Diseases
October 2010
Adopted by the California Conference of Local Health Officers with Revisions
October 2011

Introduction

A set of recommendations emerged from a meeting of public health officials, health care journalists and public health information officers, co-sponsored by the Association of State and Territorial Health Officials, the National Association of County and City Health Officials and the Association of Health Care Journalists in October 2010. A draft was circulated to ASTHO members, NACCHO and the AHCJ board, and their comments were incorporated.

The meeting was prompted by the wide variation in information released by state and local public health officials about people in their localities who died in the H1N1 pandemic of 2009. The disparate approaches - with some jurisdictions releasing specific information about the age, gender and residence of victims and others releasing little or no personal information - became the subject of news reports, distracting from health messages and inadvertently undermining public trust. Release of information must be done in such a manner as to retain the trust of the medical community, as well as of patients and their families.

Below are voluntary guidelines for journalists and public health officials to consult when decisions must be made about what information should be released about deaths, epidemics, emerging diseases or illnesses. These guidelines are deliberately flexible so they can be adapted to each case, local circumstances and local regulations. At the same time, the groups agreed that a common set of information should, with rare exceptions, be released in these situations.

A unique aspect of this process was that journalists were involved in developing the guidelines and agreed to promulgate ethical standards, calling on their peers to respect privacy and attend to context.

In California, public health officials should consult the *Health Officer Practice Guide for Communicable Disease Control in California*, which may further guide release of information. Additionally, when businesses and schools are involved, their Public Information Officers should also be consulted and involved in decisions regarding release of information.

Background

Communication with the public is a crucial role of governmental health officials, especially in times of crisis. Whether it is a natural disaster or an unfamiliar illness, people want to know what is happening, what to expect, and what actions they can take to protect themselves and their families. The public wants to know, as well, how the crisis is playing out in their local communities, including information about deaths and illnesses of individuals. Usually the best way to get such information to the public is through the media.

Nothing deepens anxiety and erodes trust more than the perception that government officials are hiding information from the public. Responses can range from unnecessary anxiety to denial, instead of informed, appropriate actions. In a public health crisis, officials need to balance the requirement to protect the confidentiality of individuals' health information against the need to keep the public informed and engaged. In media parlance, the "cover-up" can become a bigger story than the actual event. Thus, it is important for public health officials to provide as much information as possible or allowed, and for journalists to provide context for information provided.

When information is withheld, it is important for public health officials to explain why and for the media to also report why, to avoid creating unwarranted distrust. When public health officials reveal what they know and don't know, they can build trust and credibility - this is essential before people will accept advice. Openness promotes an understanding of what public health agencies do and a clearer picture of the real health risks that people face. Health officials may worry that releasing information to the media could deter individuals from cooperating in future outbreak investigations, for fear they will be identified. The recommendations below provide a consistent framework to both protect individuals' identities and fulfill the public's need for information.

Health officials also want to allay unfounded fears while explaining the risks so that people can take appropriate actions to avoid harm. Sometimes, even when there is no action to be taken, it is advisable for health officials to give out information to prevent rumors from filling the void. Otherwise people may take inappropriate or unnecessary actions or feel they had been misled.

But frequently, there are circumstances when information must be withheld. Privacy is an important consideration. Public health officials have legitimate concerns - both legal and ethical - about giving out information that could lead to the identification of individuals. *Often, releasing gender, age, and location is enough for people in the community or the media to identify the person.* The media sometimes aggressively try to locate and approach victims or their families.

Laws in nearly every state bar the release of information that could identify an individual - except when such information is needed to protect the public.

Information can be temporarily withheld until government officials and health care professionals are informed and prepared for the response. Sometimes an ongoing investigation may bar disclosure.

Guidance for public health officials

a. Overarching principles

Openness is paramount. It is an essential component of protecting the public and communicating effectively. Public health officials should strive to release as much information as possible, within the limits of the law.

Withhold information *only* when there is a clearly justified reason to keep it confidential. Explain the rationale for any decision to withhold information.

If the reason for withholding is advice from local counsel, explain the basis for the advice to the extent possible. If state, local or federal law is the reason, provide the citation of the law in question.

b. Releasing information about illnesses or deaths of interest to the public

i. When does an incident warrant a public announcement?

People get sick and die every day. Many of these illnesses are tracked by health authorities, but rarely do they require special announcement to the media.

For example, deaths from bacterial pneumonia are common occurrences that don't make the news.

ii. Consider publicizing an illness or death when:

- People can use the information to protect themselves from harm.
- A major epidemic or novel illness is emerging, or a natural disaster or other major event affecting public health has occurred or is anticipated.
- The incident has attracted public attention, and pertinent facts are needed to allay concerns and anxiety or to more effectively communicate risks. This can include incidents that involve a person or event in the news.
- The incident provides an important opportunity to communicate risks or advocate actions ("teachable moment"). For example, a health official may want to remind people about using carbon monoxide detectors after a couple dies from carbon monoxide poisoning in their home.
- Release of information may be of importance in the control of an outbreak and prevention of transmission.

c. What to reveal about individual victims

- Strive to provide information for each of the following categories: age, gender, residence, underlying condition, time and place of death (see below). The level of specificity for each category will vary based on the risk of identifying someone. For example, in heavily populated areas, more details may be less likely to identify an individual than in less dense areas or smaller communities.
- Balance specificity among categories. For example, if information about where the person lived is given in very general terms (e.g. northern part of state) then you may be able to provide more specific age and gender data without compromising confidentiality.

Strive to provide information about each of the following categories:

Age. Exact age if possible. Otherwise, report age using one of the following frameworks:

- life stage (e.g., infant, preschool, school age, teenager, college student, adult, elderly); or
- age range such as 10 year intervals (e.g., "between the ages of 35 and 45").

Gender. Even though gender often is not relevant to the illness or death, it is relevant to the effectiveness of the public health message. Without knowing gender, people will have a harder time relating to the story and thus the public health message will lose its impact. Gender by itself rarely will allow identification of the individual.

Location of victim's residence. The neighborhood, if possible -- but often this level of detail would compromise confidentiality. Otherwise, use city or town, metropolitan area, county, or region or quadrant of the state (e.g., northwest region of state).

Underlying conditions. This could range from merely stating that the person had an underlying condition, to saying it was one of several possible conditions, to actually naming the condition.

Time of death or disease occurrence. This could range from the hour of death, to the date, to the week or month of death, depending on whether the precise time will increase the likelihood of identifying the individual.

Place of death (home, health care facility, hospital). The ability to provide this information will vary by incident. Sometimes, place of death may help identify an individual. But if the place of death is different from the person's residence, providing it may help protect the individual's identity.

When public health officials learned of the case or death. Often public health officials do not learn of the incident until several days after the person died or first sought care. The public and media usually want to know the reason for such delays.

- Explain why your data may differ from information provided by the CDC or other government sources.
- Sometimes the individual's name is made public by the individual, his or her relatives, or by the media. Health officials should not feel compelled to confirm or deny the individual's identity. If the individual or family gives the public health official permission to use the name, emphasize that you have permission if you do use the name. It is important that the public and media understand that names are rarely provided in such instances. At the same time, be sensitive to the media's needs for information in situations in which a note has gone out to all families at a particular day care or school where a person's identity may be known to that community.

d. Timing of information release

- When there is a need to minimize the risk of an illness spreading, give out accurate information as soon as it is available. Speed is also critical with novel illnesses, even if the risk of spread is low.
- Whenever possible, before informing the media, every attempt should be made to notify the individual or next of kin that the case will be discussed with the media and what level of detailed information will be released.
- For a new or emerging outbreak, the first one to three cases may merit swift, special announcements (immediate press conference or press release). As the illness becomes "routine," each case need not be announced; updates can be made on a weekly or monthly basis.
- Provide updates on a regular, predictable schedule - daily, weekly or whatever makes sense, as long as it's predictable. Announce the schedule to the media and public, and adjust it as circumstances dictate.
- As you transition from daily to periodic updates, or from making announcements to merely posting information on a website or providing it upon request, be sure to announce and explain the change.
- Coordinate information release with all levels of government and with health care organizations.

Guidance for journalists

Journalists serve as a conduit of information from public health officials to the public, a weighty responsibility in times of crisis. At the same time, the media must maintain their role as watchdogs, monitoring the performance of public health officials and health care providers. Journalists should question what they are told, but also report fairly what is revealed. They should neither exaggerate nor minimize, but strive to determine the truth and report it with balance and clarity.

- When public health officials withhold information, ask them to explain why, and share the explanation with your audience. If a law is mentioned as the reason, ask for the exact citation. Read it and evaluate whether it is appropriate. (Be aware that the Health Insurance Portability and Accountability Act - known as HIPAA - generally allows for release of information that does not identify individuals.) Avoid language that casts blame on officials for appropriately following the law.
- When someone falls ill or dies from a novel illness or as part of a public health emergency, the public's hunger for information will grow. Journalists also want specific information, such as age and gender, to drive their narratives. When they ask public health officials for such details, they should understand this guidance and the limits to disclosure that local health officials may face.
- Give careful thought to any decision to identify a private individual. Circumstances in which journalists may choose to identify an individual include: when the person's identity has already become widely known, as often happens when a child is involved; when an incident involves a public person or public event; or when there is an overriding public interest to be served by identifying someone. But in other circumstances, when individuals (or their survivors) wish to remain private, respect that wish, and also respect public health officials' responsibilities to protect privacy.
- In all cases - whether the person has been publicly identified or not - demonstrate sympathy for the family's distress and respect their wishes concerning coverage of private events, such as funerals or wakes.
- Journalists also have a responsibility to provide the context that will enhance the public's understanding of an incident. For example, infectious diseases rarely observe political boundaries such as town or county. If you've been told where the person lives, make it clear if the risk extends beyond that particular area. Similarly, if a victim had an underlying condition, also list the other conditions that increase risk. Providing this context is at least as important as the details about individuals affected.

Summary

Health officials can best serve the public by providing as much information as possible within the limits of the law and the need to protect privacy, because openness fosters trust. Journalists can best serve their readers by filing complete and accurate stories that explain the full context, and by respecting individuals' desire for privacy.

Available at:

[Guidance on the release of information concerning deaths, epidemics or emerging diseases:](http://www.healthjournalism.org/secondarypage-details.php?id=965)

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