

09-SI-04

Committee: Surveillance/Informatics

Title: Process statement for Immediately Nationally Notifiable Conditions

I. Statement of the Problem:

This position statement defines the expectations of State and Territorial Epidemiologists and their staffs as part of the national notification process for nationally notifiable conditions that are immediately notifiable or have standard notification.

The Council of State and Territorial Epidemiologists (CSTE) has approved two position statements (07-EC-02 and 08-EC-02 available at: <http://www.cste.org/PS/2007ps/2007psfinal/EC/07-EC-02.pdf> and <http://www.cste.org/PS/2008/2008psfinal/08-EC-02.pdf>) aimed at defining a CSTE list of nationally notifiable conditions (NNC) which are designated for either immediate or standard (previously referred to as “routine”) case notification to CDC. The purpose of these position statements is to promote the development and implementation of a list of conditions under national surveillance as well as the development and use of reporting definitions which support the International Health Regulations and comply with the federal American Health Information Community (AHIC) recommendation for standardization to support “automated case reporting from electronic health records or other clinical information systems” to local/state/territorial public health agencies.

In order for a condition to be placed on the NNC list as stated in CSTE Position Statement 08-EC-02, a case notification request statement is required to accompany 2009 CSTE position statements. The type of information needed for the case notification request statements includes, but is not limited to: what purposes and objectives will be met by standard notification or immediate notification of this condition to CDC and how this information will be shared or distributed.

CSTE collaborated with CDC staff to define a process for how States and Territories will report cases of conditions that have (at the 2009 CSTE annual meeting) been designated as Immediately Notifiable to CDC. CDC’s National Notifiable Diseases Surveillance System Team and CSTE established a Work Group to develop the draft process statement about how the immediate notification process would work.

Conditions or situations judged to require immediate notification, but not formally listed as immediately notifiable, may also be notified using this process. In particular, state epidemiologists should notify CDC about any case or cluster of cases of a nationally notifiable disease that is suspected to be due to bioterrorism, using the ‘extremely urgent’ protocol.

II. Statement of the desired action(s) to be taken:

1. CSTE endorses the attached document Notification Process Statement for Conditions Designated as Immediately Nationally Notifiable (see brief and full versions as Attachments 1 and 2), and urges its members to follow its provisions.
2. CSTE requests CDC to adopt the attached document Notification Process Statement for Conditions Designated as Immediately Nationally Notifiable (Attachments 1 and 2).

III. Public Health Impact:

Following the process described here provides clarity to both states/territories and CDC as to the methods and timeframes for notification of CDC about cases of immediately notifiable diseases. This should facilitate rapid and definitive detection of events of national and international public health importance.

IV. Coordination:

Agencies for Response:

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Attachment 1 – summary of attachment 2 emphasizing State and Territorial Epidemiologist role.

Expectations of State and Territorial Epidemiologists and their staffs as part of the national notification process for nationally notifiable conditions that are immediately notifiable

Of all the nationally notifiable diseases or conditions, some are immediately notifiable. Among these, some are classified as urgent and some as extremely urgent.

For each immediately nationally notifiable disease or condition, criteria for making an immediate national notification are contained in the position statement making the condition immediately notifiable. These will differ by disease.

First case of an immediately nationally notifiable disease, meeting the notification criteria, in a jurisdiction:

- Notification must be made by State or Territorial Epidemiologist or delegate – not local health department, unless EOC told in advance that it can accept notifications from this local health department
- Notify the CDC Emergency Operations Center by phone. You will be called back by a subject matter expert – within an hour if extremely urgent, within four hours if urgent.
- For urgent case reports, notify within 24 hours of becoming aware that the case meets the notification criteria.
- For extremely urgent case reports, notify within 4 hours of becoming aware that the case meets the notification criteria.
- You will receive a written or e-mail confirmation that the case notification has been received by CDC.
- If you are talking to a CDC program official about a case and it becomes clear that the case meets the immediate notification criteria, you may make the notification to the CDC program official and do not need to call the CDC EOC separately.

Subsequent cases in same jurisdiction that are epidemiologically related:

- Notifications may be made to the CDC program staff member who called you back in response to your initial notification, rather than to the CDC EOC.
- You may delegate these notifications to a local health department official, at your discretion, but you must tell the EOC who that is.
- By mutual agreement, an alternate method for these subsequent case notifications may be devised.

Conditions or situations judged to require immediate notification, but not formally listed as immediately notifiable, may also be notified using this process. In particular, state epidemiologists should notify CDC about any case or cluster of cases of a nationally

notifiable disease that is suspected to be due to bioterrorism, using the ‘extremely urgent’ protocol.

Standard notification calls for notification through the disease-appropriate surveillance system within the next normal reporting cycle for that disease. For diseases of which cases are notified through the National Notifiable Disease Surveillance System (notifiable infectious diseases other than HIV/AIDS, tuberculosis or sexually-transmitted diseases), notification is required within 7 days of a case meeting the disease-specific criteria for national notification.

Information items that are needed in the initial voice notification for immediately notifiable diseases are listed in the full document. They include demographics, earliest known event date, and also a unique identifier that will be used to link together your electronic notification, your initial voice report, and subsequent information collected about the case. Notifications should not be delayed because of missing information.

For conditions notifiable to the National Notifiable Diseases Surveillance System (NNDSS), all cases meeting the criteria for immediate notification should be sent via electronic transmission to the NNDSS integrated notification system by the next business day for “extremely urgent” notifications or by the next regularly scheduled transmission cycle for “urgent” notifications. Any changes in case status classification (e.g., from suspected to probable or confirmed, from confirmed to suspected, suspected to not a case) about a case that was previously notified to the EOC should also be sent via electronic notification to the NNDSS by the next business day for “extremely urgent” notifications or by the next regularly scheduled transmission cycle for “urgent” notifications.

Attachment 2

Notification Process Statement for Conditions Designated as Immediately Nationally Notifiable June 10, 2009

Introduction:

The Council of State and Territorial Epidemiologists (CSTE) has approved two position statements (07-EC-02 and 08-EC-02 available at: <http://www.cste.org/PS/2007ps/2007psfinal/EC/07-EC-02.pdf> and <http://www.cste.org/PS/2008/2008psfinal/08-EC-02.pdf>) aimed at defining a CSTE list of nationally notifiable conditions (NNC) which are designated for either immediate or standard (previously referred to as “routine”) case notification to CDC. The purpose of these position statements is to promote the development and implementation of a list of conditions under national surveillance as well as the development and use of reporting definitions which support the International Health Regulations and comply with the federal American Health Information Community (AHIC) recommendation for standardization to support “automated case reporting from electronic health records or other clinical information systems” to local/state/territorial public health agencies.

In order for a condition to be placed on the NNC list as stated in CSTE Position Statement 08-EC-02, a case notification request statement accompanies the 2009 CSTE position statements. The type of information needed for the case notification request statements includes, but is not limited to: what purposes and objectives will be met by standard notification or immediate notification of this condition to CDC and how this information will be shared or distributed.

Conditions or situations judged to require immediate notification, but not formally listed as immediately notifiable, may also be notified using this process. In particular, state epidemiologists should notify CDC about any case or cluster of cases of a nationally notifiable disease that is suspected to be due to bioterrorism, using the ‘extremely urgent’ protocol.

Process Statement

Part I: Verbal notification to the CDC Emergency Operations Center (EOC).

a) Time frames for the various categories of immediacy.

This section describes the process for immediate notification. Immediate notification may be “extremely urgent,” requiring voice notification within 4 hours, or may be “urgent,” requiring voice notification within 24 hours. (Standard notification calls for notification through the disease-appropriate surveillance system within the next normal reporting cycle for that disease. For diseases of which cases are notified through the National Notifiable Disease Surveillance System (notifiable infectious diseases other than HIV/AIDS, tuberculosis or sexually-transmitted diseases), notification is required within 7 days of a case meeting the disease-specific criteria for national notification.)

The timeframe for voice notification of each immediately notifiable condition, either “extremely urgent” or “urgent,” is documented in CSTE position statements. Requirements for the electronic component of immediate notification are described in Part II below.

b) How to contact the CDC EOC.

Immediate notification should occur through voice contact by the State/Territorial Epidemiologist or delegate with the CDC EOC Duty Officer. **The CDC EOC phone number is 770-488-7100 and is available 24/7.** For “extremely urgent” conditions, States/Territories should contact the EOC within 4 hours of becoming aware of any condition that meets any of the case status criteria (e.g., confirmed, probable) specified in the position statement for the specified condition (see Informational Note #1). For “urgent” conditions, States/Territories should contact the EOC within 24 hours after becoming aware of the condition that meets any of the case status criteria (e.g., confirmed, probable) specified in the position statement for the specified condition (see Informational Note #1). The EOC Duty Officer will relay details of the notification to the appropriate CDC official. **For “extremely urgent” conditions, the CDC official will return the call to the State/Territory within 1 hour of the EOC receiving the call. For “urgent” conditions, the CDC official will return the call to the State/Territory within 4 hours of the EOC receiving the call.** Earlier communication or consultation with CDC, such as for technical assistance when there is high suspicion of a case, is always encouraged but does not in itself constitute official notification.

The State or Territorial Epidemiologist may delegate his or her immediate notification responsibility after the first case in any outbreak (or cluster), to specific local officials. However, CDC’s EOC will not officially log an initial notification from someone other than a State/territorial health department official unless the EOC has been officially informed (prior to the time the notification occurs) specifically which local or county jurisdictions have been delegated notification authority by the State or Territorial

Epidemiologist and for which conditions or events this authority applies. Thus, for the CDC EOC to officially log the notification, the local or county health official must notify the State or Territorial health department official about the immediate notification prior to contacting the EOC. It is not feasible for the EOC to log notifications from all the local or county health agencies in the U.S. and thus notifications made by local or county jurisdictions must be the exception rather than the rule in each state/territory. (See Informational Note #2 about the CDC Program responsibility for updating EOC triage lists)

c) Information requested for the immediate notification.

NOTE: Notification to CDC should not be delayed pending verification of any requested notification information. Notification to CDC should not be delayed if some of the notification information is not yet known or verified. Early communication with CDC is always encouraged, even when there are gaps in knowledge. The EOC is able to log the first three items below and the remainder of the requested information should be communicated to the CDC Program.

- Nationally notifiable condition being notified
- State/Territory making the case notification
- Name and working phone number of the State/Territorial official to contact for follow-up
- Information about the case or cases:
 - Unique state/territory case identifier (to link the voice notified case with the subsequent electronic record about the case (See Informational Note #3)
 - Age
 - Sex
 - Location (city and state/territory)
 - Case status classification (e.g., suspected, probable, confirmed)
 - Earliest known event date, if available. (CDC is not asking for information on all the following dates, just one date if it is readily available. **Do not delay notification to CDC to collect date information.**) The following are examples of date types:
 - exposure date
 - illness onset date
 - diagnosis date
 - laboratory specimen date
 - laboratory result date
 - earliest date reported to the local public health system
 - earliest date reported to the state/territory public health system

d) What to do if there is no response from CDC:

For “extremely urgent” immediate notifications, if the State/Territory has not received a follow-up call from the CDC official within 1 hour of calling the EOC, the State/Territory should call the EOC again. For “urgent” immediate notifications, if the State/Territory has not received a follow-up call from the CDC official within 4 hours of calling the EOC, the State/Territory should call the EOC again.

e) Handling subsequent cases.

If a case (or cases) occur(s) which is epidemiologically-linked to and has the same condition as a previously notified case, resulting notification and subsequent communications may occur directly with the responsible CDC Program (i.e., it is not necessary to contact the EOC). The EOC Duty Officer is always available to provide a communication channel with CDC Program officials if and when necessary.

By mutual agreement between the CDC program official and the State/Territorial official after the initial notification related to a larger event (e.g., outbreak), alternate methods of notification (other than immediate voice notification to the EOC) can be implemented. However, the need to submit a timely electronic notification to CDC remains as indicated in Part II below.

f) What to do if case status changes.

If after the immediate voice notification, there is a change in case status (e.g., a suspected case is later confirmed), this would require voice notification to either the CDC program official (if communication has already been established with the CDC Program) or the CDC EOC*. Note that any change in case status would also require an update to the electronic record submitted to CDC Surveillance Systems (see Part II).

*If communication has already been established with the CDC Program, but the State/Territorial official cannot reach the CDC Program, the EOC Duty Officer is always available to provide a communication channel with CDC Program officials if and when necessary.

g) CDC confirmation of receipt of notification.

The CDC official from the relevant CDC program will send the State/Territorial official submitting the voice notification an electronic or written communication (e.g., email, fax) to confirm that the CDC program and State/Territorial officials communicated about the immediately notifiable case. The electronic or paper confirmation message should include the minimum amount of information needed to identify the specific case(s)—for example, the unique state/territory case identifier; no personal identifying information such as name should be included.

h) Transition from consultation to notification.

Consultations with CDC should be distinguished from official notifications sent to CDC. State/Territory Health Department staff frequently contact CDC program officials for consultation and advice about treatment and control of a condition they suspect may be of public health concern. Through these consultations, CDC officials may learn of one or more cases of a suspected notifiable condition for which the State/Territory Health Department is conducting an investigation. This consultation often precedes an official notification to CDC, but does not constitute an official notification to CDC. In the course of this consultation, the state/territory official may make an official notification of one or more cases on behalf of the State/Territory Epidemiologist.

In such situations, the CDC program will make a written confirmation of the notification to the State/Territory official.

(i) Process when a CDC laboratory is the first to identify a case of an immediately notifiable condition

In situations where the CDC laboratory is the first to confirm the existence of an immediately notifiable condition (and CDC subsequently informs the state/territory health department), or where the state/territory provides the voice notification directly to the CDC program, the CDC program will make a written confirmation of the notification to the State/Territory official.

(j) What to do when CDC is notified prior to the state.

If CDC hears about one or more cases of one of the conditions on the immediately notifiable list first (before the State/Territory, as could occur if a clinician calls CDC and bypasses the State/Territory), the CDC official should immediately inform the State Epidemiologist of the State/Territory of the case or cases.

Part II: Timely Electronic Notifications of Cases of Immediately Notifiable Conditions to CDC's Surveillance Systems

For conditions reportable to the National Notifiable Diseases Surveillance System (NNDSS), all cases meeting the criteria for immediate notification should be sent via electronic transmission to the National Notifiable Diseases Surveillance System (NNDSS) integrated notification system by the next business day for "extremely urgent" notifications or by the next regularly scheduled transmission cycle for "urgent" notifications. Any changes in case status classification (e.g., from suspected to probable or confirmed, from confirmed to suspected, suspected to not a case) about a case that was previously notified to the EOC should also be sent via electronic notification to the NNDSS by the next business day for "extremely urgent" notifications or by the next regularly scheduled transmission cycle for "urgent" notifications.

NOTE: The recommended timeline for submitting standard notifications to the NNDSS is by the next regularly scheduled transmission cycle after becoming aware of the condition that meets any of the case status criteria (e.g., confirmed, probable) specified in

the position statement for the specified condition. The intent of the MMWR NNDSS weekly tables and Figure I is to have weekly updates describing the current status of notifiable condition incidence in the U.S. It is not recommended that States delay their case notifications to coincide with the end-of-year reconciliation process used for the publication of the MMWR Annual Summary. Case notifications of diseases that appear in the weekly tables should occur as soon as the cases meet notification criteria, but in any case within 7 days of the case meeting the notification criteria.

Part III: Informational Notes:

1: The National Notifiable Diseases Surveillance System Team at CDC will prepare a list of conditions that CSTE designates as immediately nationally notifiable, after the 2009 CSTE annual meeting. This list will also include the case status classifications for which notification has been requested for each of the immediately nationally notifiable conditions. CDC will distribute this information to all States/Territories to assist them in implementing this process statement.

2: CDC Programs must provide information to the EOC to ensure the EOC Triage lists are updated and must identify both primary and secondary CDC officials for the immediately notifiable conditions.

3: A unique state/territory case identifier is needed to link the case information from voice notifications with the subsequent electronic record submitted to the NNDSS. The unique state/territory case identifier corresponds to variable INV168 in a PHIN Case Notification (as per PHIN VADS in the generic question set) and the CASEID field in the NETSS record. In situations where the CDC laboratory is the first to confirm the existence of an immediately notifiable condition (and CDC subsequently informs the state/territory health department of the confirmation) the state/territory health department and CDC program official will share information about each of their unique case identifiers, if this is needed.

In addition, when supplemental information is collected by CDC epidemiologists about cases in an outbreak that is multistate or national in character, the unique state/territory case identifier is needed to unambiguously link the extended case data collected in the outbreak investigation to the corresponding electronic record submitted to the NNDSS and to the initial voice report.