11-SI-04

Committee: Surveillance and Informatics

Title: Revised Guidelines for Determining Residency for Disease Notification Purposes

Statement of the Problem:

In general, cases of nationally notifiable diseases are notified to CDC based on the case's place of residence, regardless of where exposure may have occurred. While usually obvious, in a small proportion of cases (e.g., children in split parental custody, travelers becoming ill away from home, persons with no fixed address) there can be ambiguity about how to determine residence for reporting purposes. With input from several CSTE members, CDC has in 2010 drafted updated guidelines for determining residence for disease reporting purposes [Attachment – Updated guidelines for determining the jurisdiction responsible for reporting notifiable diseases to CDC's National Notifiable Diseases Surveillance System (NNDSS)]. These guidelines update a previous document adopted in 2003 in CSTE position statement 03-ID-10. The principal change is that cases of nationally notifiable diseases occurring in residents of foreign countries will be identified in national notifications, but not be included in state-specific counts or rates of nationally notifiable diseases. CDC could still disseminate or publish information at the state or national level about the occurrence of nationally notifiable diseases among non-U.S. residents. These guidelines also clarify that for cases of immediately nationally notifiable diseases, the jurisdiction leading the response to the case will make the immediate national notification, even if the case is permanently notified by a different state or is in a non-U.S. resident.

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

- 1. CSTE should adopt these updated guidelines (attached) for determining residence for disease reporting.
- CDC programs participating in NNDSS will follow the 2010 updated guidelines for determining residence for notification of cases of nationally notifiable diseases. CDC's Public Health Surveillance Program Office, Office of Surveillance, Epidemiology, and Laboratory Services, which manages NNDSS, will offer technical assistance as needed regarding interpretation of the guidelines.
- 3. CDC should, as soon as is practical, add a Foreign Residence variable for all case notification messages from states to CDC, as defined in Appendix II of the attachment.
- 4. States and other notifying jurisdictions to CDC's NNDSS should collect information about U.S. residence status and should prepare to report this information to CDC when CDC updates the content of the generic and disease-specific notification messages to include the new Foreign Residence variable.
- 5. The effective date of these guidelines will be January 1 of the year following that in which the Foreign Residence variable has been made available for states' electronic case notifications to CDC.

Public Health Impact:

Adapting these guidelines is not expected to significantly alter broad geographic patterns of disease incidence. However adapting these uniform guidelines is expected to help clarify and streamline local decision-making about a small number of cases each year. In some cases there is no one "right" answer to the question of residency. The revised guidelines will help ensure complete notification and avoid duplicate notification of cases with ambiguous residency—achieving consistency without any need to agonize over each determination.

Reference: 03-ID-10 Revised Guidelines for Determining Residency for Disease Reporting Purposes.

Agencies for Response:

(1) Steve Thacker, MD, M.Sc,

Director, Office of Surveillance, Epidemiology, and Laboratory Services, CDC 1600 Clifton Road MS/E78 Atlanta, GA 30333 404-498-6001 (phone) sbt1@cdc.gov

Agencies for Information:

(1) Paul Jarris

Executive Director Association of State and Territorial Health Officials 2231 Crystal Drive, Suite 450 Arlington, VA 22202 202-371-9090 pjarris@astho.org

(2) James Buehler, MD, MPH

Acting Director, Public Health Surveillance Program Office, CDC 1600 Clifton Road MS/E90 Atlanta, GA 30333 404.498.6682 jwb2@cdc.gov

Submitting Author:

Richard S. Hopkins, MD, MSPH
Acting State Epidemiologist
Florida Department of Health
4052 Bald Cypress Way
Bin # A-12

Tallahassee, FL 32399-1720 850-245-4412 Richard_hopkins@doh.state.fl.us

ATTACHMENT

Updated guidelines for determining the jurisdiction responsible for reporting notifiable diseases to CDC under the National Notifiable Diseases Surveillance System (NNDSS)

Effective Date:

Summary of updated guidelines

For purposes of notifiable disease reporting to CDC, cases should be reported by the jurisdiction of the person's "usual residence" at the time of disease onset. For most people, usual residence is obvious and unambiguous. However, situations do arise for many people in which usual residence is less clear. The following guidelines are intended to provide uniform standards for determining usual residence for disease reporting purposes. The guidelines are modeled after provisions developed for the U.S. Census. The overarching aim of these guidelines is that all cases should be reported, but no case should be reported by multiple jurisdictions. It is important to note that following these guidelines may result in cases being reported by a jurisdiction other than where the infection was acquired. In such instances, other variables can be used to reflect "imported" infections acquired outside the jurisdiction reporting the case.

For instances in which usual residence remains ambiguous, the public health jurisdictions involved should discuss the situation and come to agreement on which jurisdiction will report the case, based on the principles contained in these guidelines. When jurisdictions cannot agree, the Public Health Surveillance Program Office (PHSPO),Office of Surveillance, Epidemiology, and Laboratory Services (OSELS), Centers for Disease Control and Prevention (CDC) is willing to arbitrate the is agreement and recommend a reporting jurisdiction.

I. Rationale for basing disease reporting guidelines on U.S. Census residency rules.

Although not developed specifically for disease surveillance purposes, residency rules used by the U.S. Census have been developed over many years to account for most circumstances of ambiguous residence. In addition, since notifiable disease data are often combined with population data, case notification guidelines based on census residence rules will contribute toward greater consistency in the numerator and denominator data used in disease rates.

II. Concept of usual residence

Usual residence is defined as the place where the person lives and sleeps most of the time, which is not necessarily the same as the person's voting residence, legal residence, or the place where they became infected with a notifiable disease. Determining usual residence for most people is easy and unambiguous. However, the usual residence for some people is not obvious. A few examples are people without housing, commuter workers, retirees who spend the winter months in warmer climates ("snowbirds"), college students, military personnel, and migrant workers.

III. Parameters for disease reporting

It is important to note that national case notification is not intended to capture the location of exposure per se. If the patient is known to have acquired their infection outside the reporting jurisdiction, the IMPORTED variable should be used in the National Electronic

Telecommunications System for Surveillance (NETSS) or the National Electronic Disease Surveillance System (NEDSS) variable INV152 (Case Disease Imported Code) in the PHIN Generic or Disease-Specific Case Notification Message should be used to reflect acquisition of infection outside the reporting jurisdiction. Additional guidance on use of the IMPORTED variable based on the NETSS and NEDSS messages is provided in Appendix I.

To determine usual residence, it is necessary to define a fixed *reference point* in time, analogous to the "census day" used for the census. In addition, for persons who regularly move between residences, it may be necessary to consider a *reference period* preceding the fixed reference point.

A. Reference Point

Date of symptom onset is selected as the reference point for establishing "usual residence." If date of symptom onset is not available, the date of diagnosis, lab result or the first case report to the health department is recommended, in that order, as the reference point. This is consistent with the use of the EVENTDATE field in NETSS, which gives priority to the "earliest known date associated with this incidence of disease." The advantages to using symptom onset as the reference point rather than diagnosis date are that onset is a more meaningful date from an epidemiological point of view (i.e. more proximal to the date of exposure). In addition, date of diagnosis is frequently unavailable or even non-existent, particularly for cases that are not labconfirmed or physician-diagnosed (e.g., epi-linked cases identified during an outbreak investigation).

B. Reference Period

If the person is on a regular schedule or cycle for moving between two or more residences, a reference period preceding onset date may be necessary to determine usual residence. Ideally this reference period might coincide with the incubation period of the disease being reported. However, given the variability and uncertainty of incubation periods for the range of notifiable diseases, basing the reference period on disease specific incubation periods would be unnecessarily complicated and impractical. Therefore, we propose defining the reference period consistent with Census Bureau rules, based on the cycle that an individual has for moving between residences. This cycle could be weekly, monthly, yearly, or some other interval. Again, reference period is only relevant for determining usual residence for individuals with a regular cycle for moving back and forth between two or more residences. When the individual takes up a new residence for an indefinite period without intending to return to the previous residence, the jurisdiction of the new residence will be the recommended reporting authority, even if this change of residence occurred shortly before disease onset.

IV. Specific guidelines for determining usual residence at time of symptom onset, for national notification of cases of routinely nationally notifiable diseases (NND)

Note that cases of NND included in scenarios IV.A through IV.I below should be included in state-specific counts or rates of NND. However, cases of NND included in scenario IV.J should not be included in state-specific counts or rates of NND.

A. U.S. residents away on vacation or business

Case notifications to CDC for cases of NNDs in U.S. residents temporarily away on vacation or a business trip at the time of disease onset should be made by the jurisdiction of their usual residence.

B. U.S. residents without housing

Cases notifications to CDC for cases of NNDs in U.S. residents without a usual residence should be made by the jurisdiction where they were staying on the day of disease onset.

C. U.S. residents with multiple residences

1. Case notifications to CDC for cases of NNDs in U.S. residents occurring in commuter workers living away part of the week while working (on a weekly cycle) should be made by the jurisdiction where they stay most of the week.

2. Case notifications to CDC for cases of NNDs in U.S. residents who live in one state most of the year but who regularly spend part of the year in another state (e.g., snowbirds) can be said to have an annual cycle and should be made by the jurisdiction of the residence where they live most of the year.

3. Cases notifications to CDC for cases of NNDs in in children in joint custody should be made by the jurisdiction of the residence where they live most of the time. If the time is equally divided, the notification is made by the jurisdiction where they were staying at the time of disease onset.

4. Case notifications to CDC for cases of NNDs in people who move between residences without any regular cycle should be made by the jurisdiction of the residence where they live most of the time. If their time is equally divided, notify based on where they were staying at the time of disease onset.

D. U.S. resident students

1. Case notifications to CDC for cases of NNDs in college or boarding school students on a typical yearly academic cycle should be made by the jurisdiction of the residence where the students live most of the year.

2. If cases occur in an individual who is an intermittent or part-time student without a regular cycle for moving between parental and school residences, then the jurisdiction where they were living at the time of disease onset should make the notification.

E. U.S. resident live-ins

Case notifications to CDC for cases of NNDs in foster children should be made by the jurisdiction where the children were living at the time of disease onset.

F. Military or merchant marine personnel in the U.S.

1. Case notifications to CDC for cases of NNDs in people in the military residing in the United States should be made by the jurisdiction at the person's usual residence, either on- or off-base.

2. Case notifications to CDC for cases of NNDs in crew members of military vessels with a U.S. homeport should be made by the jurisdiction at the crew member's usual onshore residence if they report one (the place where they live and sleep most of the time when they are onshore); otherwise, at their vessel's homeport.

3. Case notifications to CDC for cases of NNDs in crew members of U.S. flag merchant vessels engaged in inland waterway transportation should be made by the jurisdiction of the crew member's usual onshore residence (the place where they live and sleep most of the time when they are onshore).

4. Case notifications to CDC for cases of NNDs in crew members of U.S. flag merchant vessels docked in a U.S. port or sailing from one U.S. port to another U.S. port should be made by the jurisdiction of the crew member's usual onshore residence if they report one (the place where they live and sleep most of the time when they are onshore). If they have no onshore residence, follow rule IV.B and notify from nearest jurisdiction at the time of illness onset.

G. U.S. resident institutionalized persons

1. Case notifications to CDC for cases of NNDs in U.S. residents who are patients in general hospitals or wards at the time of symptom onset should be made by the jurisdiction of the patient's usual residence (the place where they live and sleep most of the time when they are not hospitalized). Case notifications to CDC for cases of NNDs in newborn babies who have not yet been discharged following delivery should be made by the jurisdiction of the mother's usual residence.

2. In general, case notifications to CDC for cases of NNDs in persons who are institutionalized for indefinite or long-term stays should be made by the jurisdiction of the facility where the people are staying at the time of disease onset.

Examples of such facilities include:

chronic or long-term disease hospitals; hospices; nursing or convalescent homes; inpatient drug/alcohol recovery facilities; homes, schools, hospitals, or wards for the physically handicapped, mentally retarded, or mentally ill; federal and state prisons, jails, detention centers, and halfway houses; orphanages; residential care facilities for neglected or abused children.

3. Case notifications to CDC for cases of NNDs in staff members living in hospitals, nursing homes, prisons, or other institutions should be made by the jurisdiction of the staff member's usual residence (the place where they live and sleep most of the time); otherwise by the jurisdiction where the institution is located.

H. U.S. resident foreign citizens

Case notifications for Individuals, regardless of citizenship, who are diagnosed in the U.S. with a notifiable disease) should be made to CDC.

1. Case notifications to CDC for cases of NNDs in foreign citizens who have established a household or are part of an established household in the U.S., including those here for work or study, should be made by the jurisdiction of their usual residence in the U.S.

2. Case notifications to CDC for cases of NNDs in foreign citizens who live on diplomatic compounds (e.g., embassies, consulates) should be made by the jurisdiction where the facility is located.

I. U.S. residents diagnosed in the U.S. but with disease onset outside the U.S. or its overseas territories.

The case jurisdiction should be based on location of "usual residence" at the time of treatment or care, and the case should be classified as "imported" as defined in Appendix I.

J. Non-U.S. residents diagnosed in the U.S.

National notification for cases diagnosed or treated in the US occurring in persons who are not residents of the United States, regardless of citizenship or immigration status, should be submitted by the jurisdiction that is handling a case report or investigation. When the notification is submitted, the Foreign Residence flag should be set to Yes in the NETSS, NEDSS, or PHIN message to ensure that the case is not included in the state-specific counts or rates of nationally notifiable diseases. See Appendix II.

K. Reporting involving U.S. territories and possessions outside the fifty states and D.C.

See Appendix I.

V. Specific guidelines for determining usual residence at time of symptom onset, for national notification of cases of immediately nationally notifiable diseases.

If the case is of an immediately nationally notifiable disease, initial telephonic notification to CDC should be done by whichever jurisdiction is leading the public health

response, or by mutual agreement by the state where the person normally resides; but final notification through NETSS or PHIN messaging should occur by the notifying jurisdiction as determined in Section IV above.

VI. Resolution of disagreements between states

When there is disagreement between states regarding who should make a notification for a case, states are encouraged to resolve their disagreement amongst themselves based on the underlying principles contained in these guidelines. If states are unable to come to agreement, Public Health Surveillance Program Office (PHSPO), Office of Surveillance, Epidemiology, and Laboratory Services (OSELS) staff are available to arbitrate the disagreement, and recommend a reporting jurisdiction.

Contact Information: James Buehler, MD Director, Public Health Surveillance Program Office Office of Surveillance, Epidemiology, and Laboratory Services, CDC 1600 Clifton Road Mail Stop E90 jwb2@cdc.gov

Appendix I. Clarification of response categories for the *Imported* variable based on the NETSS file format and the PHIN Generic Case Notification Message.

The imported variable should be used in instances when the Ill person is believed to have acquired his or her infection outside the jurisdiction making the notification, based on the usual incubation period for the disease. Below are the current response categories for the *Imported* variable, taken from page 4-12 of the <u>Manual of Procedures for the Reporting of Nationally Notifiable Diseases to CDC</u>, based on the content of the NETSS data file:

NETSS Imported data element:

Coding: Indicates if the case was locally acquired or imported into the state or the US.

Values:

- 1 = Indigenous (acquired in U.S. in reporting state)
- 2 = International (acquired outside U.S.)
- 3 = Out of State (acquired in U.S. but outside the reporting state)
- 9 = Unknown

Below are the current responses for the NEDSS *Imported* data element (INV152):

INV152 (Case Disease Imported Code) indicates if the case was locally acquired or imported into the state or the U.S.

Coding Values for INV152:

| Concept Code | Concept Name | Preferred Concept Name |
|--------------|-----------------------------|-------------------------------|
| | Indigenous, within | |
| PHC244 | jurisdiction | Indigenous |
| C1512888 | International | International |
| | Out of jurisdiction, from | |
| | another jurisdiction within | |
| PHC245 | state | In State, Out of jurisdiction |
| PHC246 | Out of state | Out of state |
| UNK | Unknown | Unknown |

Questions have arisen regarding how to categorize cases acquired in U.S. Territories. The following clarification is proposed, which is derived from language in the Code of Federal Regulations related to Foreign Quarantine. U.S. territories include only Puerto Rico, the U.S. Virgin Islands, Guam, American Samoa, the Commonwealth of Northern Mariana Islands, Palau, Marshall Islands, and Federated States of Micronesia. For the purposes of categorizing cases regarding the *Imported* variable, only Puerto Rico and the U.S. Virgin Islands should be considered inside the U.S. The rationale for this is based on regulations for foreign quarantine. All other territories should be considered outside the U.S. Therefore, while the response categories remain the same, the description of values for the *Imported NETSS and NEDSS* variables should be amended to read:

Amended description of values for the NETSS *Imported* variable:

1 = Indigenous (acquired in state or territory reporting the case)

2 = International (acquired outside U.S. [i.e. outside 50 states, District of Columbia, Puerto Rico, and the U.S. Virgin Islands]). This includes cases imported to the U.S. from the U.S. overseas territories of Guam, American Samoa, Commonwealth of Northern Mariana Islands, Palau, Marshall Islands, and Federated States of Micronesia.

3 = Out of State (acquired in U.S. [i.e. in 50 states, District of Columbia, Puerto Rico, or the U.S. Virgin Islands] but outside the reporting state).

9 = Unknown

Note: Citizenship or immigration status of the patient has no bearing on the coding of the Imported variable.

Amended description of the values for the NEDSS Imported variable (INV152):

PHC244 = Indigenous, within jurisdiction (acquired in state or territory reporting the case)

C1512888 = International (acquired outside U.S. [i.e. outside 50 states, District of Columbia, Puerto Rico, and the U.S. Virgin Islands]). This includes cases imported to the U.S. from the U.S. overseas territories of Guam, American Samoa, Commonwealth of Northern Mariana Islands, Palau, Marshall Islands, and Federated States of Micronesia.

PHC245 = Out of jurisdiction, from another jurisdiction within state (acquired in state or territory reporting the case)

PHC246 = Out of state (acquired in U.S. [i.e. in 50 states, District of Columbia, Puerto Rico, or the U.S. Virgin Islands] but outside the reporting state)

| Location Infection Acquired | Location Reporting Case | Value for <i>Imported</i> Variable |
|---|--|---------------------------------------|
| In any state (including District of Columbia, Puerto Rico, or the U.S. Virgin Islands) | In the same state as infection acquired (including District of Columbia, Puerto Rico, or the U.S. Virgin Islands) | 1 = Indigenous |
| In any state (including District of Columbia, Puerto Rico, or the U.S. Virgin Islands) | In a different state as infection acquired (including District of Columbia, Puerto Rico, or the U.S. Virgin Islands) | 3 = Out of State |
| In a U.S. overseas territory (including Guam, American Samoa, the Commonwealth of Northern Mariana Islands, Palau, Marshall Islands, and Federated States of Micronesia.) | In the same U.S. overseas territory as infection acquired (including Guam, American Samoa, the Commonwealth of Northern Mariana Islands, Palau, Marshall Islands, and Federated States of Micronesia.) | 1 = Indigenous |
| In a U.S. overseas territory (including Guam, American Samoa, the Commonwealth of Northern Mariana Islands, Palau, Marshall Islands, and Federated States of Micronesia.) | In a different U.S. overseas territory as infection acquired (including Guam, American Samoa, the Commonwealth of Northern Mariana Islands, Palau, Marshall Islands, and Federated States of Micronesia.) | 2 = International |

The following chart is intended to further assist in classifying individuals with respect to the imported variable.

| In a U.S. overseas territory (including Guam, American Samoa, the Commonwealth of | In any state (including District of Columbia, Puerto Rico, or the U.S. Virgin Islands) | 2 = International |
|--|--|-------------------|
| Northern Mariana Islands, | | |
| Palau, Marshall Islands, and | | |
| Federated States of | | |
| Micronesia.) | | |
| Outside of any state, District of Columbia, Puerto Rico, the U.S. Virgin Islands, Guam, American Samoa, the Commonwealth of Northern Mariana Islands, Palau, Marshall Islands, and | In any state, District of Columbia, Puerto Rico, the U.S. Virgin Islands, Guam, American Samoa, the Commonwealth of Northern Mariana Islands, Palau, Marshall Islands, and | 2 = International |
| Federated States of Micronesia | Federated States of Micronesia | |

Appendix II.

New Foreign Resident Variable

A new Foreign Resident variable should be established for all case notifications of nationally notifiable diseases, regardless of the software system or message format used for those notifications. This variable should have the following coding values:

- 1 = Yes non-US resident 2 = No - US resident
- 9 = Unknown whether US resident or not.

For purposes of tabulation of state-specific counts and incidence rates of nationally notifiable diseases, for example in the MMWR, only cases with values 2 and 9 for this variable should be included.