09-ID-36

Committee: Infectious

Title: Public Health Reporting and National Notification for Hansen's Disease

I. Statement of the Problem

CSTE position statement 07-EC-02 recognized the need to develop an official list of nationally notifiable conditions and a standardized reporting definition for each condition on the official list. The position statement also specified that each definition had to comply with American Health Information Community recommended standards to support "automated case reporting from electronic health records or other clinical care information systems." In July 2008, CSTE identified sixty-eight conditions warranting inclusion on the official list, each of which now requires a standardized reporting definition.

II. Background and Justification

Background[1]

Hansen's disease, commonly known as leprosy, is a chronic bacterial disease of the skin caused by *Mycobacterium leprae*. Although the mode of transmission of Hansen's disease remains uncertain, most investigators think that *M. leprae* is usually spread from person to person in respiratory droplets. Close contacts are at greatest risk. Transmission of Hansen's disease in the United States is rare, but 100-200 cases are reported each year. Most U.S. cases occur in immigrants, typically from Asia and Latin America. Symptoms may be present for years prior to diagnosis, creating an opportunity for ongoing transmission. This chronic infectious disease usually affects the skin and peripheral nerves but has a wide range of possible clinical manifestations. Ongoing surveillance is needed to facilitate case detection and control efforts.

Justification

Hansen's disease meets the following criteria for a nationally and **standard** notifiable condition, as specified in CSTE position statement 08-EC-02:

- A majority of state and territorial jurisdictions—or jurisdictions comprising a majority of the U.S. population—have laws or regulations requiring **standard** reporting of Hansen's disease to public health authorities
- CDC requests **standard** notification of Hansen's disease to federal authorities
- CDC has condition-specific policies and practices concerning the agency's response to, and use of, notifications.

[1] Much of the material in the background is directly quoted from the CDC's Hansen's disease website. See the References for further information on this source.

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

CSTE requests that CDC adopt this standardized reporting definition for Hansen's disease to facilitate more timely, complete, and standardized local and national reporting of this condition.

IV. Goals of Surveillance

To provide information on the temporal, geographic, and demographic occurrence of Hansen's disease to facilitate its prevention and control

V. Methods for Surveillance

Surveillance for Hansen's disease should use the sources of data and the extent of coverage listed in Table V below.

Table V. Recommended sources of data and extent of coverage for ascertaining cases of Hansen's disease.

	Coverage	
Source of data for case ascertainment	Population-wide	Sentinel sites
clinician reporting	X	
laboratory reporting	X	
reporting by other entities (e.g., hospitals, veterinarians, pharmacies)	X	
death certificates		
hospital discharge or outpatient records	X	
extracts from electronic medical records	X	
telephone survey		
school-based survey		
other		

VI. Criteria for Reporting

Reporting refers to the process of healthcare providers or institutions (e.g., clinicians, clinical laboratories, hospitals) submitting basic information to governmental public health agencies about cases of illness that meet certain reporting requirements or criteria. Cases of illness may also be ascertained by the secondary analysis of administrative health data or clinical data. The purpose of this section is to provide those criteria that should be used by humans and machines to determine whether a specific illness should be reported.[2]

[2] "Human-based" criteria (described below under "A. Narrative") can be applied by medical care providers and laboratory staff based on clinical judgment and clinical diagnosis. Machine-based criteria (described below under

A. Narrative description of criteria determine whether a case should be reported to public health authorities

Report any illness to public health authorities that meet any of the following criteria:

1. All persons with skin lesions and acid-fast bacilli demonstrated in skin or dermal nerve, obtained from the full-thickness skin biopsy of a lesion should be reported. Swelling or thickening of the nerves may also be present.

2. A person whose healthcare record contains a diagnosis of Hansen's disease.

Other recommended reporting procedures

- All cases of Hansen's disease should be reported.
- Reporting should be on-going and routine.
- Frequency of reporting should follow the state health department's routine schedule.

"B. Table") can be applied using computerized algorithms that operate in electronic health record systems, including computerized records of laboratory test orders and laboratory test results; other clinical data systems (e.g., hospital discharge data systems serving multiple hospitals); or administrative data (e.g., healthcare provider billing data, vital records, and EMS data).

B. Table of criteria to determine whether a case should be reported to public health authorities

Table VI-B. Proposed Table of criteria to determine whether a case should be reported to public health authorities. Note: The following criteria are proposed for evaluation before general implementation. For purposes of currently implementing reporting the narrative description in VI-A, should be used.

Criterion	Reporting	
Clinical Presentation		
Hypopigmented, anesthetic macules	O	
Erythematous nodules	C	
Erythematous papules	C	
Thickening of the skin	O	
Peripheral nerve swelling	O	
Peripheral nerve thickening	O	
Medical record contains a diagnosis of Hansen's Disease		S
Laboratory findings		
Acid fast bacilli demonstrated in skin or a dermal nerve from a biopsy of a skin lesion	N	

Notes:
S = This criterion alone is sufficient to report a case
N = This criterion in conjunction with all other "N" and any "O" criteria in the same column is required to report a case.
O = At least one of these "O" criteria in each category in the same column (e.g., clinical presentation and laboratory findings is required to report a case.
C = This finding corroborates (i.e., supports) the diagnosis of—or is associated with—Hansen's disease, but is not required for reporting.

C. Disease Specific Data Elements:

Disease-specific data elements to be included in the initial report are listed below.

Epidemiological Risk Factors

Country of birth
Prolonged residence in a developing country
Contact with a confirmed case of Hansen's disease
Armadillo contact

VII. Case Definition for Case Classification

A. Narrative description of criteria to determine whether a case should be classified as confirmed.

Clinical description

A chronic bacterial disease characterized by the involvement primarily of skin as well as peripheral nerves and the mucosa of the upper airway. Clinical forms of Hansen's disease represent a spectrum reflecting the cellular immune response to *Mycobacterium leprae*. The following characteristics are typical of the major forms of the disease:

- *Tuberculoid*: one or a few well-demarcated, hypopigmented, and anesthetic skin lesions, frequently with active, spreading edges and a clearing center; peripheral nerve swelling or thickening also may occur
- *Lepromatous*: a number of erythematous papules and nodules or an infiltration of the face, hands, and feet with lesions in a bilateral and symmetrical distribution that progress to thickening of the skin
- *Borderline (dimorphous)*: skin lesions characteristic of both the tuberculoid and lepromatous forms
- *Indeterminate*: early lesions, usually hypopigmented macules, without developed tuberculoid or lepromatous features

Laboratory criteria for diagnosis

- Demonstration of acid-fast bacilli in skin or dermal nerve, obtained from the full-thickness skin biopsy of a lepromatous lesion

Case classification

Confirmed: a clinically compatible case that is laboratory confirmed

B. Classification Tables

Table VII-B lists the criteria that must be met for a case to be classified as confirmed.

Table VII-B. Proposed table of criteria to determine whether a case is classified. Note: The following criteria are proposed for evaluation before general implementation. For purposes of current notification, the narrative description in VII-A, should be used.

	Case Definition
Criterion	Confirmed
Clinical Presentation	
Hypopigmented, anesthetic macules	O
Erythematous nodules	O
Erythematous papules	O
Thickening of the skin	O
Peripheral nerve swelling	O
Peripheral nerve thickening	O
Medical record contains a diagnosis of Hansen's Disease	
Laboratory findings	
Acid fast bacilli demonstrated in skin or a dermal nerve from a biopsy of a skin lesion	N

Notes:
N = This criterion in conjunction with all other "N" and any "O" criteria in the same column is required to classify a case.
O = At least one of these "O" criteria in each category in the same column (e.g., clinical presentation and laboratory findings is required to classify a case.

VIII. Period of Surveillance

Surveillance should be on-going.

IX. Data sharing/release and print criteria

Notification to CDC of confirmed cases of Hansen's Disease is recommended.

Electronic reports of Hansen's Disease cases in NNDSS are summarized weekly in the MMWR Tables. Annual case data on Hansen's Disease is also summarized in the yearly Summary of Notifiable Diseases. State-specific compiled data will continue to be published in the weekly reports and annual MMWR Surveillance Summaries. The frequency of release of additional publications of these data will be dependent on the current epidemiologic situation in the country. These publications might include annual epidemiologic summaries in the MMWR or manuscripts in peer-reviewed journals. Aggregate case data will be shared with WHO as requested.

X. References

Centers for Disease Control and Prevention (CDC). Case definitions for infectious conditions under public health surveillance. MMWR 1997; 46 (No. RR-10):1–57. Available from: http://www.cdc.gov/mmwr/

Centers for Disease Control and Prevention (CDC). National notifiable diseases surveillance system: case definitions. Atlanta: CDC. Available from: http://www.cdc.gov/ncphi/disss/nndss/casedef/index.htm Last updated: 2008 Jan 9. Accessed:

Council of State and Territorial Epidemiologists (CSTE). CSTE official list of nationally notifiable conditions. CSTE position statement 07-EC-02. Atlanta: CSTE; June 2007. Available from: http://www.cste.org.

Council of State and Territorial Epidemiologists (CSTE). Criteria for inclusion of conditions on CSTE nationally notifiable condition list and for categorization as immediately or routinely notifiable. CSTE position statement 08-EC-02. Atlanta: CSTE; June 2008. Available from: http://www.cste.org.

Council of State and Territorial Epidemiologists (CSTE). Revised Case Definitions for Public Health Surveillance: Infectious Disease. 1996-18. Atlanta: CSTE; June 1996. Available from: http://www.cste.org.

Council of State and Territorial Epidemiologists (CSTE). Data Release Guidelines of the Council of State & Territorial Epidemiologists for the National Public Health System. Atlanta: CSTE; June 1996.

Council of State and Territorial Epidemiologists, Centers for Disease Control and Prevention. CDC-CSTE Intergovernmental Data Release Guidelines Working Group (DRGWG) Report: CDC-ATSDR Data Release Guidelines and Procedures for Re-release of State-Provided Data. Atlanta: CSTE; 2005. Available from: http://www.cste.org/pdffiles/2005/drgwgreport.pdf or http://www.cdc.gov/od/foia/policies/drgwg.pdf.

Heymann DL, editor. Control of communicable diseases manual. 18th edition. Washington: American Public Health Association; 2004.

Levis WR, Ernst JD. *Mycobacterium leprae* (Leprosy, Hansen's Disease). In: Mandell GL, Bennett JE, Dolin R, editors. Principles and Practice of Infectious Diseases, 6th edition. Philadelphia: Churchill Livingstone; 2005.

XI. Coordination:

Agencies for Response:

(1) Thomas R Frieden, MD, MPH
Director
Centers for Disease Control and Prevention
1600 Clifton Road, NE
Atlanta GA 30333
(404) 639-7000
txf2@cdc.gov

XII. Submitting Author:

(1) Raoult Ratard
Louisiana Office of Public Health
3101 W. Napolean Ave.
Metairie, LA 70001
504-219-4522
Raoult.ratard@la.gov

Co-Authors:

(1) Associate Member
Harry F. Hull, Medical Epidemiologist
HF Hull & Associates, LLC
1140 St. Dennis Court
Saint Paul, MN 55116
(651) 695-8114
hullhf@msn.com

(2) Associate Member
Cecil Lynch, Medical Informaticist
OntoReason
7292 Shady Woods Circle
Midvale, UT 84047
(916) 412.5504
clynch@ontoreason.com

(3) Associate Member
R. Gibson Parrish, Medical Epidemiologist
P.O. Box 197
480 Bayley Hazen Road
Peacham, VT 05862
(802) 592-3357
gib.parrish@gmail.com