



Syndrome Definitions for Diseases Associated with Critical Bioterrorism-associated Agents

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Introduction

Recent events, including the emergence of severe acute respiratory syndrome (SARS), West Nile virus, and monkeypox, have resulted in the implementation of alternate methods of disease surveillance that can potentially identify clusters of cases before traditional methods. Some surveillance systems utilize International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) coded health information from physician visit records or emergency department discharge data (1). Other systems abstract data from emergency department logs, 911 calls, or nurse call line data through analysis of text or other developed coding systems (2). Such surveillance methods are often referred to as syndromic surveillance since they typically monitor the non-specific clinical information that may indicate a bioterrorism-associated disease before specific diagnoses are made. Syndromic surveillance systems often utilize data sources that already exist but have not been designed specifically for public health surveillance purposes. Two data sources that may be available to augment a public health agency's surveillance activities are ICD-9-CM-coded discharge diagnoses for outpatient visits and emergency department visits.

ICD-9-CM codes were developed to allow assignment of codes to diagnoses and procedures associated with hospital utilization in the United States and are often used for third-party insurance reimbursement purposes. ICD-9-CM codes have been monitored in several settings to support public health surveillance (3-6). Syndromic surveillance using ICD-9-CM-coded health information may be considered because the codes are readily available for use by health care systems, are used in multiple clinical settings (e.g., outpatient, inpatient, emergency departments), are often available electronically, and can be shared easily between different information systems. However, prior to implementing surveillance based on the use of ICD-9-CM-coded health information, public health agencies should evaluate their usefulness with regard to the goals of the surveillance system (7, 8). For example, there may be a substantial delay in ICD-9-CM code assignment or the availability of that information in an electronic health information system. Since timeliness is a critical requirement, use of ICD-9-CM-coded information that is not timely may not be appropriate. Additionally, nonspecific ICD-9-CM codes may be used in an outpatient setting yielding low specificity for the outcome of interest. There may be bias in the use of the codes by some data providers (e.g., using codes for greater severity of illness to justify patient treatment). Use of a limited number of ICD-9-CM codes to describe a clinical encounter may limit appropriate interpretation. However, given the widespread availability and use of ICD-9-CM codes, it is prudent to provide some guidance regarding their use and to encourage the evaluation of their use for syndromic surveillance.

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Beginning in 1999 to support several enhanced syndromic surveillance activities associated with high-profile community events (e.g., national political conventions), the Centers for Disease Control and Prevention (CDC) identified syndrome categories to be monitored that were indicative of the clinical presentations of several critical bioterrorism-associated conditions. The Department of Defense's ESSENCE program also developed broad syndrome groups using ICD-9-CM codes that approximate natural infectious disease outbreaks or bioterrorism. These syndrome groups are currently under routine surveillance at military medical treatment facilities (9). Other public health agencies have also developed syndrome-based definitions and code groupings specific to their data sources and surveillance goals. By combining our experiences, Department of Defense, CDC, and other investigators developed a suggested list of syndrome groups, definitions, and corresponding ICD-9-CM codes that can be used in syndromic surveillance programs.

A multi-agency working group was established to identify and define candidate syndrome groups. Eleven syndromes and corresponding code sets were selected based on a systematic selection process (Table). Definitions for each syndrome group were created by consensus. Individual ICD-9-CM codes were selected as candidates for inclusion in defined syndrome groups after an exhaustive search through all possible codes (Appendix). The codes were divided into three categories based on overall association with a syndrome or specific disease and by observed frequency of code usage in three clinical data sources (representing discharge diagnoses for outpatient visits and emergency department visits). The following categories within syndrome groups were defined:

Category 1 - Consists of codes that reflect general symptoms of the syndrome group and also include codes for the bioterrorism diseases of highest concern or those diseases highly approximating them.

Category 2 - Consists of codes that might normally be placed in the syndrome group, but daily volume could overwhelm or otherwise detract from the signal generated from the Category 1 code set alone.

Category 3 - Consists of specific diagnoses that fit into the syndrome category but occur infrequently or have very few counts. These codes may be excluded to simplify syndrome category code sets.

The working group also assessed the trends over time, frequency of code use, and subsequent contribution of selected codes to background 'noise' of the ICD-9-CM-coded syndrome groups using two large medical data sets: DoD outpatient visits and civilian emergency department visits. This analysis is ongoing but emphasized the need to evaluate the performance of the code sets in each data source.

These syndrome definitions and associated ICD-9-CM-coded syndrome groups can be used in syndromic surveillance systems to allow for comparability and evaluation among programs. However, analysis of the syndrome groups and subcategory distributions in individual data sources must be done as the frequency of code usage may vary by data source and will dictate which codes are best included for a particular surveillance program. Additional guidance from the working group will be forthcoming regarding statistical analysis methods that can be used to systematically choose ideal combinations of codes for syndrome groups. At this time, the working group wanted to share the syndrome groupings so that other public health agencies can have access to the results of their deliberations regarding defined syndrome groupings.

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