

# REPORT OF THE COUNCIL ON SCIENCE AND PUBLIC HEALTH

CSAPH Report 1-I-19

Subject: Mandatory Reporting of Diseases and Conditions (Resolution 915-I-18)

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Referred to: Reference Committee K

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Resolution 915-I-18, introduced by the American College of Emergency Physicians and referred by the House of Delegates asks:

That our American Medical Association oppose mandated reporting of entire classes of patients and specific diagnoses unless compelling evidence exists to demonstrate that a serious public health and/or safety risk will be mitigated as a result of such reporting.

## METHODS

English language reports were selected from searches of the PubMed, Google Scholar, and Cochrane Library databases from January 2009 to August 2019 using the search terms: “mandatory reporting,” “nationally notifiable condition,” “electronic case reporting,” “public health surveillance,” “chronic disease registry,” “mandatory reporting” and “noncommunicable disease.” Additional articles were identified by manual review of the reference lists of pertinent publications. Web sites managed by federal agencies, applicable professional organizations, and foundations were also reviewed for relevant information.

## CURRENT AMA POLICY

The AMA has numerous policies calling for improved public health surveillance (e.g., antibiotic use and resistance, cannabis, Creutzfeldt-Jakob disease, firearm-related injuries and deaths, human immunodeficiency virus, infant mortality, lead poisoning, maternal mortality, new psychoactive substances, radon exposure, tobacco consumption, tuberculosis, vector-borne diseases, zoonotic diseases, etc). These policies do not address mandatory reporting or the burden of reporting on physicians. AMA policy also does not address the work underway to modernize public health surveillance and implement electronic case reporting (eCR) thereby removing the burden on physicians, labs, hospitals, and others required to report for the purposes of public health surveillance.

This report will define public health surveillance, explain the difference between mandatory reporting and nationally notifiable conditions, discuss the history of public health surveillance and its expansion beyond infectious diseases, and explain work underway to implement electronic case reporting (eCR) to both improve surveillance and alleviate the burden of reporting on those required to report. The Council on Science and Public Health recognizes public health surveillance is not without risks for individual participants and can pose ethical dilemmas. However, when conducted ethically, public health surveillance is justified for the common good to promote population health and reduce inequalities.<sup>1</sup> The ethical framework for conducting public health surveillance is outside the scope of this report.

## BACKGROUND

Public health surveillance is the ongoing systematic collection, analysis, interpretation and dissemination of health data for the planning, implementation and evaluation of public health action.<sup>2</sup> Public health surveillance is an essential public health function.<sup>3</sup> Surveillance data can be used to estimate the magnitude of health problems, determine the distribution of illness in a population, depict the natural history of a disease, generate hypotheses, stimulate research, evaluate control measures, monitor changes, and facilitate planning.<sup>4</sup>

Disease surveillance usually begins in the health care setting as public health agencies collect disease information from health care providers, facilities, and clinical laboratories required to report diseases and conditions to public health agencies.<sup>5</sup> In the United States, the authority to require notification of cases of diseases resides with the jurisdiction's state legislature.<sup>6</sup> As a result, the list of diseases and conditions that are reported varies by state.<sup>6</sup> In addition, the time frames for reporting, agencies receiving reports, persons required to report, and conditions under which reports are required also differ.<sup>6</sup> Traditionally, disease reports were made manually or by telephone, mail, or fax.<sup>5</sup> Reporters have indicated that manual submission of disease reports is time-consuming and disruptive to workflow.<sup>5</sup>

The Nationally Notifiable Disease List differs from mandatory reporting in that notifiable diseases are reported to the Centers for Disease Control and Prevention (CDC) on a voluntary basis by each jurisdiction. The Council of State and Territorial Epidemiologists works with the CDC to determine which conditions reported to local, state, and territorial public health departments are nationally notifiable.<sup>8</sup>

This Council on Science and Public Health report stems from the enactment of legislation in California in 2017 that requires the State Department of Public Health to collect data on the incidence of Parkinson's disease in California.<sup>8</sup> The legislation also requires a hospital, facility, physician and surgeon, or other health care provider diagnosing or providing treatment to Parkinson's disease patients to report each case of Parkinson's disease to the department, beginning July 1, 2018.<sup>8</sup>

## DISCUSSION

Historically, surveillance focused on infectious diseases, it then broadened to other topics, including chronic diseases (e.g., cancer and diabetes), occupational health, environmental health, hazard surveillance (toxic chemicals and physical and biological agents), and injury control (e.g., firearm-related injury).<sup>9</sup> It is expected that additional diseases and conditions will be explored in the future.<sup>9</sup> As state legislatures consider adding to their jurisdiction's list of diseases and conditions that are required to be reported to public health agencies, they should consult with state and national medical societies and public health agencies to ensure the requirements are based on scientific evidence and will meet the needs of population health.

### *Chronic Disease Surveillance*

Chronic diseases are conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both. Chronic diseases such as heart disease, cancer, and diabetes are the leading causes of death and disability in the United States and the leading drivers of health care costs.<sup>10</sup> The rise in chronic disease burden led to the development of chronic disease surveillance systems. In the 1970s, morbidity from select chronic diseases came under surveillance through disease registries.<sup>11</sup> In the 1980s and 1990s, CDC and state health agencies

collaboratively developed additional surveillance systems to monitor behavioral risk factors for chronic disease.<sup>11</sup> This led to the use of the Behavioral Risk Factor Surveillance System and the Youth Risk Behavioral Surveillance System to monitor health risk behaviors.<sup>11</sup> In 1992, Congress authorized the National Program of Cancer Registries at CDC to monitor local trends in cancer incidence and mortality with statewide, population-based cancer registries.<sup>11</sup> The benefits of public health surveillance on these conditions include determining incidence and survival rates, evaluating treatment efficacy, targeting educational and screening programs, and conducting research on etiology, diagnosis and treatment.

#### *Neurological Conditions Surveillance*

In 2016, as part of the 21st Century Cures Act, Congress authorized CDC to initiate development of a National Neurological Conditions Surveillance System to begin collecting and analyzing data on neurological disorders.<sup>20</sup> The CDC will begin by exploring and synthesizing data from existing sources to gain an increased understanding of multiple sclerosis and Parkinson's disease.<sup>20</sup> Once model approaches for surveillance are identified, the NCSS will be extended to other neurological conditions as resources allow.<sup>20</sup>

On the state level, Nebraska was the first jurisdiction to implement a Parkinson's disease registry. The law requires that physicians and pharmacists report individuals diagnosed with Parkinson's and patients taking anti-Parkinson's medications to the Nebraska Department of Health and Human Services Regulation and Licensure.<sup>12</sup> In 2015, Utah launched its Parkinson's Disease Registry to understand the apparent rise in the disease in the state and uncover causes of the disease. Effective March 12, 2015, the Utah State Board of Health began requiring health care providers to report cases of Parkinson's Disease and related movement disorders.<sup>13</sup> California was the third state to require reporting of Parkinson's Disease. Since July of 2018, 122,727 records have been submitted to the California Parkinson's Disease Registry.<sup>14</sup> These data will be used to: (1) determine the incidence and prevalence of Parkinson's disease in California; (2) examine disparities in Parkinson's disease risk; and (3) conduct demographic and epidemiological research and other studies of Parkinson's disease.<sup>15</sup> These provisions under the California law are set to expire in 2020, but legislation is currently being considered to extend the registry and reporting requirements beyond 2020.

#### **DIGITAL BRIDGE**

The Digital Bridge, funded by the Robert Wood Johnson Foundation and the de Beaumont Foundation, provides a forum for key decision-makers in health care, public health and health information technology (IT) committed to promoting bidirectional, or two-way, information exchange between the health care and public health sectors.<sup>16</sup> The Digital Bridge promotes the use of national health IT infrastructure to alleviate the administrative burden and costs of outdated, siloed data exchange practices.<sup>16</sup> Goals for the Digital Bridge include: (1) easing the burden and costs for all stakeholder groups through a unified approach to information exchange; (2) advancing greater standards-based information exchange across public health and health care; and (3) laying the foundation for greater bidirectional exchange of data so that clinicians can be more informed about population health, environmental risks and outbreaks.<sup>16</sup> The AMA is currently a member of the Governance Body for the Digital Bridge. Electronic case reporting (eCR) was the first use case for the Digital Bridge.

## *Electronic Case Reporting (eCR)*

With more than 80 percent of office-based physicians having adopted electronic health record (EHR) systems, it is not surprising the future of public health surveillance is eCR, a process by which reportable conditions are automatically generated from EHR systems to public health agencies for review and action, in accordance with applicable health care privacy and public health reporting laws<sup>17</sup> (see Figure). The advancement of eCR could lead to more accurate and timely case data for public health action resulting in improved detection of outbreaks, earlier identification of disease risk factors, and a decreased burden on mandatory reporters, including physicians.<sup>17</sup>

The electronic initial case report (eICR) would be identified in the EHR through a standard set of trigger codes that flag when a provider diagnoses a reportable condition based on International Classification of Diseases, Tenth Revision codes for diagnoses, LOINC (Logical Observation Identifiers Names and Codes) for laboratory testing orders, or SNOMED CT (Systematized Nomenclature of Medicine–Clinical Terms) for clinical information and laboratory results.<sup>16</sup> The Association of Public Health Laboratories, Council of State and Territorial Epidemiologists, and CDC have already vetted the reportable trigger codes for 5 conditions (e.g., gonorrhea, chlamydia, salmonella, pertussis, and Zika virus infections) and are in the process of identifying codes for all reportable conditions.<sup>17</sup>

After potential cases are identified through trigger codes, the eICR will automatically be generated with case information.<sup>17</sup> The eICR will contain a minimum set of data elements that have been established to be used for all conditions in all jurisdictions. The eICR will be transmitted from the EHR to an intermediary platform via secure, broadly used data transport mechanisms.<sup>16</sup> On these platforms, a software application will assess the reportability of the disease or condition via a logic model based on the jurisdiction's mandated reporting requirements and then will route adjudicated cases to the appropriate agencies.<sup>17</sup>

The Reportable Conditions Knowledge Management System (RCKMS) is a software application that will unpack, transform, and adjudicate the eICR automatically in a secure environment to determine whether the potential case meets minimal criteria consistent with mandated reporting based on a standard logic specific to jurisdictional requirements. RCKMS will transmit reportable cases to jurisdictions for final classification and action.<sup>17</sup> Health care providers will be informed when cases have been reported.<sup>16</sup> CDC has supported the Health Level 7 Consolidated Clinical Document Architecture as the initial structure for transmitting the eICR, based on standards that are already in use.

Houston was the first pilot site under the Digital Bridge initiative to successfully launch eCR. Partners involved in the Houston demonstration include Houston Health Department, Houston Methodist, and Epic Systems.<sup>18</sup> California, Kansas, Massachusetts, Michigan, New York, and Utah have also been selected as pilot sites.<sup>19</sup> The CDC recently identified Parkinson's disease for inclusion as a test case for the Digital Bridge. The Digital Bridge and CDC have committed to working with the California Department of Public Health to implement eCR across California health systems to collect data on Parkinson's disease cases seen by health care providers in a burden-free manner.

## CONCLUSION

Public health surveillance is an essential public health function and coordination between health care and public health agencies is essential for the monitoring, control, and prevention of disease. The AMA has numerous policies calling for improved public health surveillance on a wide range

of topics. A policy opposing mandatory reporting for specific conditions due the burden it places on physicians could jeopardize our understanding of disease occurrence and severity (e.g., cancer), as well as new causes, risk factors, and early identification of disease clusters. In addition to increases in disease incidence, reporting can also demonstrate the decline in disease among the population and help with the evaluation of prevention programs (e.g., vaccines).

To ensure that new diseases reporting requirements are based on the scientific evidence and will meet the needs of population health, the AMA encourages state legislatures to engage state and national medical specialty societies and public health agencies when proposing mandatory disease reporting requirements. The AMA should also support the modernization of public health surveillance systems and recognize the benefits of eCR in both improving public health surveillance through more accurate and timely data and alleviating the reporting burden on physicians.

## RECOMMENDATIONS

The Council recommends that the following recommendation for new policy be adopted in lieu of Resolution 915-I-18, and the remainder of the report be filed.

### Public Health Surveillance

That our AMA: (1) recognizes public health surveillance as a core public health function that is essential to inform decision making, identify underlying causes and etiologies, and respond to acute, chronic, and emerging health threats; (2) recognizes the important role that physicians play in public health surveillance through reporting diseases and conditions to public health authorities; (3) encourages state legislatures to engage relevant state and national medical specialty societies as well as public health agencies when proposing mandatory reporting requirements to ensure they are based on scientific evidence and meet the needs of population health; (4) recognizes the need for increased federal funding to modernize our nation's public health data systems to improve the quality and timeliness of data; (5) supports electronic case reporting, which alleviates the burden of case reporting on physicians through the automatic generation and transmission of case reports from electronic health records to public health agencies for review and action in accordance with applicable health care privacy and public health reporting laws; (6) will share updates with physicians and medical societies on public health surveillance and the progress made toward implementing electronic case reporting.  
(New HOD Policy)

Fiscal Note: less than \$1,000.

Figure



Source: The Digital Bridge

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