

Alternative Approaches to Public Health Surveillance of IDDM

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OBJECTIVE— To assess the appropriateness of national surveillance of IDDM.

RESEARCH DESIGN AND METHODS— We reviewed the structure and function of national disease surveillance, the diverse goals of IDDM surveillance, and prior experience with IDDM as a reportable disease.

RESULTS— Surveillance is the systematic and ongoing collection, analysis, interpretation, and dissemination of data linked to public health action. The potential goals of surveillance of IDDM are to understand the etiology and trends in incidence of IDDM, to measure the burden of IDDM and its complications, and to assess mortality. Problems associated with surveillance of IDDM include underreporting, delayed reporting, and lack of funding.

CONCLUSIONS— To make IDDM a nationally reportable disease is neither warranted nor feasible at this time. Although surveillance is needed to understand diabetes better and for diabetes control, proposed initiatives, such as major expansions of IDDM reporting, should be developed to address specific questions, problems, and needs—still recognizing real-world issues of competing priorities and limited resources.

In a commentary in *Diabetes Care*, LaPorte and Baba (1) proposed a disease prevention strategy using epidemiology and public health be developed to eradicate childhood diabetes. They said, "It is time that IDDM becomes a report-

able disease. . . . The Centers for Disease Control in the U.S. and the Ministry of Health in Japan should take on this responsibility."

Before the publication of this commentary, the CDC arranged a con-

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IDDM, INSULIN-DEPENDENT DIABETES MELLITUS; CDC, CENTERS FOR DISEASE CONTROL AND PREVENTION; NNDSS, NATIONAL NOTIFIABLE DISEASE SURVEILLANCE SYSTEM; CSTE, COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS; WHO, WORLD HEALTH ORGANIZATION; ADPH, ALABAMA DEPARTMENT OF PUBLIC HEALTH; HMO, HEALTH MAINTENANCE ORGANIZATION.

ference to: 1) review the history, process, and use of public health surveillance in the U.S.; 2) identify opportunities for intervention based on IDDM surveillance; 3) review prior experience with IDDM as a reportable disease; and 4) assess the appropriateness of national surveillance of IDDM.

The conference was convened on 31 January 1992. A document listing the participants and summarizing the presentations, discussions, and recommendations is available from the corresponding author.

OVERVIEW OF PUBLIC HEALTH SURVEILLANCE

Public health surveillance is an essential function of CDC in its mission as the lead federal agency for disease and injury prevention and control. We define surveillance as the systematic and ongoing collection, analysis, interpretation, and dissemination of data linked to public health action (2). Its functions include measuring disease burden, defining public health priorities, formulating and evaluating public health programs, and conducting research.

The NNDSS is one of the many surveillance systems used by CDC (3). Reports of 45 diseases or conditions are sent by physicians, laboratories, and hospitals through state (and a few large city and territorial) epidemiologists to CDC. Completeness of reporting varies by disease and reporting site from 6% (aseptic meningitis) to 95% (gonorrhea). Completeness usually is relatively constant over time (4).

Recent developments in NNDSS include adoption of standardized data elements (5), publication of uniform case definitions with clinical and laboratory criteria (6), and reporting through the National Electronic Telecommunications System for Surveillance (7). The attributes of NNDSS are confidentiality (patient identifiers are kept by the states) and timeliness (5 days between reporting to CDC and publication and wide dissemination through the *Morbidity and Mortality Weekly Report*).

CSTE determines the list of diseases reported through NNDSS (3). The two major factors considered in making a disease or health problem reportable through NNDSS are actual or potential disease burden and preventability, i.e., the existence of practical proven-effective public health interventions. CSTE's recommendations are not binding on states. Although legislation mandates reporting to state health departments, reporting to CDC is voluntary. Experience has shown that surveillance works best when local interest is high and disease control activities are clearly defined and adequately funded.

GOALS OF IDDM SURVEILLANCE

— The potential goals of public health surveillance of IDDM are: 1) to understand the etiology, risk factors, and natural history of IDDM, and to track temporal trends in disease incidence; 2) to measure the burden of IDDM and its complications; and 3) to assess the extent of and reasons for premature mortality. Ultimately, these goals must be linked with proven-effective interventions to prevent IDDM and reduce its complications and premature mortality.

These goals have implications regarding the nature, scope, and cost of a national surveillance system. No single system can address all of these goals adequately. To initiate etiological studies and track temporal trends in disease incidence, incidence registries are required. To measure the burden of IDDM and its complications, prevalent cases with IDDM must be identified and monitored. Measuring mortality requires the linking of prevalent cases and mortality data. The more precisely the particular goal is defined, the more feasible the creation of an appropriate surveillance system is.

PRIOR EXPERIENCE WITH IDDM AS A REPORTABLE DISEASE

— The WHO-sponsored DIAMOND Project already has established 119 childhood IDDM registries in 65 coun-

tries, modeled on the long-standing registry in Allegheny County, PA (8). A total of 220 million children are under surveillance (7% of all children worldwide). These registries have resulted in increased understanding of IDDM and the potential to identify possible etiological factors.

In 1978, the Alabama State Board of Health added IDDM to its list of reportable diseases (Wells SJ, Roseman JM, unpublished observations, see ACKNOWLEDGMENTS). The purpose of Alabama's incidence registry was to address issues related to the epidemiology of IDDM and public health. Initially, the ADPH was reluctant to assume the additional work associated with making IDDM a reportable disease, but did so after the University of Alabama at Birmingham agreed to collect the reports. Later reporting was done directly to ADPH. Publicity for the registry consisted of a press release, a letter to physicians, and a journal article. Initially, a survey of a 10% sample of state physicians indicated 21% were aware of the reporting requirement (28% of pediatricians). After a second letter was sent to physicians, 38% were aware (92% of pediatricians). Most reporting came from hospitals (Wells SJ, Roseman JM, unpublished observations).

A major problem with the registry was that completeness of reporting was never established. As a result, funding agencies were not willing to sponsor studies based on the registry. At the same time, those agencies were not interested in funding the validation process. Other problems with the registry involved sample size and selection of appropriate controls for epidemiological studies. Some were concerned about the possible stigma associated with making IDDM a reportable disease like syphilis or gonorrhea.

CONCLUSIONS: THE APPROPRIATENESS OF NATIONAL SURVEILLANCE OF IDDM

— Diabetes surveillance is needed to understand the etiology, risk

factors, and natural history of the disease better; to track temporal trends in disease incidence; to measure the burden of diabetes and its complications; to assess diabetes-related mortality; to target high-risk populations; and to design and evaluate interventions (10,11). The present model developed for diabetes control at CDC incorporates surveillance in the planning, targeting, and evaluation of complication-specific interventions.

The international network of IDDM registries has begun to clarify the epidemiology of this disease and is providing important leads for research and prevention activities. Because of the strong familial distribution of IDDM, etiological studies assessing both genetic and environmental risk factors appear most promising. Such etiological investigations are done best in populations with interested and committed epidemiological, clinical, and laboratory investigators, such as the Allegheny County IDDM registry. National surveillance of IDDM would add little to this effort.

Because interventions for the primary prevention of IDDM are not yet clinically validated, no public health action can be taken in response to reported cases. In addition, a national IDDM incidence registry without rigorous validation of completeness and accuracy would result in multiple apparent clusters arising by chance alone and numerous pseudoepidemics of reporting, the investigation of which would deplete resources (12). Funding and staff resources for public health-based diabetes programs already are insufficient for more immediate needs, such as assuring basic preventive care for underserved populations with diabetes. Therefore, the development of a national incidence registry is neither warranted nor feasible at this time.

Although the tracking of all patients with IDDM (prevalence registry) is feasible in defined populations, the NNDSS is not well suited to this purpose, because it does not maintain personal identifiers. The systematic use of

practice-based tracking systems clearly is more efficient and consistent with the existing health-care delivery system. Large HMOs and state-based medical payment systems may provide additional opportunities for IDDM reporting. Of patients with IDDM, ~80% are cared for by general practitioners and family physicians, and practicing physicians (as opposed to sentinel physicians, hospitals, and laboratories) often are the weakest link in disease reporting.

When prevalence registries are established, mortality studies become feasible by searching for prevalent cases among descendants included in data systems such as the National Death Index (13). Unfortunately, difficulties may remain in identifying prevalent cases and defining appropriate comparison groups to assess risk factors for premature mortality.

Further evaluation of existing IDDM registries and clarification of what might be achieved by developing expanded or new systems are appropriate. We need to explore potential sources of data for both IDDM and NIDDM surveillance, which would benefit from better collaboration among voluntary agencies, universities, federal, state, and local health departments, health-care providers, and payers. The process of achieving consensus may be difficult and time consuming but is necessary to insure an appropriate and useful surveillance system.

Proposed initiatives, such as major expansions of IDDM reporting, should address specific questions, problems, and needs, while recognizing real-world issues of competing priorities and limited resources. The first requirements are to specify clearly and precisely the

questions, the appropriate surveillance systems, and the specific public health actions that would be taken.

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The unpublished manuscript by Wells and Roseman, "The First U.S. Diabetes Registry Based on Legally Mandated Physician Reporting: A Case Report," can be obtained from Dr. Jeffrey Roseman, University of Alabama at Birmingham, School of Public Health, University Station, Birmingham, Alabama 35294-0008.

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