

July 25, 2016

VIA E-MAIL & FIRST CLASS MAIL

Bridget Bagley
Department of Health and Human Services
Maine Center for Disease Control and Prevention
11 State House Station
Augusta, ME 04333-0011

**RE: Comments on Data Release Rule, 10-144 CMR, Ch. 175 by the
Portland Press Herald / Maine Sunday Telegram**

Dear Ms. Bagley:

The Portland Press Herald / Maine Sunday Telegram respectfully urges the Department not to proceed with the proposed Data Release Rule. As the Fact Sheet accompanying the rule makes clear, it would make certain public health data secret by “expand[ing] definitions to address privacy protections.”

The Press Herald opposes the proposed Data Release Rule for two primary reasons. First, public health data should be made public to the maximum extent possible, so long as no specific individual is identified. Second, the proposed rule is in conflict with state law, which requires that the Department provide public access to data that does not identify any individual. Under the proposed rule, information that does not identify any individual would become secret. If changes are to be made to the public’s right of access to Department records and information, the appropriate body to do so is the Maine Legislature.

The Press Herald published a story on the proposed Data Release Rule under the headline “Maine CDC Wants to Limit What You can Know About Disease Outbreaks,” attached as Exhibit A. The public comments on the story show that the general public does not support the proposed rule. The Press Herald also published an editorial, “Maine CDC Should Share not Squelch, Disease Data,” attached as Exhibit B.

I. About the Portland Press Herald / Maine Sunday Telegram

The Press Herald, part of Maine’s largest newsgathering organization, regularly covers Mainers’ public health, including the incidence and location of

infectious disease outbreaks, vaccination rates, public health policy and legislation. Last year, the Press Herald published a series of news stories on Maine's relatively low rate of vaccination against infectious diseases. It has also covered infectious disease outbreaks in Maine and investigated the linkage between these outbreaks and vaccination rates. All of this reporting relied upon access to public health data obtained from the Department.

II. Prior Litigation Regarding Access to Locations of Disease Outbreaks

The Press Herald filed an appeal in Cumberland County Superior Court last year from the Department's denial of a request for information concerning recent infectious disease outbreaks in Maine schools. *Portland Press Herald v. Maine Dept. of Health and Human Svcs.*, Docket No. CV-2015-323. That appeal was settled in October 2015 by the Department's release of the names of the schools that had suffered outbreaks (Exhibit C, attached). The proposed rule would make secret the same information the Press Herald requested and received last year, but without any corresponding change in state statutes.

III. State Law on Access to Medical and Epidemiologic Information

The statute governing public access to Department records distinguishes between "records that contain personally identifying medical information," which are confidential under 22 M.R.S. § 42(5), and records that contain "medical and epidemiologic information in such a manner that an individual can not [sic] be identified," which are not confidential. *Id.* Because records containing non-identifying medical and epidemiologic information are not made confidential by statute, those records are "public records" for purposes of the Freedom of Access Act, 1 M.R.S. §§ 401 *et seq.* They must be made available for public inspection and copying as required by the Act. 1 M.R.S. § 408-A.

The Freedom of Access Act provides that public records cannot be made confidential by rule. 1 M.R.S. § 402(3)(A). The Act excludes from the definition of "public records" those "[r]ecords that have been designated confidential by statute[.]" *Id.* A rule is not a statute; the Act contains no language authorizing state agencies to make public records confidential by rule. To the extent the Data Release Rule extends confidentiality beyond the scope of the relevant statute, which the Press Herald believes it does, the rule is unlawful.

IV. Section-by-Section Comments on Proposed Data Release Rule

The Press Herald offers the following section-by-section comments on the proposed Data Release Rule:

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Introduction – Section 1. The statement of intent in the introduction to the rule is slanted in favor of too much secrecy.

The introduction is borrowed from portions of the Model State Public Health Privacy Act. But the Model Act makes clear that confidentiality should be limited only to personally identifiable health-related information, i.e., information which describes a particular individual’s personal medical or health information. According to the Model Act, “Individual interests in the privacy of health-related information are significantly reduced when the information is acquired, used, disclosed, or stored in non-identifiable forms.” In contrast to the proposed rule, which focuses on privacy, the Model Act is meant to “[e]ncourage wide use and disclosure of non-identifiable health information because this information does not implicate privacy and security concerns at the individual level and may greatly facilitate the accomplishment of legitimate public health purposes[.]”

The Maine CDC’s Privacy Policy (Aug. 9, 2012), which would be superseded by the proposed rule, also recognizes of the importance of public disclosure of non-identifiable health related data. According to the policy:

Despite risks associated with inappropriate data release, Maine CDC data are vitally important to maintaining the health of all people, and have wide and varied uses both within State government and in the larger public health community. Therefore, Maine CDC programs must make data available and accessible to the broadest possible constituency, while at the same time maintaining strict standards to protect individual privacy.

In a public statement issued last year the Maine CDC also emphasized “the importance of sharing information when it benefits public health,” noting that it has a “long history of providing information when members of the public can take action to improve their health or prevent harm.”

Definitions – Section 2. The definition of “Indirect identification” makes confidential a great deal more information than is necessary to avoid identifying particular individuals. The portion of the proposed rule addressing “geographic areas or organizations within the State” is not readily understandable and should be clarified, but appears to mean that:

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a) if the entire population in a school, town, or organization is less than 2,000, and the number of infected individuals is less than 6 people *or* all of the population of the school, town, etc. have a disease except less than 6 people; or

b) the entire population of the school, town, or organization is less than 50, regardless of how many people are reported to be infected or have the disease,

then the data are confidential. The rule makes data confidential under circumstances where an individual cannot be identified. For example, if 5 people out of a population of 1,000 have a disease, that would merely disclose that 0.5% of a population have the disease, which does not disclose anyone's identity. But under the proposed rule, this information would be secret. The definition of "indirect identification" goes too far, particularly in a small state like Maine.

In Maine, towns, schools, and organizations typically have fewer than 2,000 people, so the rule would effectively defeat the public's right to know about many disease outbreaks. No high school in Maine has more than 2,000 students – the largest school (Lewiston High School) has about 1,500 students – and most Maine schools are much smaller. Under the proposed rule, disease outbreaks at Maine schools would be kept secret from the public, including most of the information the Department disclosed to the Press Herald last summer.

The definition of "indirect identification" is also contrary to 22 M.R.S. § 42(5). As mentioned above, that statute provides public access to records containing medical and epidemiologic information in such a manner that an individual cannot be identified. Because "indirect identification" is defined in the Data Release Rule very broadly to include data that does not and cannot identify any individual, it creates far more secrecy than is allowed by statute.

Data Release – Section 3. The proposed rule states at Section 3(A) that the Department will not be obligated "to provide the data in the form requested." This limitation on access to records conflicts with the Freedom of Access Act. The Act requires that an agency or official having custody of any electronically stored public record must make the record available as a printed document or "in the medium in which the record is stored, at the requester's option." 1 M.R.S. § 408-A(7). The Department cannot lawfully exempt itself from the requirement, applicable to all other custodians of public records, that records be made available in the format specified by the requester.

V. Public Access to Public Health Data Serves the Common Good.

The Press Herald has interviewed many experts in the field who all say that state policy should provide as much health data as possible. “Public health officials should strive to release as much information as possible, within the limits of the law. Withhold information only when there is a clearly justified reason to keep it confidential,” according to the joint statement by the National Association of County and City Health Officials, the Association of State and Territorial Health Officials, and the Association of Health Care Journalists. The Data Release Rule is not good policy, because non-identifying public health information services important public interests.

Public health information allows the public to protect itself from harm. Members of the public can avoid locations where disease outbreaks have occurred only if those locations are known. Such information is particularly important for immune-compromised individuals or others who are at special risk if they come into contact with an infected population. If an outbreak is known, members of the public also can be on guard to identify new cases, which can lead to prompt treatment and stop the spread of disease.

Public health data fosters an informed and educated public on questions of public health policy. Among its functions, the Department assesses public health problems, takes steps to protect public health, and seeks funding for its public health related programs and initiatives. Public health data allows the public to assess the efficacy of public health policy and the performance of health agencies and officials. Without public health data, the public cannot know if the population is healthy, whether policies are working effectively, and what changes – including changes in levels of funding – may be warranted. As noted above, the Press Herald has repeatedly relied on public health data from the Department to inform the public on important public health issues, including disease outbreaks and vaccinations.

Public health data are used by health care providers and researchers in ways that serve the common good. Epidemiologic investigators and researchers rely on public health data to study and help solve public health problems. Health care providers need information to prepare for and respond to outbreaks.

Informing the public about infectious disease outbreaks is a recognized best practice for public health agencies. According to the American Public Health Association:¹

¹ Communicable Diseases Manual (20th ed. 2015) at A9 - A10.

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Regular communications about the outbreak and risk of infection is one of the most important parts of an outbreak response and serves to reassure the population that a response is underway, avoid undue panic or concern, create an environment where additional cases can be identified, and help individuals and communities understand how transmission can be stopped. Time spent explaining the evidence and control measures with responsible journalists – whether they are from newspaper, radio, television, or other outlets – will facilitate the outbreak response by creating an environment of understanding. Regular simple information (outbreak facts such as case numbers, case definition, studies underway, and suspected incubation period) should be provided at intervals.

The proposed rule would stymie such communications or make them subject to ad hoc determinations by the agency.

Finally, individual privacy interests, such as a specific person's health or medical condition, are not threatened by the disclosure of non-identifiable data. Identifiable information such as names, social security numbers, dates of birth or the like can be maintained as confidential in order to protect reasonable individual privacy interests. On the other hand, aggregate statistical data on a population does not reasonably implicate personal privacy interests.

VI. Conclusion

The Press Herald appreciates the opportunity to comment on the proposed Data Release Rule and urges the Department to change course and ensure maximum possible public access to non-identifiable public health data.

Very truly yours,

/s/ Sigmund D. Schutz

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SDS:jac

Enclosures

cc: Cliff Schectman, Executive Editor (*via email*)
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