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TO: The Honorable Deb Patterson, Chair
The Honorable Senator Tim Knopp, Vice-Chair
Senate Committee on Health Care

FROM: Collette Young, PhD, Administrator
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SUBJECT: Senate Bill 719

Chair Patterson, Vice-Chair Knopp, and members of the committee; I am Collette Young, Administrator for the Center for Public Health Practice at the Oregon Health Authority's Public Health Division. This written testimony provides information on the potential impact of Senate Bill 719 on disease investigation and public information.

Oregon Revised Statute 433.008 protects the confidentiality and related sources for information obtained in the course of investigating reportable diseases and related outbreaks. ORS 433.008 allows OHA to release information in specific situations to protect health and to publish statistical compilations. Senate Bill 719 would broadly specify that *any* aggregate data from our investigations are not confidential and would be open to requests under Oregon's public records act.

During an investigation of an outbreak, many statistical compilations and data aggregates are produced as hypotheses arise and are subsequently discarded. For example, in one outbreak of *E. coli* O157 infection, we suspected association with hummus. Our epidemiologists identified four out of five cases that reported eating hummus, which demonstrated a significant statistical difference compared to background rates of hummus consumption. A sixth case was identified, and that person purchased tahini, which is a main ingredient in hummus, so we were naturally suspicious. However, all six cases had also eaten spinach, which is a known vehicle for some previous O157 outbreaks. Therefore, we held off on naming a food vehicle, and ultimately, food tracebacks proved that spinach was the actual culprit.

Had we been required to release our statistical compilations prematurely, they would have incorrectly impugned the hummus. Investigations into such outbreaks routinely

produce statistical compilations of several “most likely” suspects before we hone in on the actual cause. Moreover, a requirement to respond to a public records request for data in such situations would derail the epidemiologist who was collecting and analyzing the data, slowing the investigation, and delaying the outbreak solution.

Furthermore, the release of “aggregate” data from numerically small populations could lead to the identification of individuals. For example, “two Asian males >X years old in Y County contracted Disease Z,” may readily be used to identify individuals. Naming the reportable disease causing a death in a person of a specific age, such as an infant in a small county, would effectively tell what the infant died of to those who know of the death. Correlating relatively uncommon demographic features with diseases, even in aggregate, can betray protected health information.

In accordance with ORS 433.008, we currently publish weekly summaries of our reportable disease data with safeguards for small numbers, and we have recently developed an extensive suite of data “dashboards,” which allow users interaction with the data on a near-real-time basis. We believe that these are useful and are open to suggestions for extending or otherwise improving them to help meet the transparency goals of Senate Bill 719.

Thank you for the opportunity to testify. I’d be happy to take any questions.