

Starter Language for the Data Sharing for Public Health Action Act

Last updated: December 2, 2024

Purpose: This document contains initial “starter” language for proposed legislation to streamline and improve DOH’s ability to share data.

Audience: DOH’s internal and external public health partners involved in the bill development process.

Bill Language	Subsection Goals
<p data-bbox="107 402 701 427">Data Sharing for Public Health Action</p> <p data-bbox="107 464 1241 578">An act relating to public health data sharing; amending RCW 43.70.057, 43.70.052, 70.225.040, 70.58A.005, 70.58A.010, 70.58A.020, 70.58A.040, 70.58A.520, 70.58A.540, [list of RCWs]; adding a new section to chapter 43.70 RCW; and repealing RCW 42.56.365.</p> <p data-bbox="107 618 1062 643">BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF WASHINGTON:</p> <p data-bbox="107 678 1226 732">NEW SECTION Sec.11 A new section is added to chapter 43.70 RCW to read as follows:</p> <ul data-bbox="163 769 1241 1369" style="list-style-type: none"><li data-bbox="163 769 1241 1003">(1) The legislature finds that providing access to public health data for public health purposes is a service of the department and that timely access and use of public health data is critical to developing timely and effective public health interventions. Therefore, the legislature intends that the department must modernize its data sharing practices to enable a data-driven public health system in Washington and for the benefit of Washington communities.<li data-bbox="163 1105 1241 1369">(2) The department may grant public health authorities access to confidential public health data without a written agreement. Notwithstanding any Federal law, or law of Washington State to the contrary, any public health authority accessing public health data in such a way must:<ul data-bbox="260 1252 1241 1369" style="list-style-type: none"><li data-bbox="260 1252 1241 1305">(a) Use the data only for public health purposes as defined in this section; and<li data-bbox="260 1312 1241 1369">(b) Comply with department policies and standards established under subsection (3) of this section.	<p data-bbox="1287 792 1976 979">Subsection (1) is intended to very broadly outline the intent of the new section and establish DOH’s responsibility to responsibly share data with its partners. It gestures towards goals that are elaborated on later, namely data sharing process reforms, enshrining partners’ data access rights, and establishing a new data governance framework.</p> <p data-bbox="1287 1117 1976 1336">Subsection (2) firmly establishes DOH’s ability to share data with PHAs and grants the agency more administrative flexibility in approving data sharing with established governmental partners. The intent of this is to streamline individual instances of data sharing with established partners by creating a way by which DSAs can be bypassed with mutual agreement.</p>

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<p>(3) The department must define and maintain policies or standards for data accessed under subsection (2) of this section. Such policies or standards:</p> <ul style="list-style-type: none"> (a) Must include relevant requirements from those established by Washington technology solutions in accordance with chapter 43.105.054 RCW; (b) Must consider national and industry best practices; (c) Must define the means of data access, set requirements for the protection of privacy, security, and confidentiality, and other items as deemed appropriate by the department; (d) Must be distributed to the recipient of data under subsections (2) or (4) of this section prior to granting data access; and (e) Only apply to the data recipient when data is shared in accordance with subsection (2) or (4) of this section. <p>(4) In the event of an emergent public health threat, public health emergency, or natural disaster, the department may waive the requirement for a written data sharing agreement and make confidential public health data available to public health authorities responding to the threat. The department may disclose only the minimum amount of information necessary, to the fewest number of people, for the least amount of time required.</p> <p>(5) Confidential public health data may be shared with a government agency in support of their official duties except where otherwise prohibited by Federal or State law, or with any recipient when deemed by the department to be in the public's interest, and not for the purpose of commercial or private gain. For processing such a request, the department must:</p> <ul style="list-style-type: none"> (a) Establish a standardized data sharing framework that outlines the processes and protocols for data exchange designed to minimize administrative burden and enable efficiency in data sharing. (b) Centrally track all open requests for data not subject to public disclosure under chapter 42.56 RCW; (c) Respond to the request within 60 days; and (d) If providing data in response to the request, make every effort to complete any written agreement as required by chapters 39.34.240 or 39.26.340 RCW and share the data within 120 days of responding to the request. 	<p>Subsection (3) establishes DOH's responsibility to concretely define their data sharing policies and standards that apply to data accessed without a DSA, as well as keep its data sharing practices in line with statewide standards and best practices.</p> <p>Subsection (4) addresses one of the main goals of the bill: to give DOH more flexibility to streamline data sharing during emergent public health crises. Modeled after the statute governing RHINO data, it allows DOH to temporarily waive written agreements under certain circumstances. This is intended to prevent lengthy administrative processes from hindering timely public health responses during emergency situations.</p> <p>Subsection (5) outlines another of the bill's main goals: reforms to DOH's process for responding to data requests. It lays out time requirements for responding to requests and adds the responsibility to centrally track data requests for process monitoring and improvement.</p>

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<p>(6) Requests for data for human subjects research, as research is defined 45 CFR 46, requires approval of an institutional review board. The department shall work with researchers to identify a single Institutional Review Board to review the project. The Department may accept the findings of institutional review boards managed by the State, academic institutions, or other research organizations. Requests for data for research where no individual is reasonably identifiable do not require approval of an institutional review board. No use of public health data for public health purposes by a public health authority, as those terms are defined in this section, may be considered research.</p>	<p>Subsection (6) is intended to streamline data sharing for research purposes by allowing IRBs other than the State IRB, such as the IRBs of academic institutions or other research organizations, to review projects. This is in line with national standards (as of 2024). This section also protects data access for PHAs conducting official public health actions by clearly delineating the definitions of research and public health activities conducted by PHAs as part of their mandated responsibilities.</p>
<p>(7) Denials of requests for data must be made in writing. The department may deny a request for data for reasons including, but not limited to:</p> <ul style="list-style-type: none"> (a) The data requested does not fit the purpose described in the request; (b) The proposal lacks scientific merit, would not produce actionable information of potential public benefit, or recreates well established facts; (c) The request would result in an unreasonable use of resources related to data preparation and analysis; (d) The requestor cannot meet the requirements for protecting the confidentiality of the data; or (e) The requestor is out of compliance with an existing written agreement or a policy required by this section. 	<p>Subsection (7) lays out circumstances under which DOH can deny data requests and is intended to allow the agency to ensure data privacy even as data sharing becomes more streamlined.</p>
<p>(8) Notwithstanding any other Federal or State law to the contrary, or subsection (7) (d) or (7)(e) of this section, the department may not deny a public health authority operating within Washington State access to public health data concerning individuals or events within that authority's geographic jurisdiction when the data is requested for public health purposes for which the requesting authority is legally responsible. The department must provide such data in accordance with a method defined in this section, unless otherwise prescribed or allowed for by federal or state law.</p>	<p>While previous sections outlined DOH's right to share data with PHAs and local partners, Subsection (8) enshrines PHAs' right to access data concerning their own constituents when that data is necessary for the PHA to conduct public health activities that they are legally responsible for.</p>

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<p>(9) Notwithstanding any Federal law, or law of Washington State to the contrary, the restrictions in this subsection apply to any public health data accessed or obtained through any method described in this section;</p> <p>(a) No recipient of data that does not contain direct identifiers or otherwise contain personal information as defined in this section may attempt to reidentify individuals</p> <p>(b) No recipient of public health data concerning the care or treatment of individuals may use or provide access to the data for any civil or criminal action unless otherwise required by Federal law, or allowed for in the laws of Washington State; or</p> <p>(c) No recipient of confidential public health data collected under chapter 70.58A RCW may:</p> <p>(i) Redistribute confidential data without the department's written consent;</p> <p>(ii) Use birth or fetal death record data to attempt to contact individuals or their families without the department's written consent, except by a public health authority when clearly required for a public health purpose as those terms are defined in this section.</p> <p>(10) The department must balance privacy protections with the public's need to remain informed of threats to the health of Washington communities. At the same time, the legislature finds that advancements in technology create new and evolving risks to personal information and privacy. Balancing these needs requires a flexible, risk-based approach to privacy protection.</p> <p>(a) The department must develop de-identification policies or standards for public health data. The department must consider utility of the data and health equity so that de-identified data which is made public can be used by Washington communities in their health planning. These policies or standards must be updated as needed to maintain privacy protections in an evolving threat landscape.</p> <p>(b) Data elements that are determined to be direct or indirect identifiers for any public health data can only be identified in RCW or in agency policies or standards and not in rule.</p>	<p>Subsection (9) intends to further enshrine privacy protections against reidentification by any methods not involving direct identifiers, prohibiting use of data in civil or criminal cases except as allowed in Washington law, and dataset specific protections, like prohibiting data recipients from contacting people using birth or fetal death records.</p> <p>Subsection (10) serves multiple purposes. While further emphasizing the need for privacy protections, it also explicitly calls attention to the tension between the need for privacy protections and the responsibility to inform the public. While other subsections also establish DOH's responsibility to inform, this language makes clear that the two responsibilities are both high-priority and must be balanced.</p> <p>This also replaces the practice of prescribing specific privacy protections directly in statute (such as directly listing direct and indirect identifiers) with a standards-based framework that can more flexibly adapt to privacy threats and best practices.</p>

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<p>(11) The legislature intends that the department take steps to better inform the public and to promote transparency in health and public health related issues within the State by making aggregate data, such as summary statistics, as well as datasets that meet the department's standards for de-identification, available to the public through its website or State open data portal. The department must define policies, processes, or procedures to promote this goal.</p> <p>(12) The department, its officers, or employees are not liable, nor shall a cause of action exist, for any loss or damage based upon the release of public health data if the department, its officers, or employees acted in good faith in attempting to comply with the provisions of this section or those of chapter 42.56 RCW.</p> <p>(13) Nothing in this section may be construed to:</p> <ul style="list-style-type: none"> (a) Prevent the department or those requesting data from it from entering into a written agreement with alternative terms or data uses; (b) Give authority to the department or data recipients to sell or provide access to lists of individuals when requested for commercial purposes; or (c) Transfer ownership of data. <p>(14) For the purposes of this section:</p> <ul style="list-style-type: none"> (a) "Direct identifier" is data that is unique to an individual and unambiguously identifies them. (b) "Indirect identifier" is a data element, such as uncommon race, ethnicity, extreme age, or unusual occupation, that is not unique to an individual. No single data element may be considered an indirect identifier on its own and is only an indirect identifier if it can reasonably be combined with other information to pose a reasonable risk of being used to identify an individual. (c) "Personal information" means: <ul style="list-style-type: none"> (i) The same as "personal information" as defined in chapter 42.56.590 RCW; 	<p>Subsection (11) establishes DOH's open data mandate, outlining their responsibility to proactively make data that does not pose a significant privacy risk available to the public.</p> <p>Subsection (12) is intended to protect DOH and its employees from liability for good-faith data sharing.</p> <p>Subsection (13) establishes that none of the tools outlined to streamline data sharing are intended to strip away protections and that traditional DSAs can still be implemented in any circumstances if it is deemed appropriate. This section will be used to place limits on interpretation as needed.</p> <p>Subsection (14) establishes standardized definitions of terms used throughout the bill, especially for those that have historically had unaligned definitions across multiple statutes or have been ambiguous.</p>

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<p>(ii) Information that identifies or is reasonably capable of being associated or linked, directly or indirectly, with a particular person; and</p> <p>(iii) "Personal information" does not include publicly available information which has legally or voluntarily been made public.</p> <p>(d) "Privacy" means the same as described in chapter 42.56.050 RCW.</p> <p>(e) "Public health authority" refers to an agency or authority of the United States government, a State, a territory, a political subdivision of a State or territory, or federally recognized tribe that is responsible for public health matters as part of its official mandate, as well as a person or entity acting under a grant of authority from, or under a contract with, a public health agency.</p> <p>(f) "Public health data" or "data" means data about human and animal health, health systems, the environment, and events that impact public health that is collected, created, or used by a public health authority to serve a public health purpose.</p> <p>(g) "Public health purpose" means activities conducted by public health authorities that are aimed at preventing or controlling disease, premature mortality, injury, or disability, or promoting health and a healthy environment. This can include the reporting of diseases or injuries, monitoring vital events such as births and deaths, monitoring for potentially harmful environmental conditions, and conducting public health surveillance, investigations, interventions, or epidemiological research or developing and evaluating public health policy. These activities are essential for identifying and mitigating health threats to the public.</p> <p>(h) "Public health surveillance" means the ongoing, systematic collection, analysis, and interpretation of health data, essential to the planning, implementation and evaluation of public health practice, closely integrated with the dissemination of these data to those who need to know and linked to prevention and control. Public health surveillance activities, including the collection and analysis of identifiable health data, are not considered research. These activities are conducted to monitor, assess, or investigate potential public health signals,</p>	

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disease outbreaks, or conditions of public health importance, and do not require the same approvals as research activities.	