



DOH and Data:

Collection, Storage, Management and Governance

April 27, 2022

What data does Department of Health (DOH) collect and store?

Disease Surveillance

DOH collects a variety of data to assess and track diseases among people in Washington. We call this disease surveillance data. The data include the rates of infectious diseases such as COVID-19, tuberculosis, influenza, sexually transmitted infections and other [notifiable conditions](#), which are required to be reported to local health jurisdictions.

DOH also collects information from a variety of other data sources that are not specific to a single disease. These data sources include:

- [Vital statistics](#) like birth and death reports
- Hospital discharge data ([CHARS](#))
- Emergency department and other healthcare encounter data ([RHINO](#))
- Emergency medical services ([WEMSIS](#) and [Trauma Registry](#))

DOH uses these data sources to explore a variety of diseases and health-related issues including:

- Injuries
- Overdoses
- Chronic conditions (e.g., diabetes, heart disease)
- Maternal and child health concerns (e.g., low birthweight, preterm delivery, infant and maternal morbidity and mortality)
- Environmental issues (e.g., wildfire smoke exposures, pesticide exposures, childhood lead poisoning, legionella, extreme weather event-related emergency department visits and hospitalizations)
- Communicable diseases (e.g., foodborne illnesses, hepatitis)
- Mental health concerns
- Emerging public health threats (e.g., new disease outbreaks like foodborne outbreaks, respiratory infections, and vapor-associated lung injury)

Other data systems allow DOH to track:

- [Cancer illness and deaths](#)
- [Maternal mortality](#)
- [Violent deaths](#)
- Prescriptions of controlled substances ([PMP](#))

Surveys

DOH collects health behavior data through surveys. Three key surveys with ongoing data collection include the:

- Behavioral Risk Factor Surveillance System ([BRFSS](#))
- Healthy Youth Survey ([HYS](#))
- Pregnancy Risk Assessment Monitoring System ([PRAMS](#)).

DOH also conducts ad hoc and periodic surveys, including the [Smile Survey](#) of youth oral health.

Health Care and other Service Delivery

DOH collects a variety of data related to the provision of health care and other services. These include:

- [Newborn screening data](#) to detect treatable rare conditions at birth
- [Newborn hearing screening data](#)
- [Immunization data](#)
- [Breast, cervical and colorectal cancer screening data](#)
- [Women, Infants and Children \(WIC\) nutrition data](#)
- Home Visiting – Department of Children, Youth and Families (DCYF) oversees collection of this data and DOH helps process and report data to clinical partners with agreements
- Intake data for children and youth with special health needs
- AIDS drug assistance program
- Universal developmental screening
- [Death with dignity](#)
- [Abortion and pregnancy data](#)
- [Sexual and reproductive health program data](#)
- [Medical marijuana authorization data](#)
- Childhood lead risk and exposure data
- Pesticide illness data

Licensing, Regulating, and Monitoring

- DOH licenses [health care providers and facilities](#) and collects information
- DOH regulates [drinking water](#), [shellfish growing areas](#), and [commercial shellfish licensing and certification](#)
- DOH inspects [x-ray machines](#)

Other data

DOH also uses and interprets data that other agencies collect, and in some situations combines this data with DOH data to add meaning. For example, DOH uses disease data from hospitalizations or deaths in combination with population estimates provided by the Office of Financial Management in order to calculate disease rates. While DOH does not provide oversight regarding these data, interpretation of these data will also be governed by the Tribal Data Sharing Agreement:

- [Washington Poison Center](#)
- [All Payer Claims Data](#)
- [Clinical Data Repository](#)
- Urban Indian Health Institute Needs Assessment on colorectal cancer screening
- [US Census/American Community Survey](#)
- [Washington State Population Estimates](#)
- [Tribal Lands of Washington – Dept. of Ecology](#)
- Map layers and reference maps of schools, commercial businesses, health care facilities, etc.

What DOH data includes race and ethnicity?

All or almost all DOH disease surveillance systems collect race and ethnicity, including whether someone identifies as American Indian or Alaska Native in response to a question on racial identity. Most, but not all, DOH data systems that collect this information allow individuals to select multiple races. Ethnicity is usually collected using a separate question.

What DOH data includes Tribal affiliation or membership?

DOH collects residence on a Tribal reservation as part of birth and death registration. Tribal residence is collected in these instances because Washington State rules (WAC 246-491-029, WAC 246-491-149) require the use of [US standard forms](#), and these forms collect “Name of the enrolled or principle tribe” as part of parents and decedent’s race.

DOH collects Tribal affiliation as part of shellfish licensing and certification. In this instance, DOH is acting on behalf of the federal government and works with Tribes through the Shellfish Sanitation Consent Decree following the 1994 Rafeedie decision reaffirmed treaty shellfish rights to facilitate harvesting, licensing and certification in support of commercial sales.

What DOH data includes facility and/or provider identification?

DOH collects health care facility or provider information which could be used to identify Tribal facilities and/or providers in several data systems. These include:

- Electronic Laboratory Reporting – these are laboratory test results for notifiable conditions, including COVID-19.
- Washington State Immunization Information System – this is our state’s lifetime immunization registry with records for Washington residents.
- COVID-19 vaccine provider enrollment – this is the list of health care providers who are receiving COVID-19 vaccines.
- Teen Pregnancy Prevention Grant evaluation data – this is data collection to assess whether specific pregnancy prevention activities are meeting their objectives.
- Maternal Mortality Review – this is an in-depth review of women who have died while pregnant or within a year of pregnancy.
- WIC data system – this is the data system that houses medical information on women and children receiving WIC nutrition services.
- Washington Emergency Medical Services Information System (WEMSIS) – this is data collected on all EMS responses in the state.
- Trauma Registry – This is data collected on all trauma patients seen at a designated trauma facility (levels I – V)
- Rapid Health Information Network (RHINO) – this is data collected from healthcare encounters including all Emergency Department visits and in-patient hospital admissions in the state as well as a sample of primary care provider visits.
- Washington State Cancer Registry (WSCR) – this is data collected about all cancer diagnosis, treatment and death in the state.
- [PMP](#) – this is data collected on all controlled substance prescription drugs that are scheduled II – V (Schedule 2 to Schedule 5) and dispensed by Washington pharmacies, excluding drugs prescribed for less than or equal to 24 hours, administered or given to a patient in the hospital, dispensed from a Department of Corrections pharmacy (unless an offender is released with a prescription), and those from an Opioid Treatment Program.
- ILRS
- Healthy Youth Survey – the Healthy Youth Survey collects student health behavior data including the name of the student’s school. Information on the school is only released with Superintendent permission.
- Immunization School Report – The Immunization School Report collects aggregate student vaccination status including the name of the school.

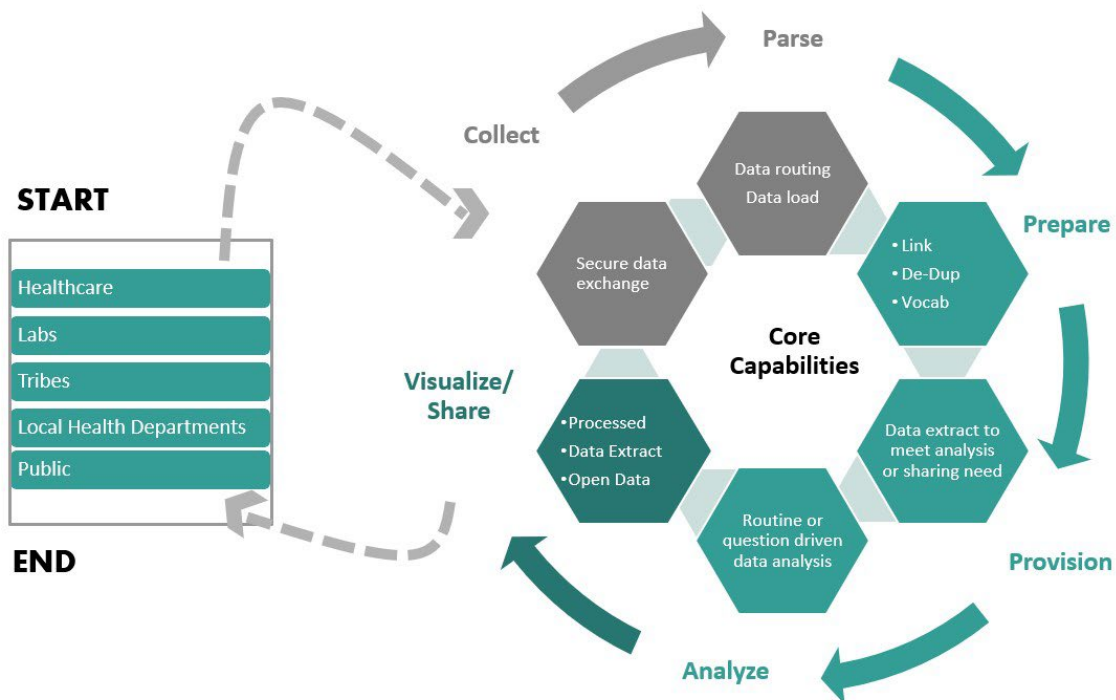
What DOH data includes addresses?

Many DOH data systems (birth, death, COVID-19 tests, COVID-19 vaccinations, cancer, STIs, HIV, controlled substance prescriptions, WIC recipients, licensed health care providers and possibly other data) collect address information which is geocoded to a latitude and longitude. Census tract and block group are generated from this information. These data may be used to identify and investigate disease clusters or explore disease across different geographic areas including census tracts, school districts, legislative districts, or health reporting areas. In addition, environmental information that does not have individual records may be reported by census tract, including pollution levels and lead exposure risk.

Geocoded information is often combined with social and economic information from the American Community Survey (poverty, education, housing, unemployment, limited English proficiency, disabled population, single head of household) and other sources (land use mix, alcohol outlet density, health care facility and provider information) to identify underserved areas. Currently, information on the [Washington Tracking Network](#) includes all census tracts across Washington State.

How does DOH handle data?

DOH describes the processes of data handling and use as part of a data cycle. This cycle, illustrated below, identifies the different processes that data go through as they are collected, managed and analyzed for a variety of uses:



During the different steps of the data cycle, a variety of specific processes or actions may be done. These actions are similar across data systems, but every data system does not undergo every process, and the order of the processes may vary.

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Examples of specific processes or actions:

- **Data Collection** – data come into DOH through a variety of routes (electronic, web-based, manual upload) and we store it.
- **Data Parsing** – we review data to make sure it meets the required format and we identify specific elements so the data can later be routed to the appropriate processes and programs.
- **Data Preparation** – we review data to make sure it is complete and accurate, multiple records are de-duplicated, any linkage to existing records occurs, address data is validated and geocoded, additional standard codes are applied to the data, and new variables are created.
- **Data Provisioning** – specific data elements are removed, linked to elements from other data streams, aggregated and/or de-identified as needed for specific purposes and stored in a variety of formats including, robust record level data for analysis and research, limited and deidentified record level data for public release, and aggregate data for automated reports.
- **Data Analysis** – involves applying statistical algorithms to explore the data by demographic variables, health behaviors, settings and situations, and co-morbidity, determine trends, and identify outliers.
- **Data Reporting** – may include the development of documents and dashboards for use by DOH staff, public health partners, and the public.
- **Data Sharing** – includes making the data available through different methods for distinct clinical, public health, and research purposes.

Throughout each of these processes, the data that we originally collected may be transferred into separate databases, and all or a portion of the data may be handled and managed. These separate “streams” may or may not include data related to race, ethnicity, or tribal affiliation.

How does DOH protect the security of data?

Data security means making sure the data are available when needed to those who need access, but are not accessed by those who aren’t authorized to see the data. As a state agency, DOH must follow standards developed by the Office of the Chief Information Officer (OCIO) as described in [Policy 141.10: Securing Information Technology Assets Standards](#). These standards address requirements for data security that include:

- Categorizing data according to the sensitivity of the data, with requirements for handling the data that are more strict for more sensitive data
- Data sharing requirements that specify access, transport, storage and disposal methods in alignment with data categories.

Detailed data security methods can be described if desired.

How does DOH protect the privacy of data?

Data privacy relates to the protection of personal information. It is governed by the Office of Privacy and Data Protection (OPDP) at the OCIO. The OPDP has the duty to promote privacy principles and best practices. Although these principles are not required by law, the OCIO Standard 141.10 is a standard that must be followed by state agencies and includes information on protecting privacy of data that is being shared. These principles include:

- Collect, use and share information in alignment with legal authority
- Share the minimum amount of data needed for any stated purpose
- Require a specific, limited purpose for data sharing
- Be transparent and accountable for why data are being collected and how they are being used
- Take reasonable steps and care to follow legal authority and policies in sharing data with a third party
- Provide individuals control of their information whenever possible
- Follow appropriate security practices to protect confidentiality of personal information

In addition, there are specific state laws (RCWs) that require state agencies to protect the privacy of personal and health information, as well as the State constitutional right to privacy. DOH incorporates these principles into data handling and sharing practices through annual training of DOH staff, the requirement that all staff sign a confidentiality statement annually, and through the development and review of data sharing agreements.

What data does DOH share?

A variety of Washington State laws govern the collection and release of DOH data resulting in many unique data systems. For this reason, there are also individual and distinct processes governing the collection, storage, management, analysis, reporting and sharing of data for public health activity. DOH is working on streamlining and standardizing these processes.

Some data, like individual birth and death records have well defined rules and processes for protecting privacy and confidentiality, and are widely shared with public health authorities, state agencies and researchers. Other data systems, especially those related to service provision, focus on their specific public health goals and generally report data in aggregate or as a total. There may be legal restrictions to some data sharing, or they may not have well-defined data sharing procedures.

In addition to sharing data for public health activity, DOH shares data with researchers after approval by the [Washington State Institutional Review Board \(WSIRB\)](#). All research studies using DOH data must receive WSIRB approval. WSIRB ensures that any research is conducted in alignment with federal standards ([45 CFR 46](#)) that protect the rights and welfare of people participating in the research, minimizes any risk to participants, and uses appropriate study methods. A confidentiality agreement is required for research studies using state agency data that involve personally identifiable or protected health information used without the study subjects' written permission.

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DOH is subject to the Public Records Act ([RCW 42.56](#)) and any individual can ask to see written records, including individual level records. In these instances, data that identifies an individual such as a name or address will be removed to protect privacy, but information identifying a health care facility or provider, or dates of service are not currently allowed to be removed.

DOH has begun a process to 1) help identify Tribal data associated with a public disclosure request, and 2) alert Tribes and/or the American Indian Health Commission at least 10 days in advance of releasing data in response to a public disclosure request that may identify a Tribe, tribal facility, or tribal provider, so the Tribe can seek an injunction to prevent the release of this data.



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