

Requesting Additional Death with Dignity Act Data

In 1997, Oregon enacted the Death with Dignity Act (the Act), which allows terminally-ill Oregonians to end their lives through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose. This law requires the Oregon Public Health Division to collect and analyze data on who participates in the Act and issue an annual report. These data are important to parties on both sides of the issue. Our position is a neutral one, and we offer no subjective opinions about these questions. We routinely receive requests for data beyond those published in our annual reports, and this document was designed to answer a few frequently asked questions related to additional data requests.

Q: How do I request additional data, beyond what was published in the annual report?

A: Requests for Death with Dignity data should follow the same process used for other data requests made to the Center for Health Statistics (CHS). In order to request data, an email should be sent to Craig New, Mortality Research Analyst, craig.c.new@state.or.us. The requestor will then be sent a data use agreement to complete and return to CHS. Upon receiving the completed form, CHS will evaluate the request and, upon approval of the request, provide a time and cost estimate, if necessary.

Q: Are there restrictions on access or use of the Death with Dignity data?

A: The Death with Dignity Act requires the Oregon Public Health Division to collect and analyze data on who participates in the Act and issue an annual report. The law guarantees the confidentiality of all participating patients and physicians. If the additional information requested would violate confidentiality, the request will be refused.

Death with Dignity data will only be released in de-identified tables (not raw data sets) in order to ensure confidentiality.

The Public Health Division will abide by the “10 and 50” rule mentioned in Policy 01-01-27 issued on January 1, 1999 when releasing Death with Dignity data. In general, confidentiality guidelines require that release of a health statistic should only occur if the denominator of the health statistic is more than 50 when the denominator is a population (a group of people with certain age, race, and sex characteristics who live in a particular place) or more than 10 when the denominator is a cohort (a group of people whose membership is defined by the occurrence of some event). The numerator must also be greater than 10 for release of a health statistic.

Because of these guidelines and the requirement to protect the confidentiality of participating patients and physicians, the Public Health Division will not routinely release cell sizes smaller than ten.

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<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/datarequest.pdf>