

CEDR Tier Level Access

The Comprehensive Epidemiologic Data Resource (CEDR) is an electronic database comprised of health studies of Department of Energy (DOE) workers, contractors, and environmental studies of areas surrounding DOE facilities. DOE recognizes the benefits of data sharing and supports the public's right to know about worker and community health risks, furthering scientific research and transparency, and in bolstering educational pursuits. However, DOE also recognizes the need to maintain privacy of the workers and contractors included in the data repository. To ensure both goals are being met, CEDR began implementing a tiered access system for its datasets in 2024.

With this system, all accounts must still be approved by the DOE Program Manager and must have a valid mailing address (no PO Boxes). However, accessing the process for accessing individual datasets may be different. For more information, please review the information below. If questions arise, please contact us at CEDR@orau.org.

Tier 1

Tier 1 Access provides comprehensive access to all datasets that have any data not related to demographics and where the fields are not designated for higher tier access. Tier 1 access has a specific focus on safeguarding demographic information. Under this level, users can explore a wide array of datasets, with the understanding that all demographic identifiers, except for the year of birth, will be meticulously removed to ensure privacy and confidentiality. This policy is uniformly applied across datasets containing individual level data, ensuring that demographics, including sex, race, marriage status, job titles, and similar personal details, are not included in the datasets users download. Additionally, the International Classification of Diseases (ICD) codes will be restricted to their first three characters to further protect individual privacy as applicable. There are, nonetheless, specific exceptions to these rules. If a dataset exclusively contains information about individuals who are known to be deceased, such as the Radium Dial Painter datasets, or if the dataset does not pertain to individual-level data but rather consists of summarized or simulated data, the standard restrictions on demographic information may not apply. This nuanced approach ensures that while access to valuable data is maintained, privacy and ethical considerations are rigorously upheld.

Tier 2

Tier 2 Access is tailored for users engaged in research or publication activities and necessitates adherence to specific regulatory and ethical standards. To access data under this level, users must have an Institutional Review Board (IRB) protocol determination, which could be either from the Department of Energy (DOE) or an accredited

institution (e.g. college or university). This requirement underscores the commitment to conducting research responsibly and ethically, ensuring that the data used adheres to established standards of privacy and integrity.

Access under Tier 2 is more focused compared to Tier 1, with permissions being granted to specific datasets rather than a broad spectrum. This targeted access allows researchers to delve into detailed analyses with the confidence that they are operating within the bounds of their approved IRB protocol. A significant advantage of Tier 2 access is the availability of demographic data within the specified datasets. This level of access facilitates a deeper understanding of the data, enabling researchers to draw more accurate and meaningful conclusions from their work, all while adhering to the ethical standards set forth by their IRB protocol.

Tier 3

Tier 3 Access, like Tier 2, requires an Institutional Review Board (IRB) protocol and it is limited to specified datasets. In Tier 3 datasets with special considerations including ethical and social implications which may result in additional sensitivities to data sharing. Tier 3 goes a step further by also requiring approval from the designated "owner" of the datasets. This dual requirement ensures that both ethical standards and specific concerns of the dataset owners are addressed before access is granted, providing an extra layer of scrutiny and protection for unique information. The process for obtaining data from Tier 3 datasets is primarily an internal procedure for CEDR; however, it is possible the "owner" of the specified datasets may request additional information from the researcher before granting approval.