§ 2022. Establishment of registry. 1. The department shall establish an ALS and MND registry for the collection of information on the incidence and prevalence of ALS and MND. The department may consult with ALS and MND experts, including neurologists, patients living with ALS and MND, and ALS and MND researchers to assist in the development and implementation of such registry, and to determine what data shall be collected.

2. All information maintained by the department under the provisions of this section shall be confidential except as necessary to carry out the provisions of this section and shall not be released for any other purpose.

3. The department may enter into an agreement to provide data collected in the ALS and MND registry to the federal centers for disease control and prevention, or successor agency, to local health officers, or health researchers for the study of ALS and MND for public health and research purposes. Data shall be provided in summary, statistical, aggregate, or other form such that no individual person can be identified.

4. On or before January first, two thousand twenty-seven, the department shall create and maintain a public website called the "New York state ALS and MN Disease registry" which shall include information on the incidence and prevalence of ALS and MND in the state by county, and demographic information on affected patients.