

Treatment: NINDS CDE Project

Working group: Treatment

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The development of the Common Data Elements (CDEs) for the Treatment Subgroup followed the same general process as for the other subgroups. A Treatment CDE draft was developed by the Treatment subgroup and edited both by the subgroup members and by a broader group of appropriate individuals at workshops and think tank meetings over the course of two years. Drafts of the CDE files were also released to the entire Chiari and Syringomyelia Foundation Advisory Board and internationally to participating Chiari-interested caregivers, researchers and industry representatives.

Treatment CDEs were developed using the collective experience of neurosurgeons, neurologists, psychologists, and patient advocates and range from conservative measures (e.g., activity limitations, physical therapy) to the full complement of surgical approaches and techniques employed to treat Chiari, syringomyelia, and related conditions. Surgical treatment is highly variable based on surgeon exposure, experience, and preference, and every effort was made to ensure that the current Treatment CDEs be comprehensive and inclusive of all treatment methods. Additionally, the subgroup meticulously detailed relevant perioperative parameters, treatment complications, and therapeutic shortcomings along with the treatments employed to manage these events (e.g., craniocervical fusion for induced instability).

By design, the Treatment CDEs were developed as part of the larger Chiari and syringomyelia CDE project and thus comport with the CDEs from the other sections. Redundancy in CDEs (e.g., surgical complications vs outcomes) was minimized as possible.