

International SCI Data Sets

The National Institute of Neurological Disorders and Stroke (NINDS) developed and posted the Spinal Cord Injury (SCI) Common Data Elements (CDE) in 2015. At that time the NINDS CDE Team partnered with the [American Spinal Injury Association \(ASIA\)](#), and [International Spinal Cord Society \(ISCoS\)](#) to incorporate the [International SCI Data Sets](#) into the NINDS SCI CDEs.

Members of the Executive Committee of the International SCI Standards and Data Sets Committees (ECSCI) worked with the NINDS CDE Project to integrate the International SCI Data Sets with the other NINDS CDE resources. This effort included the development of standard variable names for the data elements in the International SCI Data Sets and suggested database structures (i.e., relational data tables for the data sets). These recommended variable names and database structures are free to use by clinicians and researchers, so that they can more easily share and combine clinical/research data^{1,2}.

To avoid duplication of effort, in 2024, the NINDS and the SCI CDE Oversight Committee decided to remove the International Data Sets and associated CDE data dictionaries from the NINDS CDE SCI Data Standards page so they would be available and maintained in one place on the ISCoS website. Therefore, they were removed from the NINDS CDE website as of October 2024.

Current versions of the International SCI Data Sets may be found on the International Spinal Cord Injury Society (ISCoS) [website](#).

References:

- 1 Biering-Sørensen F, Charlifue S, Devivo MJ, et al. Incorporation of the International Spinal Cord Injury Data Set elements into the National Institute of Neurological Disorders and Stroke Common Data Elements. *Spinal Cord*. 2011;49(1):60-64.
2. Biering-Sørensen F, Charlifue S, DeVivo M, et al. International Spinal Cord Injury Data Sets. *Spinal Cord*. 2006;44(9):530-534.