



National Institute of
Neurological Disorders
and Stroke



NINDS Common Data Element (CDE) Project – Investigator Presentation Series

2016





NINDS CDE Disease Areas – over 11,000 CDEs & 575 Instruments

General CDEs

Epilepsy*

Cerebral palsy (*new*)

Chiari I Malformation (*new*)

Headache

Mitochondrial disorders*

Movement disorders

- Parkinson's disease
- Huntington's disease

Multiple sclerosis

Spinal cord injury (SCI)*

Stroke*

Traumatic brain injury*

Neuromuscular disorders*

- Amyotrophic lateral sclerosis
- Friedreich's ataxia
- Muscular dystrophies
 - *Congenital, Duchenne/Becker, Facioscapulohumeral, Myotonic*
- Myasthenia gravis
- Spinal muscular atrophy

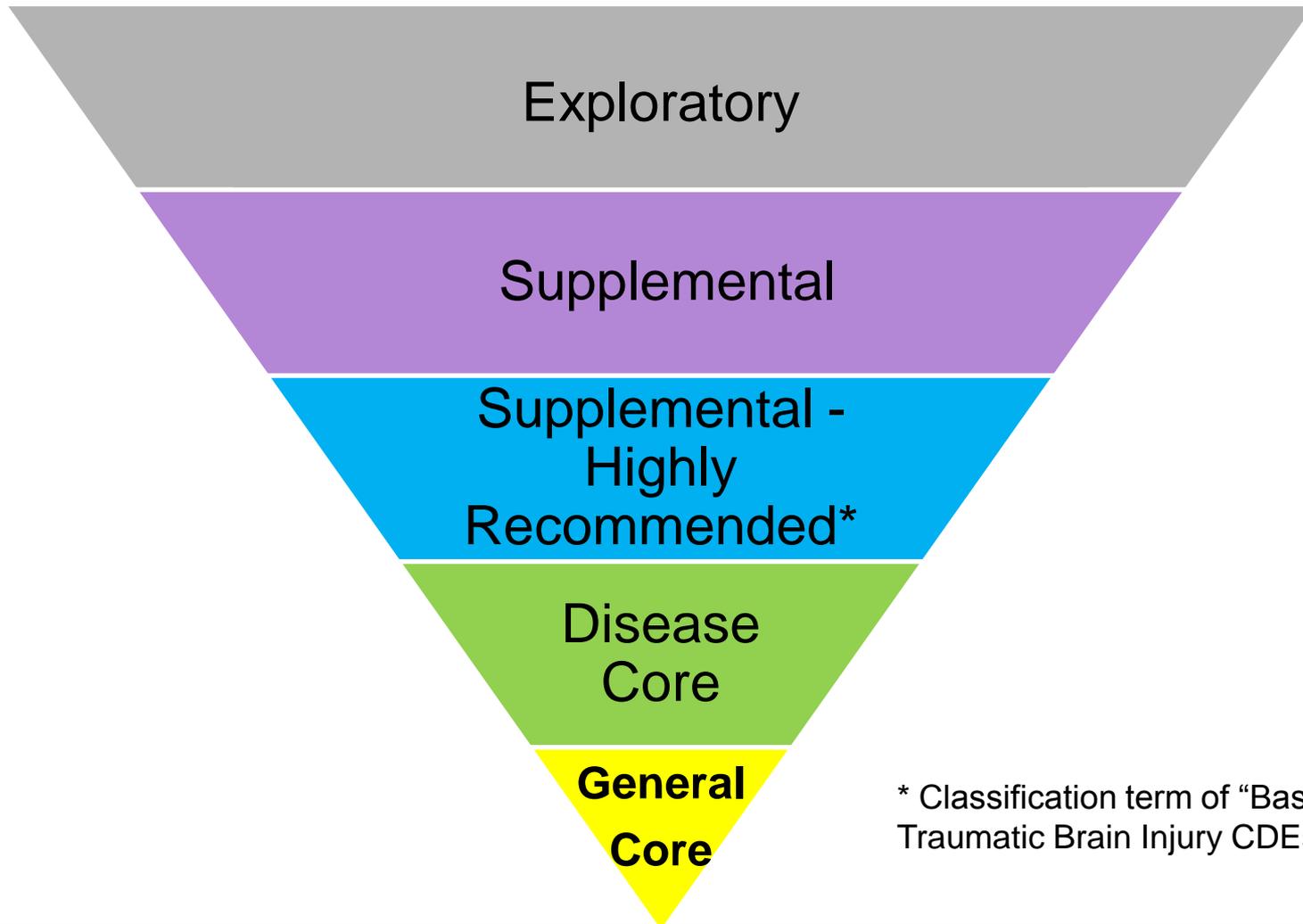
Subarachnoid hemorrhage (in development)

Sports-Related Concussion (in development)

* *Pediatric Specific Recommendations*



CDE Terminology – Classifications



* Classification term of “Basic” used for
Traumatic Brain Injury CDEs



What is the CDE Project?

- NINDS initiated the development of Common Data Elements (CDEs) as part of a project to develop data standards for funded clinical research in neuroscience.
- The CDEs are content standards that can be applied to various data collection models and are intended to be **dynamic** and **may evolve** over time.
- CDEs are **not** a database.