

Parkinson’s Disease Version 2.0 NINDS CDE Project Functional Neurosurgery Subgroup Summary

The Functional Neurosurgery Subgroup focused on recommendations related to the treatment of Parkinson’s disease (PD) with deep brain stimulator implantation. Pre-operative, intra-operative and post-operative time points as well as surgical complications were included the subgroup’s purview. Lesioning procedures and focused ultrasound were not included.

The subgroup reviewed and updated the v1.0 Functional Neurosurgery CRF based on advancements in the field. Subgroup members updated information on targeting, image guidance, software, surgical technique, and complications. The name of CRF was changed from “Functional Neurosurgery” to “Functional Neurosurgery: Deep Brain Stimulation” for PD v2.0 since it specifically does not include lesioning procedures. There are no standardized instruments for functional neurosurgery.

The Functional Neurosurgery: Deep Brain Stimulation CRF does not address any specific sub-populations.

Summary of Recommendations

CRF Name	Subdomain	Classification
Functional Neurosurgery: Deep Brain Stimulation	Surgeries and Other Procedures	Supplemental

The subgroup considered the types of data that are commonly collected in the field in revising the CRF. Questions regarding the administration of the UPDRS and complication severity aligned with the Common Terminology Criteria for Adverse Events are also included.

Pre-operative data points that are important to include and standardize for PD surgery data collection are duration of disease, time that a patient has had the motor response complications, fluctuations, and dyskinesias. Standardization of recording whether a patient is on or off medication should also be included in PD research.

The current version of the CRF does not address lesioning techniques or focused ultrasound. These areas were not addressed since they are still in development and there are no established standards.

The existing CDEs are mainly US centric and do not include all internationally available technologies.