Language for Informed Consent Form:

The results of this study may also be published in scientific journal articles and may be widely disseminated. However, your name or personal identifiers will not be used in any of these reports of results. Unidentified data (information with no names or other personal identifiers) collected in this study will be stored in registries or other research-related databases such as the Northwestern University Neuroimaging Data Archive (NUNDA). Your research data may be shared with your treatment team. After the study is over, we may make available the unidentified data to other qualified researchers in the wider scientific community.

Please note that:
• By signing this consent, you agree that your unidentified research data (information with no names or other personal identifiers) will be stored in the Northwestern University Neuroimaging Data Archive (NUNDA) for research purposes only.

Language for Research Protocol:

For this project, we will deploy an XNAT-based data repository for capturing clinical, cognitive, and imaging data on NUNDA. NUNDA’s features include: 1) a range of image upload/download methods, including DICOM, FTP, and web interface; 2) incorporation of new data types by automatically generating the necessary databasing components; 3) quality control modules and audit trails; 4) a secure web-based user interface; 5) a sophisticated search engine; 6) an online image viewer; and 7) automatic image processing pipeline support. In particular, data security and integrity features involve the following: data are transmitted over secure channels using SSL, and stored on a RAID 5 device with backup; data access is restricted to authorized users with specific privileges (create, delete, read, edit) according to their role in the study. Quality control features include: upon uploading to the system, imaging sequence details are validated against a study specific protocol to ensure acquisition compliance; noncompliant scans are flagged for immediate follow-up; automated routines are executed to determine overall image quality; for fMRI, for example, signal to noise and movement histograms are generated. NUNDA also supports optional web-based radiological evaluation and manual quality assessments.

We will utilize the XNAT system’s protocol-based data security features for data sharing with the research team members. At each time point, clinical, cognitive and imaging information will be uploaded into the repository. The acquired image data will be sent directly from the scanner at CTI to the NUNDA DICOM receiver. The research coordinator and assistant will be responsible for scan transfers and for entering information using built-in web-based forms.