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The Uniform Data Set of the Alzheimer's Disease Centers in the US: The Process and Products

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The Alzheimer Disease Centers (ADC) Program of the National Institute on Aging (NIA) in the US began in 1984 when five institutions were awarded grants to create centers of excellence in the study of Alzheimer disease (AD) and related disorders. In the 22 years of this program's existence, the number of funded centers has grown to 34. Up to now, although all the centers collected similar data, each center had defined its own methods for enrolling and following subjects. This approach fostered unprecedented advances in our understanding of AD and of the clinical markers that predict progression from normal cognition to MCI and from MCI to AD. However, methodological differences in data collection among centers meant that the thousands of subjects collectively followed could not be easily compared or combined for study. In 1998, in an effort to standardize data collection methods, the Minimum Data Set (MDS) was introduced. This consisted of a cataloguing method whereby all centers contributed a limited set of data on all subjects for record-keeping purposes. This led to an increase in the number of cross-center collaborative studies and to the creation of the National Alzheimer Coordinating Center (NACC) to house the data and to support cross-center initiatives.

The centers now face a new challenge with the recognition that AD, and perhaps other forms of dementia, begin far earlier than the appearance of clinical symptoms and the focus has shifted to preclinical detection of AD. In 2002, the NIA and NACC supported the creation of an ADC Clinical Task Force given the charge of further promoting standardized data collection methods so that a large number of individuals would be examined in the same way at each center. The goal was to create a large cohort of subjects studied in a standardized way who would be ready in the event that a truly effective treatment could be applied in preclinical stages.

This presentation describes the process the ADC Clinical Task Force followed to achieve the UDS and the current recommendations with respect to clinical and neuropsychological data collection. The first version of the UDS focuses on the normal-MCI-AD continuum. Future revisions will also place emphasis on standardizing data collection for non-AD dementia.