Data Management Plan for Open-Source Digital Twins (phantoms) in AD/ADRD Research

Introduction

- Purpose of the Plan: This DMP details the approach for managing, storing, sharing, and supporting the open-source digital twins data used in Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD) research.

Data Description

- Type of Data: The dataset comprises digital twins (simulated patient data) with demographic, diagnostic, and procedural information.
- Data Format and Standards: Data will be formatted in universally readable formats (e.g., CSV, JSON) and will conform to open-source standards to ensure wide accessibility and compatibility.

Roles and Responsibilities

- Data Collection and Generation: A team of data scientists will oversee the generation of digital twins using the project's software tools.
- Data Management: A data manager will supervise the data's storage, backup, and accessibility.

Data Storage and Preservation

- Storage Solutions: The digital twins data will be stored on secure cloud-based servers with adequate encryption and backup solutions.
- Data Preservation: The data will be maintained in an open-source repository with long-term preservation policies, such as GitHub or a similar platform.

Data Security

- Access Control: Access to the data will be controlled through secure login credentials, with different levels of access depending on user roles.
- Data Protection: Measures will be in place to ensure that the integrity of the data is maintained, preventing unauthorized access or alterations.

Data Sharing and Accessibility

- Open Source Licensing: The data will be shared under an open-source license to maximize accessibility and collaborative potential.
- Data Distribution: The dataset will be available for download from the project website or a recognized open-source data repository.

Support for Use

- Software Assistance: The project team will provide documentation and support for users interested in using the software to generate additional digital twins.
- Community Engagement: Forums or user groups will be established for users to share experiences, troubleshoot issues, and discuss best practices.

Ethical Considerations

- Privacy and Compliance: Although the data are simulated, all efforts will be made to ensure that they do not inadvertently replicate or reveal sensitive personal information.

- Intended Use: Guidelines will be provided to ensure the ethical use of digital twins data in research.

Review and Update of DMP

- Regular Review: The DMP will be reviewed annually to ensure it remains relevant and effective.
- Updates: Adjustments will be made in response to technological advancements, user feedback, and evolving research needs.