

# Fundamentals of Data Management for the Brain Resilience Study

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October 11, 2024





# Data Management

- Ensures that data collected is useable
  - Data integrity
  - Backups
  - Documentation
- Improves efficiency of data handling
  - Findable (standardized locations & filenames)
  - Documentation
  - Improves data reuse potential





# Data Integrity & Backups

- Do not delete data (e.g. on laptop, tablet) even if it's already been transferred to Cedar
- Do not edit data manually
  - If data needs to be changed, get in contact with Ethan
  - Document your proposed changes
- Fill out the data acquisition documentation as soon as data is collected
  - Document important comments
  - TBD: Notion vs Completeness.csv
- Follow established file naming standards and storage locations
  - Rename and organize collected data, once data acquisition for a participant is complete, according to the file/folder structure outlined in Data Management Plan before upload to staging/ in Cedar via Globus
- Read the Data Management Plan (link via Notion)
- If you're unsure about anything to do with data management, post your question to the RA slack channel

# Participant Privacy

## Personal, Sensitive Data

- Information that could be used to identify a participant
- Information that has a risk of harm a participant, if released
- Name, D.O.B., E-mail address, IP address, Physical address
- Health information, brain images with facial features



"Your blog indicates I'm not doing well at all."



# Importance of Participant Privacy

- Protection of Dignity and Right to Privacy
- Risk of Harm
- Compliance with Research Ethics Board (REB)
  - Breaches of privacy could lead to suspension of research and/or loss of funding
- Reputation and Trust

# How we Protect Participant Privacy

- Cybersecurity Best Practices
  - Participant data should always be password protected
  - Use a strong password
  - Do not share your account passwords
  - If you write down your password, keep it in a location that only you have access to
  - [Protect yourself from phishing attacks](#)
- DO NOT add participant data to email, cloud storage, or your personal USB
  - e.g. Google Drive, Dropbox do not adhere to our data protection standards; you may ONLY use the [SFU Sharepoint](#) system with appropriate sharing permissions
- NO PERSONAL/SENSITIVE DATA should go on Cedar
- If you're unsure, ask us :)

