An electronic data entry system: Experience in designing and implementing the system

Roger A Mueller, BA
Mayo Clinic ADRC
October 6, 2012
History of Mayo ADRC

- 1990 funded as ADCC
- 1995 successful renewal
- 1998 responded to RFA for ADRC’s
- 1999 funded as P50
- 2004 renewed as P50
- 2009 renewed as P50
- 2014 anybody’s guess
Current Projects

- Mayo Clinic ADRC in MN and FL sites
  - ~700 active subjects
  - 1700+ subjects enrolled since inception
  - ~250 UDS and UDS related subjects with autopsies

- Subjects also participate in sub-studies
  - ~1700 subjects with MR scans
  - ~200 subjects with PET scans
  - ~1700 subjects with blood samples
  - ~40 subjects with CSF draws
Current & Future States

• SAS database, 120 tables, 6000 variables with SAS interface

• Integrated custom infrastructure, tracking subjects end to end

• Paper-based geared for heads down data entry

• GOAL: Recreate infrastructure in Rave so schedulers, physicians, coordinators, and psychometrists all perform direct entry
External Warehouse Design

- C1: Admin, Clinical, bios, imaging, etc.
- C2: Admin, Clinical, bios, imaging, etc.
- C3: Admin, Clinical, bios, imaging, etc.
- C4: Admin, Clinical, bios, imaging, etc.
- C5: Admin, Clinical, bios, imaging, etc.
- C6: Admin, Clinical, bios, imaging, etc.
- C7: Admin, Clinical, bios, imaging, etc.
Making our Goals Happen with an Integrated Design

• Divided our research into two parts

• Built Rave Master Track Registry for flexibility and tracking subjects on one or more studies: Administration side

• Built Rave individual research projects to collect specific research data: Research side

• Built custom function and web service infrastructure so multiple Rave projects can talk to each other
Challenges

• Rave technology for multi-project cross-talk available, but limited experience

• Design for entry vs. batch loading

• Master Track
  • Flexibility to add and close out sub-projects
  • Minimize where to change code when new studies are added

• Define a generic structure to which all research studies conform
What it took to make it work

- **On the Administration side**
  - 27 forms
  - 400 edit checks
  - 40 of 50 CFs for project cross-talk

- **On the ADRC Research side**
  - 71 forms
  - 2340 edit checks
  - 5 of 57 CFs for project cross-talk
# Administration Design Overview

## Subject Summary

- **Main Address Line 1:** 100 Goofy Lane
- **Main Address City:** Orlando
- **Main Address State:** Florida
- **Main Address Zip Code:** 85656
- **Primary Phone Area:** 855
- **Primary Phone:** 8555555
- **Cell Phone Area:**
- **Cell Phone:**

## Subject Characteristics

- **Title:**
- **First Name:** Mickey
- **Middle:**
- **Last Name:** Mouse
- **Suffix:**
- **Date of Birth:** 14 Feb 1928
- **Death Status - Has subject died?:** No
- **If Yes, Is Year of Death known?:**
- **If Year of Death known, Date of Death:**
- **Gender:** Male

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## Additional Details

- **Mayo Clinic Number:** 3746952
- **BARD Number:**
- **FL Fake MC Number:**
### Administration Design Overview

#### Subject: 85638-ALZ

**Patient Information:**
- Mayo Clinic Number: 3745962
- NACC Number: [Redacted]
- Date of Birth: 14 Feb 1928
- BARD Number: [Redacted]
- Last Name: Mouse
- First Name: Mickey
- Gender: Male

#### Studies

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<th>Study</th>
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<th>Baseline Visit</th>
<th>UDS Visit</th>
<th>UDS Accepted Visit</th>
<th>Tot Num Study Visits</th>
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Add a new Log line, inactive
### Administration Design Overview

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<th>Order ID</th>
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Research Design Overview

Enter Mayo Clinic Number ONLY and then save form.

Mayo Clinic Number

Verify the following patient information AFTER Mayo Clinic Number has been entered and form has been saved.

If any changes are made, be sure to also update ALZ1002 Master Track.

Title
First Name
Middle
Last Name
Suffix
Date of Birth
Gender
# Research Design Overview

<table>
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<tr>
<th>Mayo Clinic Number</th>
<th>FLfake MC Number</th>
<th>NACC Number</th>
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<tbody>
<tr>
<td>3745952</td>
<td>Mickey</td>
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**Subject:** ALZ

**Page:** Post-Visit Summary - Cycle 01

### Section 2: To be recorded after the subject is done with the visit.
- Non-psychometric validity: 1 = Satisfactory

### Section 3: To be recorded after all possible data is collected and entered for this visit.
- Is Visit Complete?: Yes
- Were there any Adverse Events?: No
Research Updating Master Track

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</table>

Mayo Clinic Number: 3745952
NACC Number: 
Date of Birth: 14 Feb 1928

BARD Number:
Last Name: Mouse
Gender: Male

Subject: 85638-ALZ
Page: Subject History
Feedback & Lessons Learned

• Sporadic slowness
• Larger computer monitors beneficial
• Most CRA questions pertain to training, dealing with change, and getting used to a new system
• CRAs suggested few form and field tweaks
• Few edit check glitches
• Overall positive feedback by users
Feedback & Lessons Learned

• Upfront work of interviewing stakeholders to determine workflow processes

• Testing, testing, and more testing

• Training, training, and more training

• We contributed to Mayo’s new institutional platform for research data management across the enterprise

• Input and flexibility of Lilah Besser and Leslie Phillips from NACC re: UDS electronic forms
Thank You!!

Questions?