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

Roger A Mueller, BA

Mayo Clinic ADRC
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Mayo ADRC





Rochester, MN

Jacksonville, FL



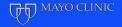
History of Mayo ADRC

- 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



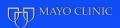
Challenges

- Rave technology for multi-project crosstalk 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

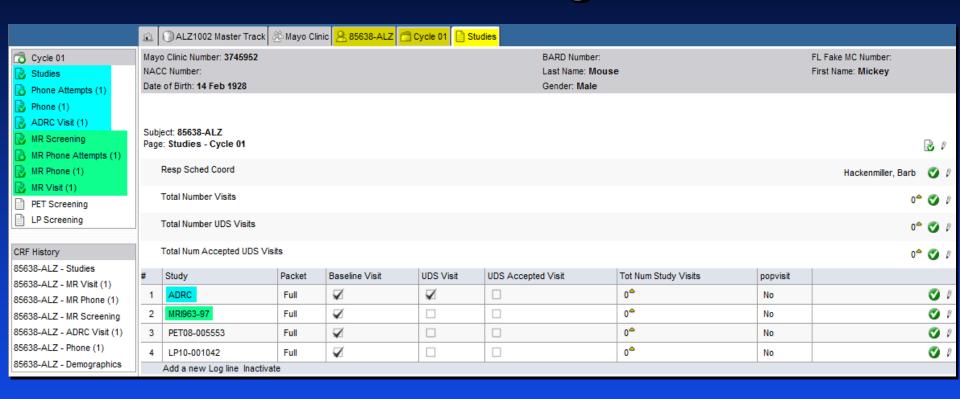


Administration Design Overview



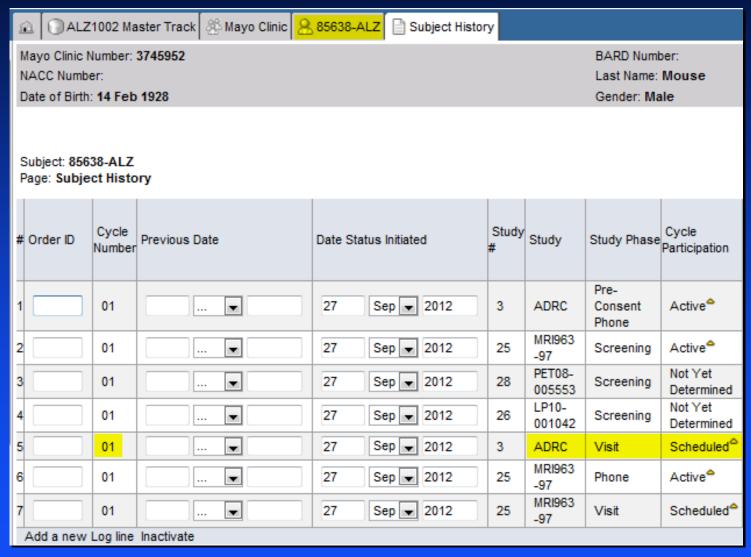


Administration Design Overview





Administration Design Overview



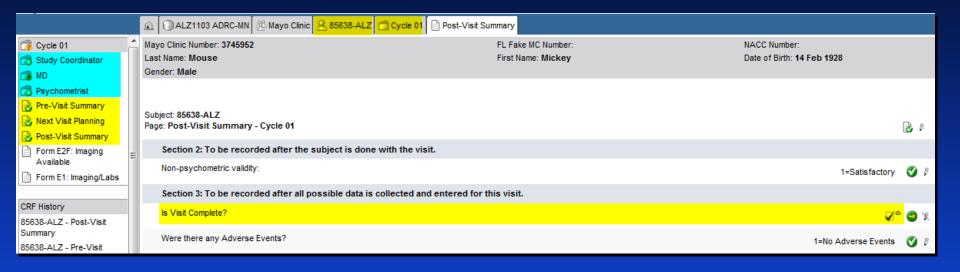


Research Design Overview



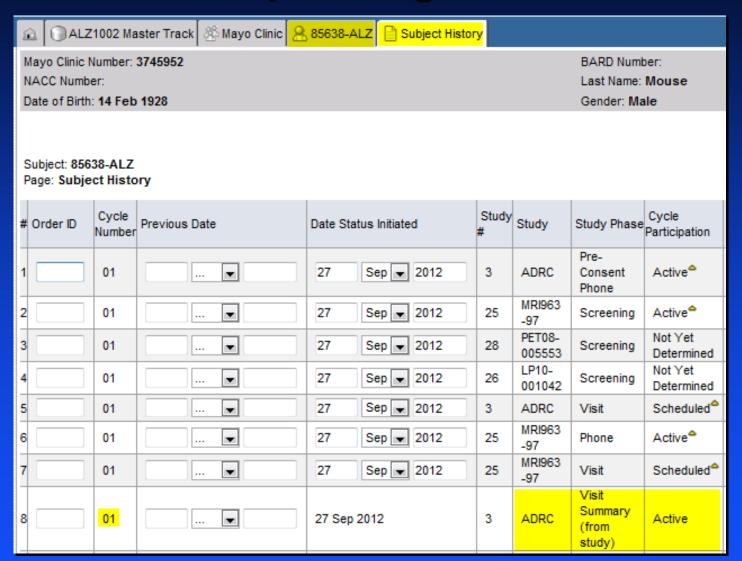


Research Design Overview





Research Updating Master Track





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?

