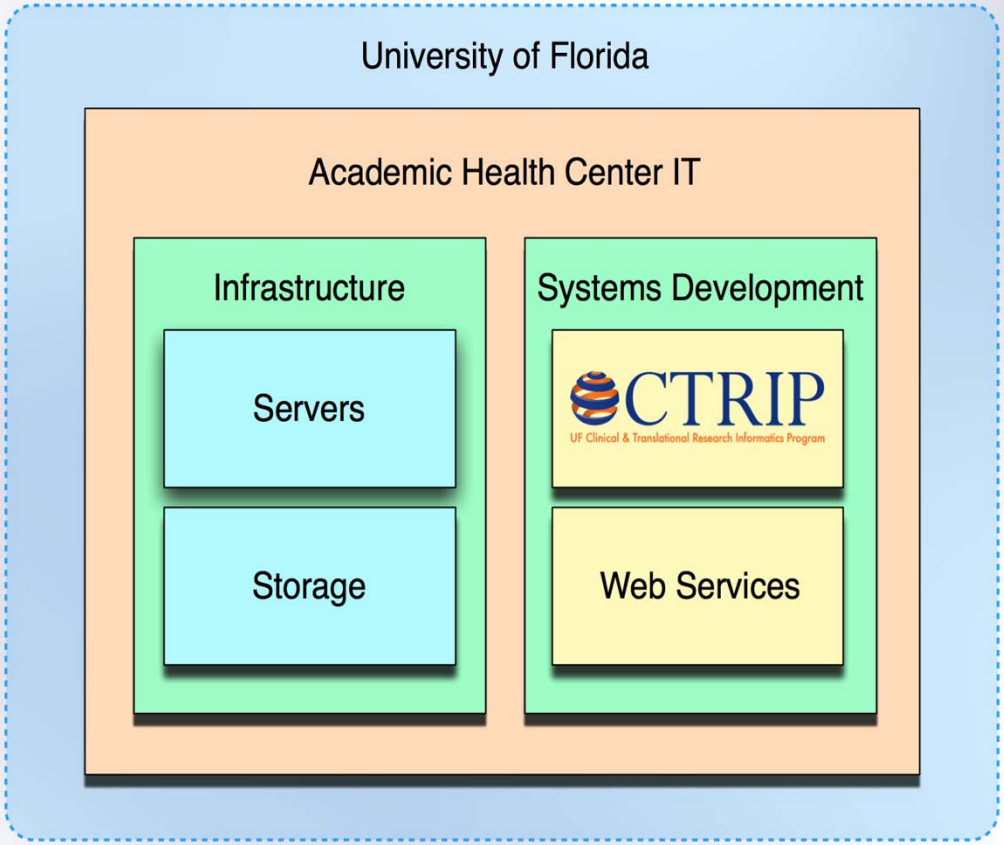
# Informatics Systems for ImagingDMD Multicenter Study

Narayan Raum

# University of Florida AHC & CTRIP

- 25 Software Engineers in CTRIP
- 100+ active and supported projects
- Informatics support for:
  - Univ. of Florida
  - Grants, contracts
  - State, Federal and Private entities



# Primary Goals

- Engineer solutions and systems to facilitate the ImagingDMD study
- Leverage open source technologies
- Assist and support research team from technical and operational standpoint

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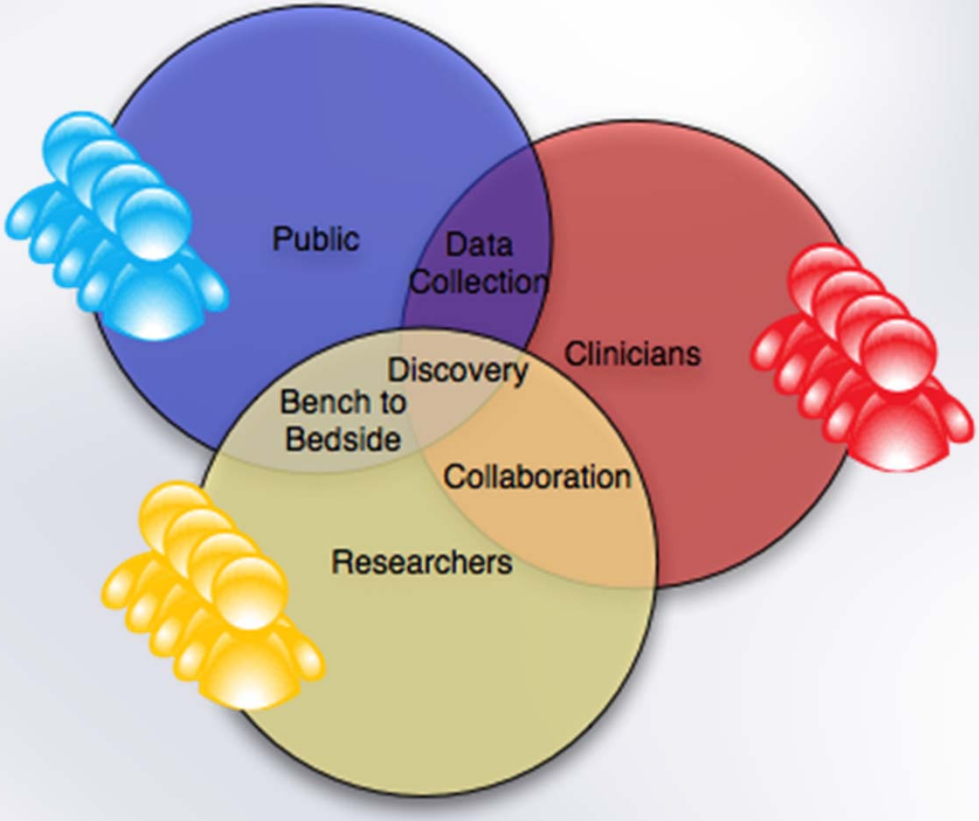
# Ultimate goal: Discovery

- Public informed and enrolled in study
- Data collection and management
- Query and analysis of data

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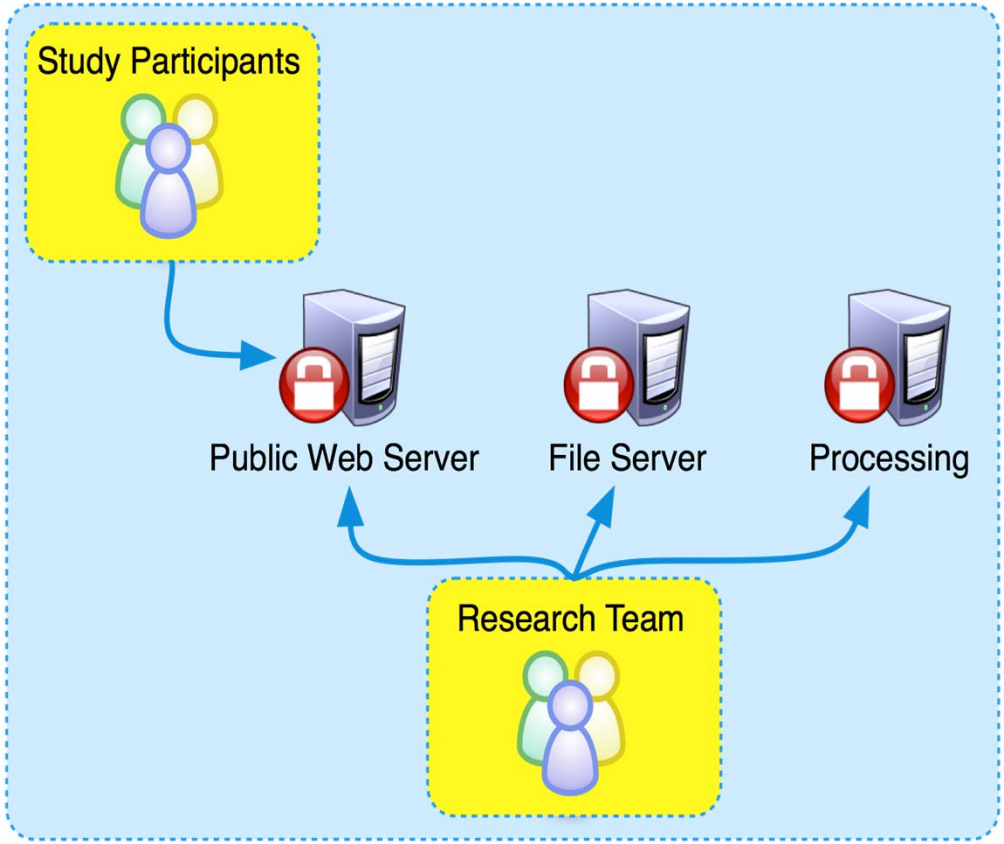
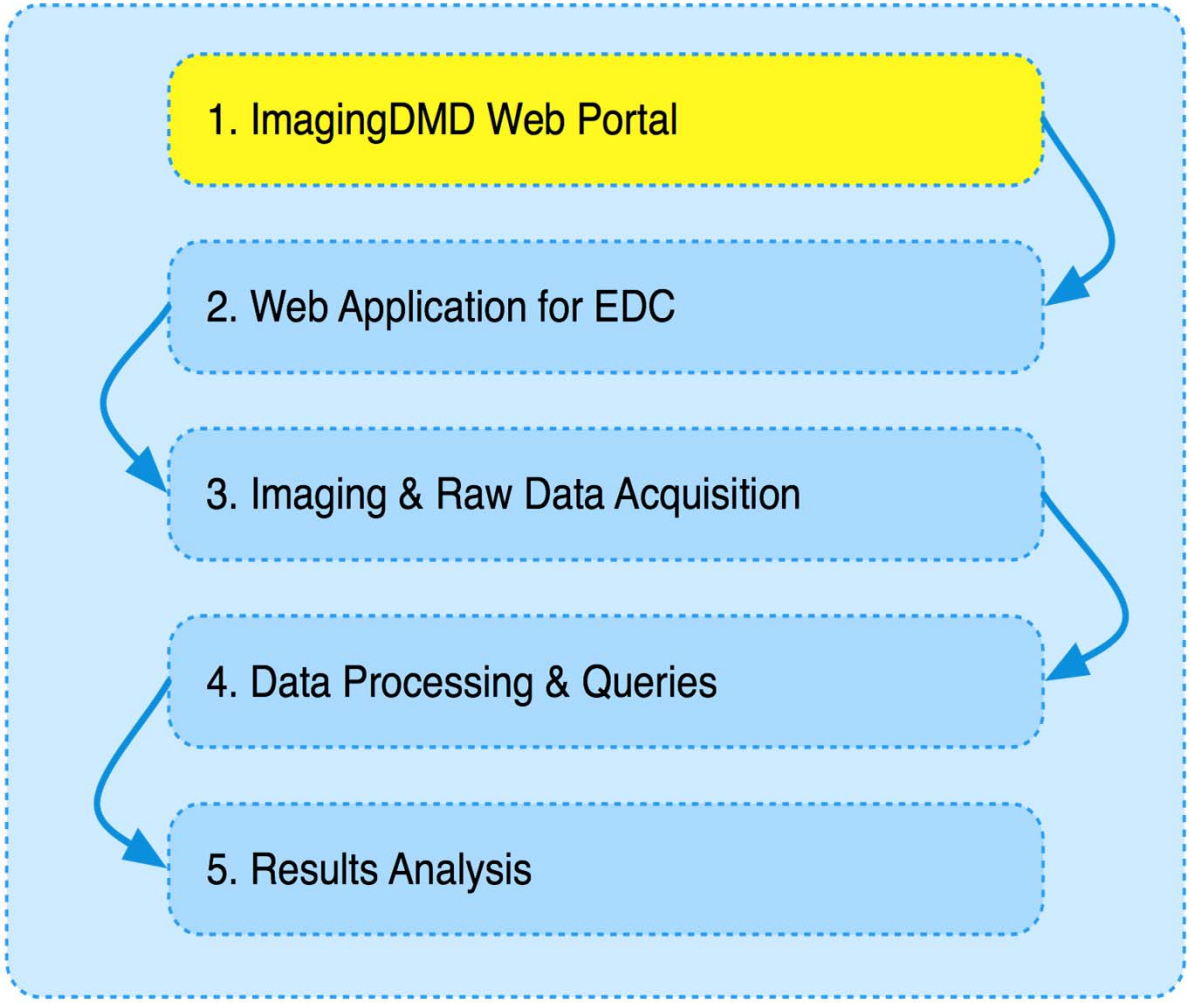
# ImagingDMD Systems Overview

- Public web server
  - ImagingDMD portal
  - EDC Application
  - File transfer access
- File server
  - MR Storage
  - All other files related to subject
- Processing Server
  - IDL/Matlab
  - MySQL
- Multi-site systems
  - centrally managed data
  - Sites see own data only
  - Flexible access control lists
  - Low operating costs
- Expandable
  - Add on studies
  - New projects
  - Low startup costs

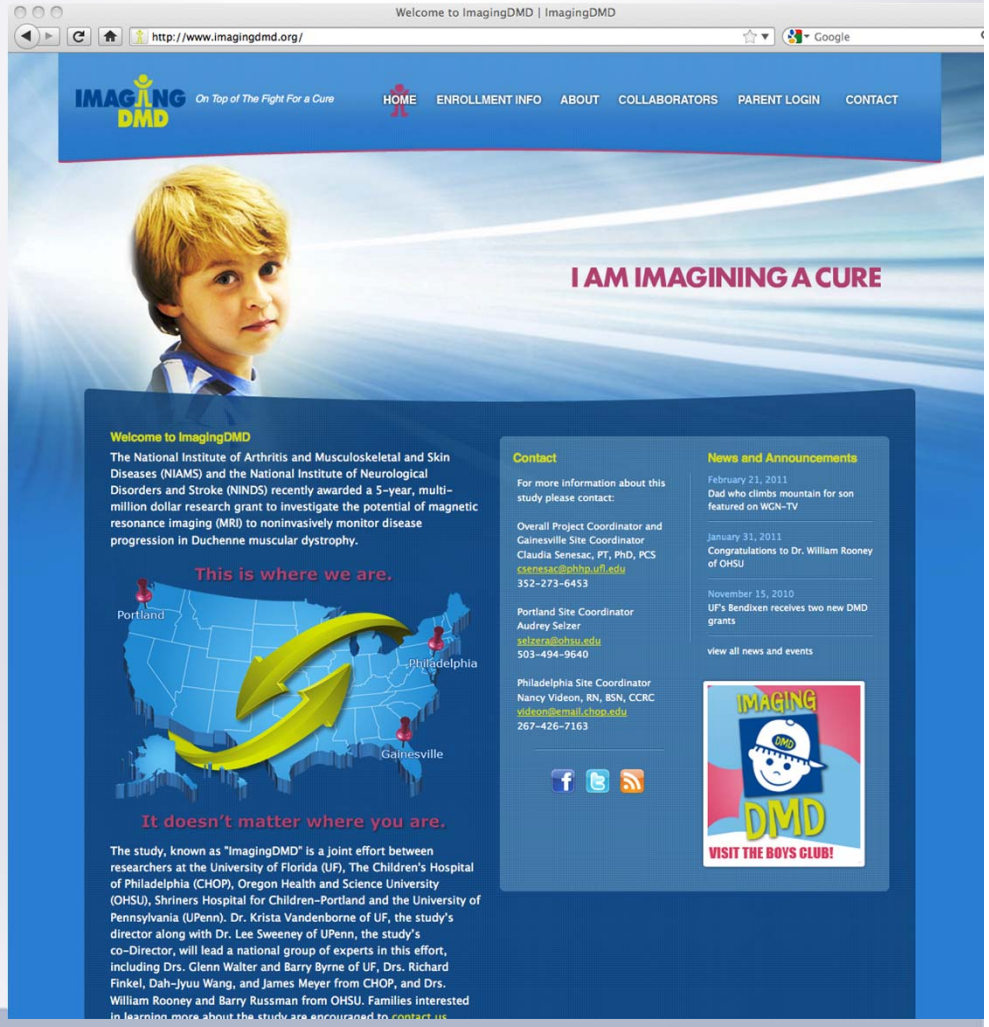


# ImagingDMD Web Portal



# Public Web Site

- imagingdmd.org
- Study and enrollment info
- Drupal Content Management System
- Customer-updated content

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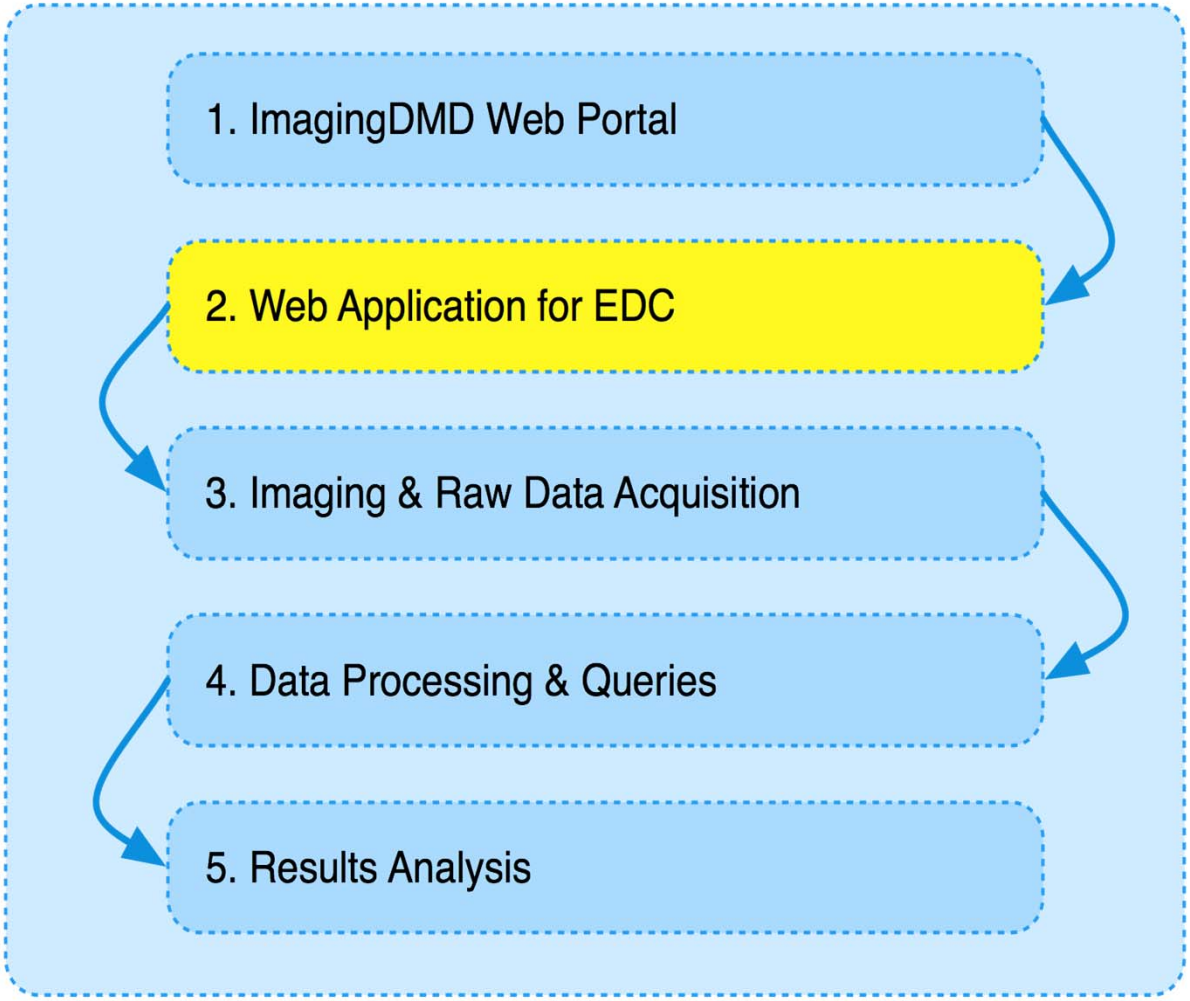
# For Boys

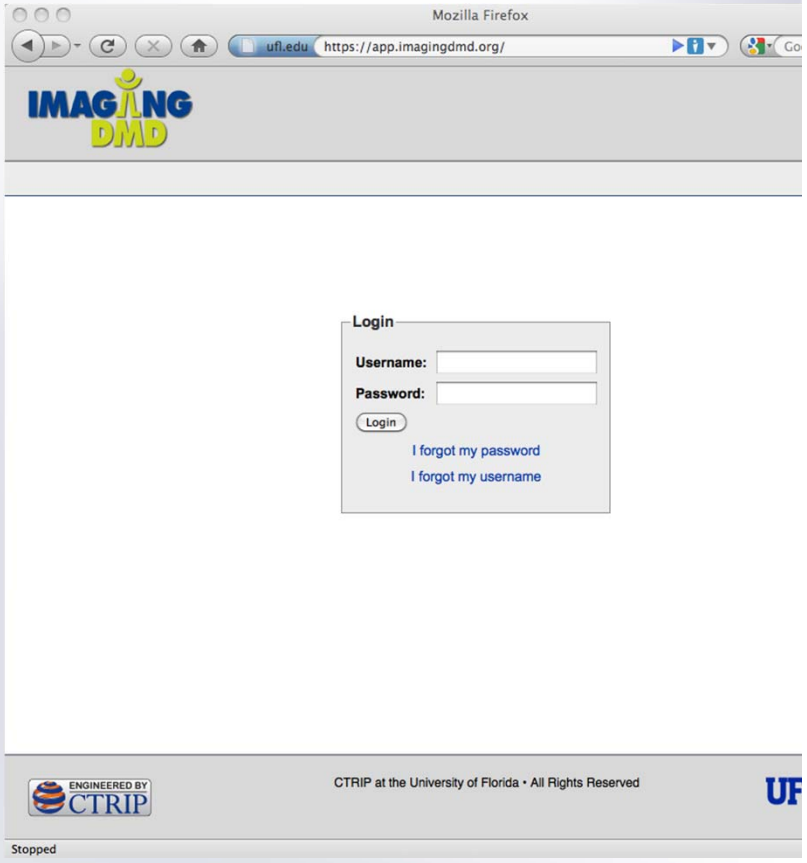
Boys Club | ImagingDMD
http://www.imagingdmd.org/?q=boys
Google
IMAGING DMD
On Top of The Fight For a Cure
HOME
ENROLLMENT INFO
ABOUT
COLLABORATORS
PARENT LOGIN
CONTACT
Word Search!
Level 1: Gainesville
Level 1: Philadelphia
Level 1: Portland
Level 2: Gainesville
Level 2: Philadelphia
Level 2: Portland
Level 3: Gainesville
Level 3: Philadelphia
Level 3: Portland
Coloring Pages!
Classic Car
Space Shuttle
Porsche
Skull & Crossbones
Ninja Turtles
Lamborghini
FUN STUFF TO DO!
Hey Boys,
Here are some activities to help pass the time while you're on the road or in the air making your way to visit us in one of our Labs. Ask your Mom or Dad if you can download and print out these sheets to carry with you while you travel.
We'd also like to hear from you (in your own words) any stories you'd like to share about your experience participating in ImagingDMD. Did anything funny happen while you were in one of our Labs? Do you want to share your feelings about the study or anything else with the other boys who are participating? Did you have an opportunity to learn anything about the equipment we use in the Lab or did you meet anyone on our investigation teams that made an especially important impact on you?
We realize that participating in ImagingDMD might not be the most fun thing you've ever done, but we try to keep things light and entertaining. Did you view a good video while in the magnet? Send us your original stories, pictures, poems or jokes that relate to the
Travel Bingo!!
Bingo Card #1
Bingo Card #2
Madlibs!
Madlib #1
Madlib #2: Gainesville
Madlib #2: Philadelphia
Madlib #2: Portland
Madlib #3
Mazes!

# Web Application for EDC



# Web Application Technology

- Homegrown application
- Open Source
  - CakePHP Framework
  - MySQL Backend
- Modular
- SSL Encrypted
- Hosted in HSC Infrastructure
- Parents pre-enter data
  - Demographics
  - Medical History
- Coordinators manage data
  - Anytime via web application
  - Report data via web app

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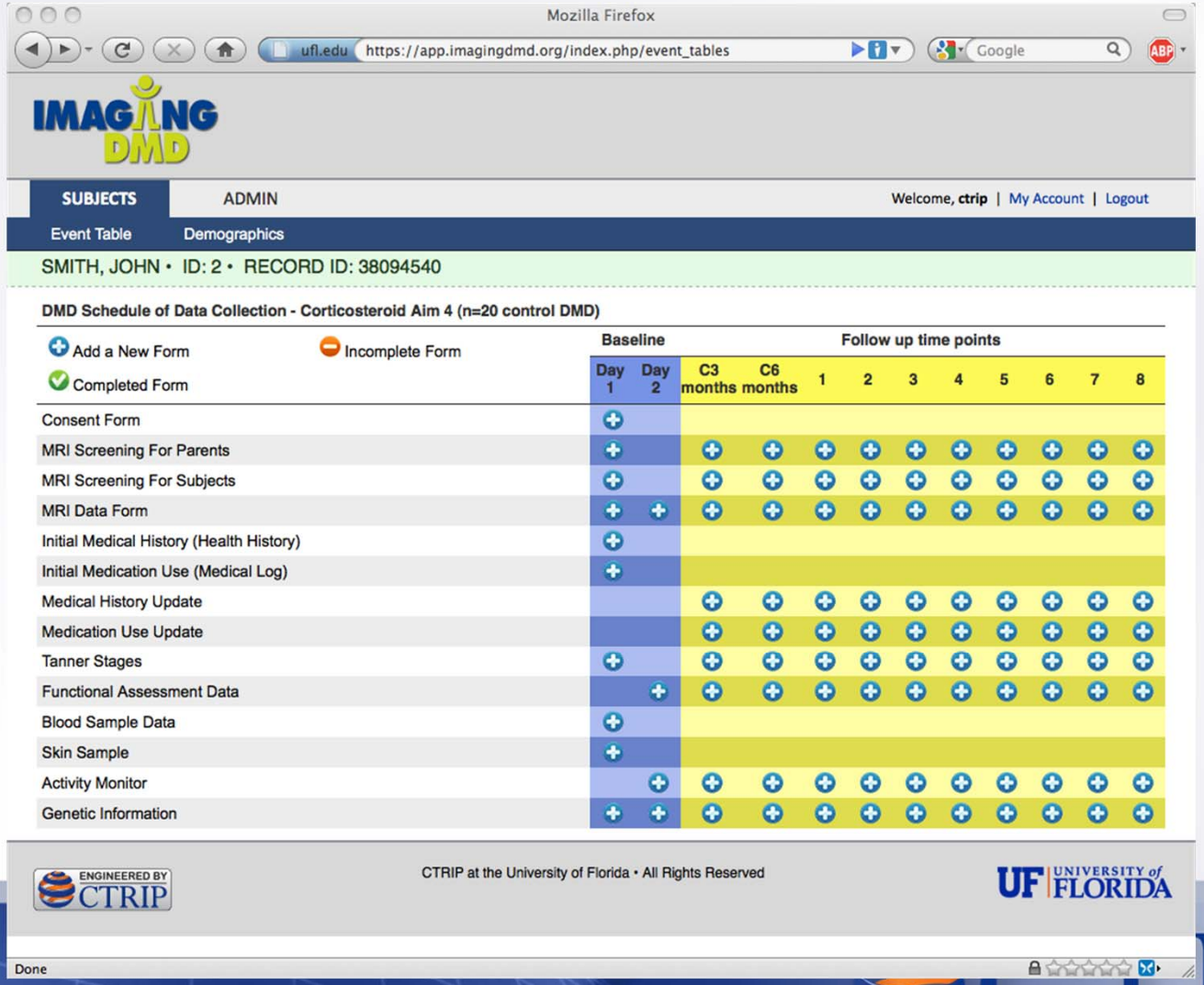
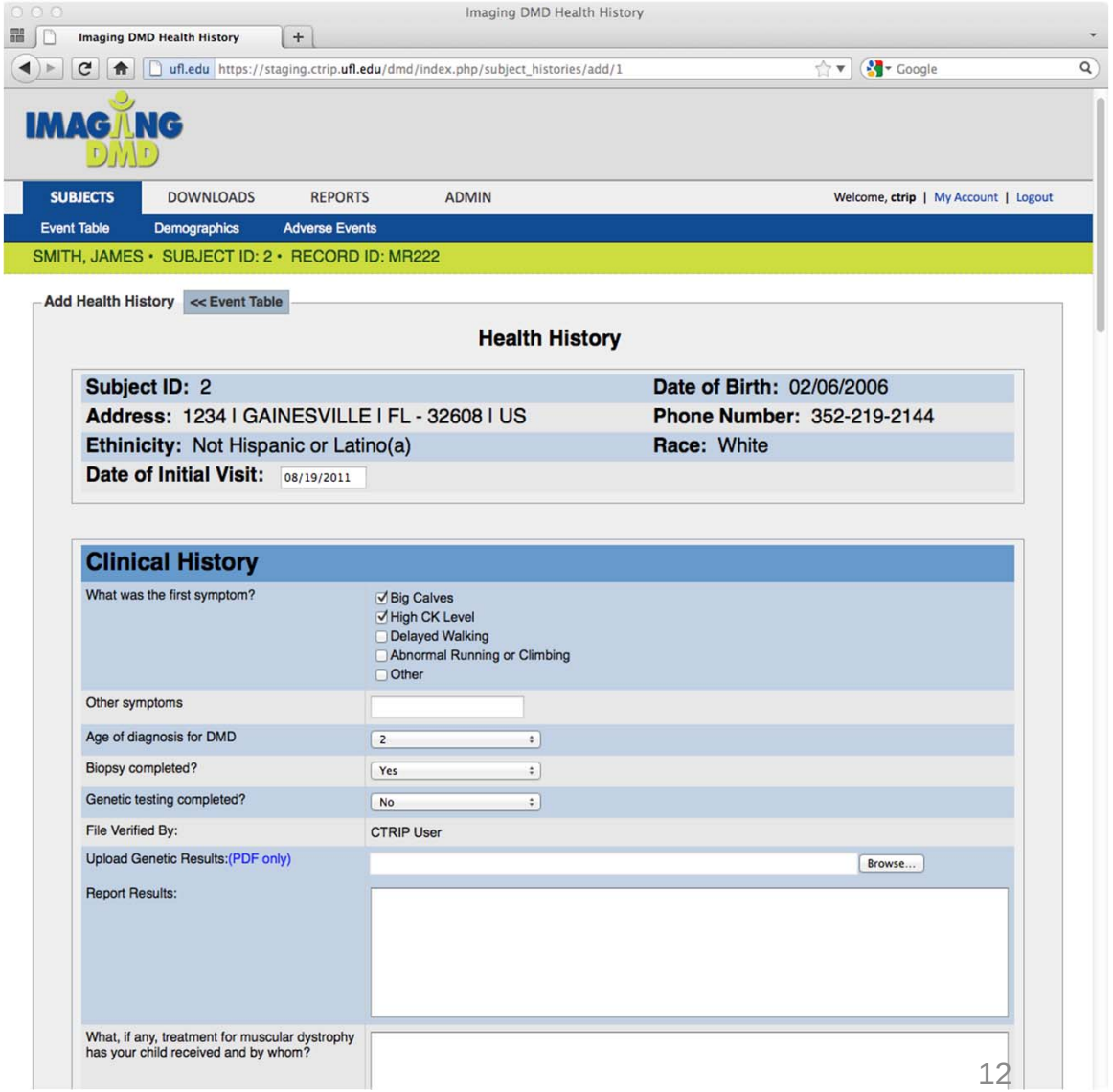
# Time & Events Matrix



# EDC Interfaces

- Medical History
- Medications
- File Uploads
- Skin Samples
  - Sample ID
  - Email Notifications to Upenn/fedex tracking
- Functional Assessment
  - Procedural Videos
- Biodex Data
- Etc.



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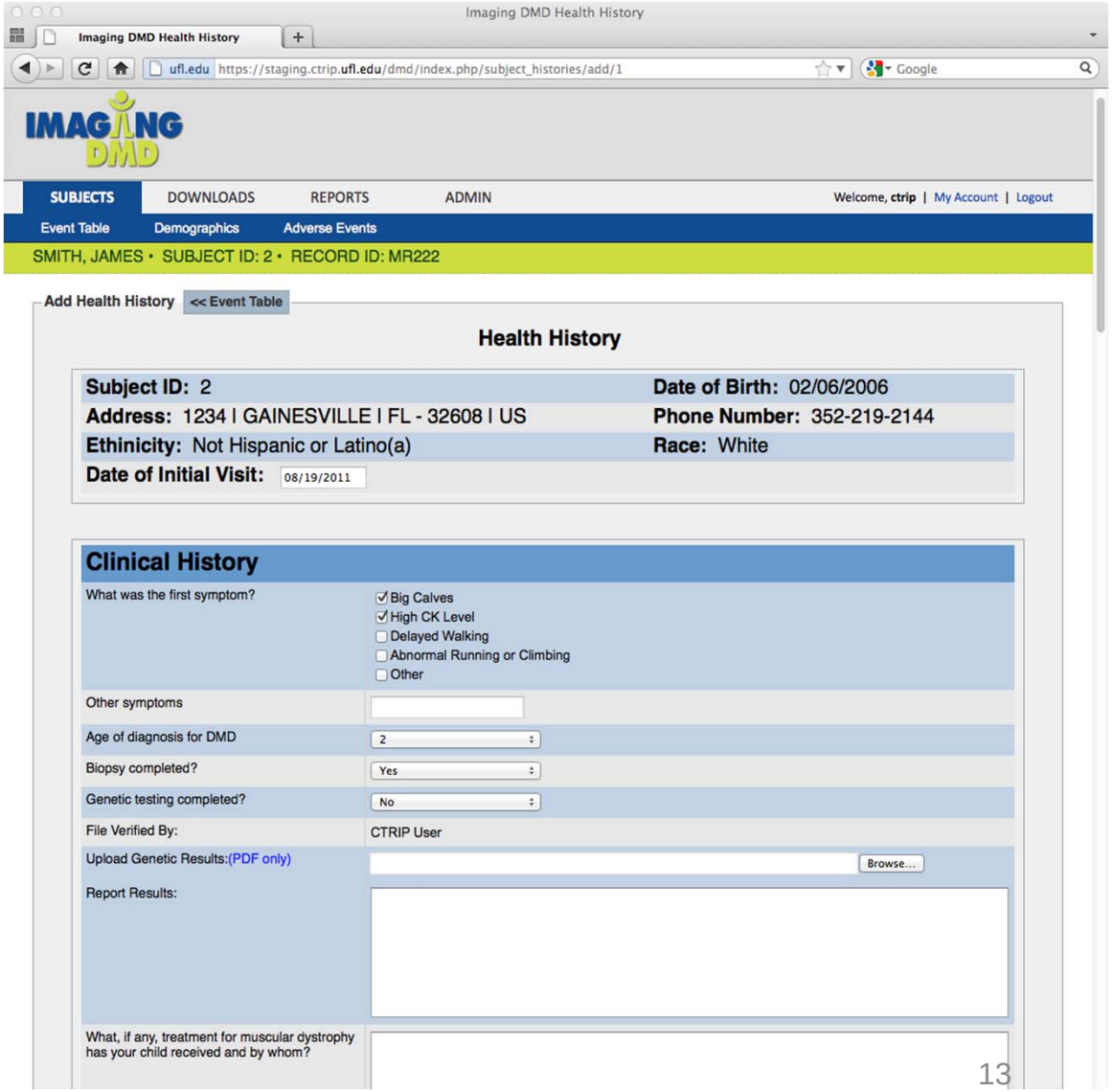
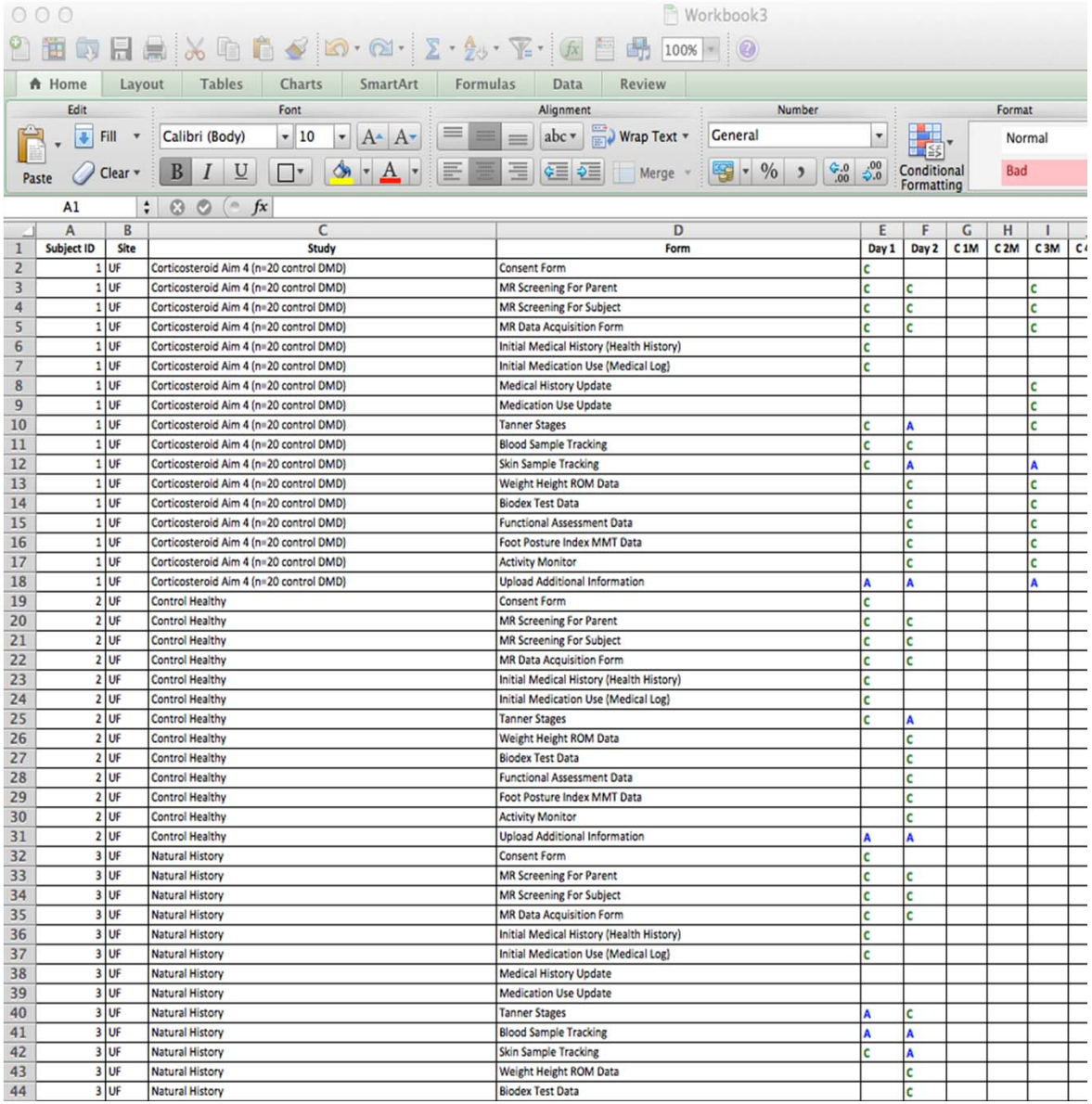


# Web-based Canned Reports

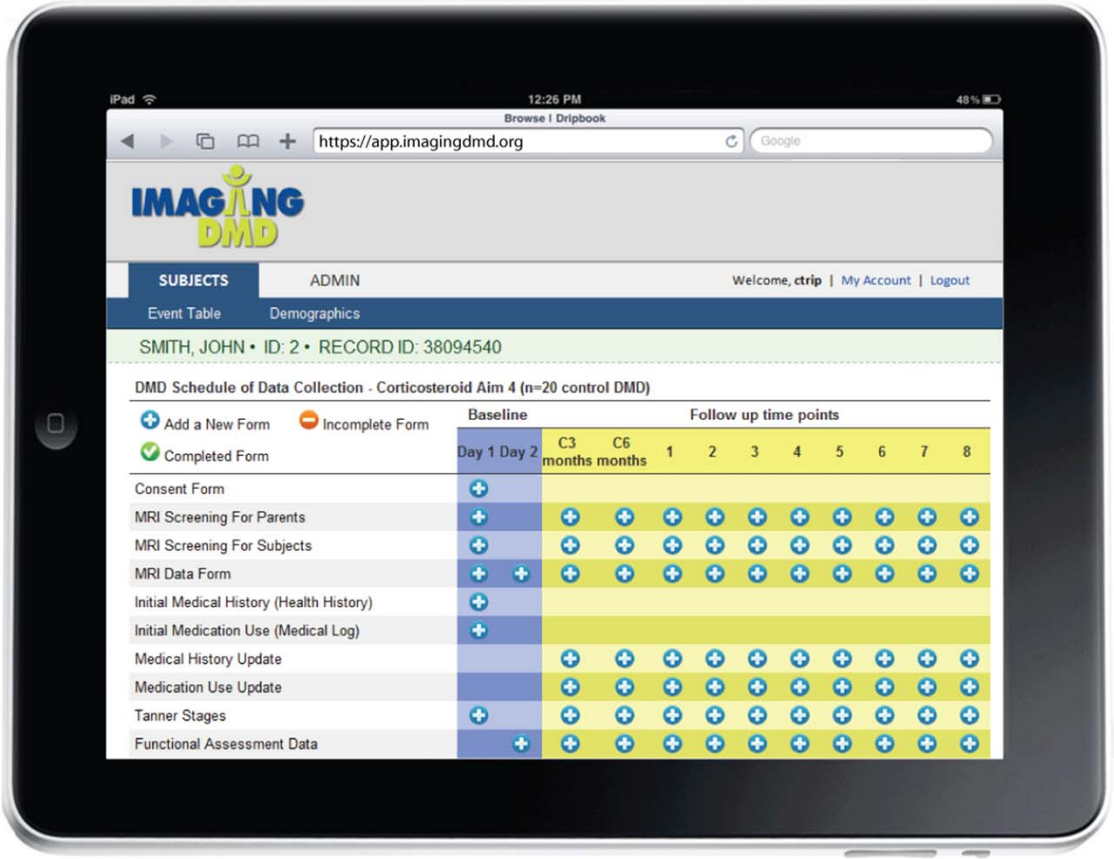
- Support daily study mgmt.
- Instant web-based reports:
  - Safety report
  - Adverse events
  - Protocol deviations



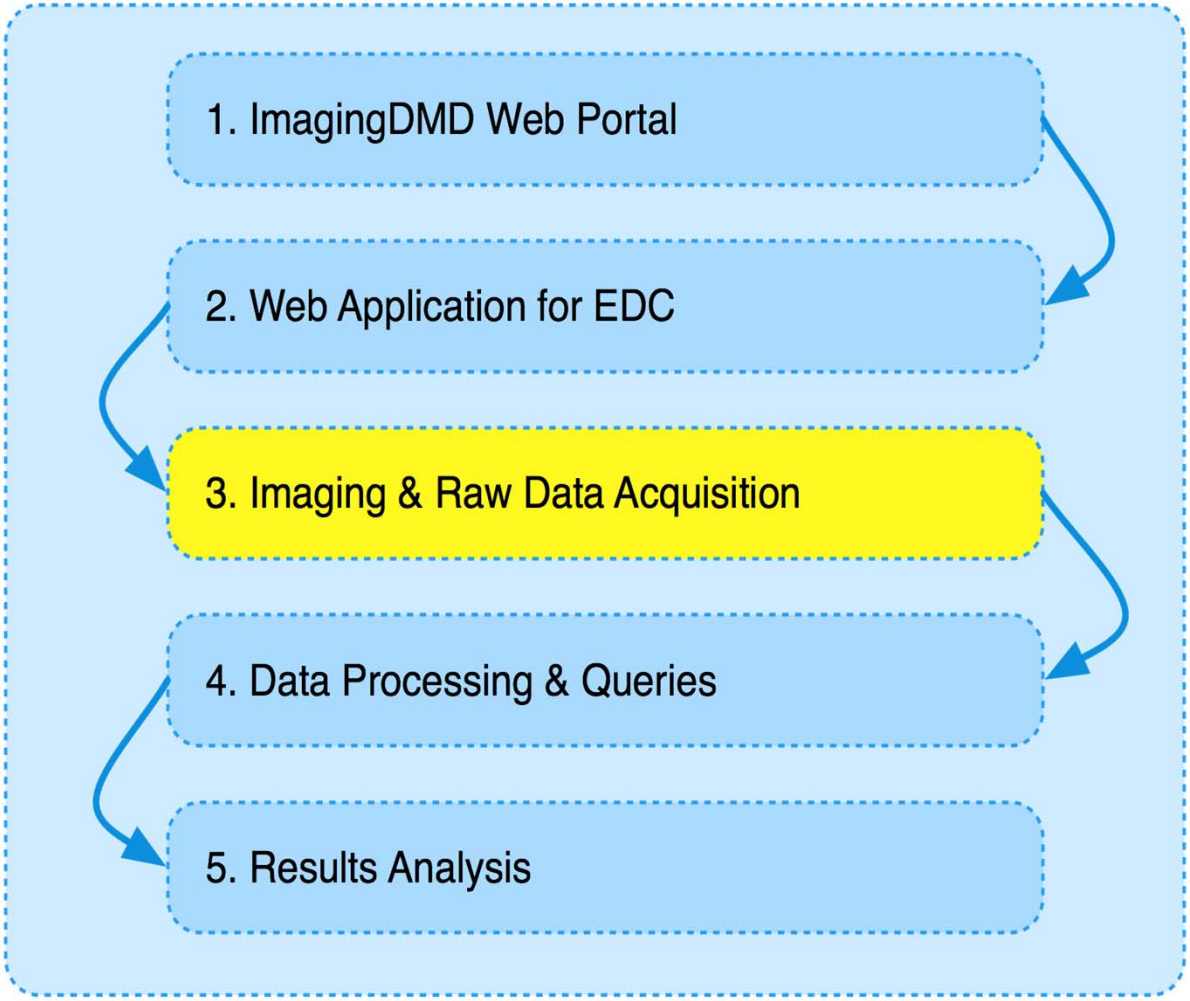

| | A | B | C | D | E | F | G | H | I |
|---|---|---|---|---|---|---|---|---|---|
| 1 | Subject ID | Site | Study | Form | Day 1 | Day 2 | C 1M | C 2M | C 3M |
| 2 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Consent Form | C | | | | |
| 3 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | MR Screening For Parent | C | C | | | C |
| 4 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | MR Screening For Subject | C | C | | | C |
| 5 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | MR Data Acquisition Form | C | C | | | C |
| 6 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Initial Medical History (Health History) | C | | | | |
| 7 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Initial Medication Use (Medical Log) | C | | | | |
| 8 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Medical History Update | | | | | C |
| 9 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Medication Use Update | | | | | C |
| 10 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Tanner Stages | C | A | | | C |
| 11 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Blood Sample Tracking | C | C | | | |
| 12 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Skin Sample Tracking | C | A | | | A |
| 13 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Weight Height ROM Data | | C | | | C |
| 14 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Biodex Test Data | | C | | | C |
| 15 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Functional Assessment Data | | C | | | C |
| 16 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Foot Posture Index MMT Data | | C | | | C |
| 17 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Activity Monitor | | C | | | C |
| 18 | 1 | UF | Corticosteroid Aim 4 (n=20 control DMD) | Upload Additional Information | A | A | | | A |
| 19 | 2 | UF | Control Healthy | Consent Form | C | | | | |
| 20 | 2 | UF | Control Healthy | MR Screening For Parent | C | C | | | |
| 21 | 2 | UF | Control Healthy | MR Screening For Subject | C | C | | | |
| 22 | 2 | UF | Control Healthy | MR Data Acquisition Form | C | C | | | |
| 23 | 2 | UF | Control Healthy | Initial Medical History (Health History) | C | | | | |
| 24 | 2 | UF | Control Healthy | Initial Medication Use (Medical Log) | C | | | | |
| 25 | 2 | UF | Control Healthy | Tanner Stages | C | A | | | |
| 26 | 2 | UF | Control Healthy | Weight Height ROM Data | | C | | | |
| 27 | 2 | UF | Control Healthy | Biodex Test Data | | C | | | |
| 28 | 2 | UF | Control Healthy | Functional Assessment Data | | C | | | |
| 29 | 2 | UF | Control Healthy | Foot Posture Index MMT Data | | C | | | |
| 30 | 2 | UF | Control Healthy | Activity Monitor | | C | | | |
| 31 | 2 | UF | Control Healthy | Upload Additional Information | A | A | | | |
| 32 | 3 | UF | Natural History | Consent Form | C | | | | |
| 33 | 3 | UF | Natural History | MR Screening For Parent | C | C | | | |
| 34 | 3 | UF | Natural History | MR Screening For Subject | C | C | | | |
| 35 | 3 | UF | Natural History | MR Data Acquisition Form | C | C | | | |
| 36 | 3 | UF | Natural History | Initial Medical History (Health History) | C | | | | |
| 37 | 3 | UF | Natural History | Initial Medication Use (Medical Log) | C | | | | |
| 38 | 3 | UF | Natural History | Medical History Update | | | | | |
| 39 | 3 | UF | Natural History | Medication Use Update | | | | | |
| 40 | 3 | UF | Natural History | Tanner Stages | A | C | | | |
| 41 | 3 | UF | Natural History | Blood Sample Tracking | A | A | | | |
| 42 | 3 | UF | Natural History | Skin Sample Tracking | C | A | | | |
| 43 | 3 | UF | Natural History | Weight Height ROM Data | | C | | | |
| 44 | 3 | UF | Natural History | Biodex Test Data | | C | | | |

# Touchscreen Device Friendly

- Carried w/ patient throughout visit
- Interfaces touch-friendly
  - Calendars
  - Select menus
- Video playback for real-time training
  - Position of leg in scanner
  - Functional assessment

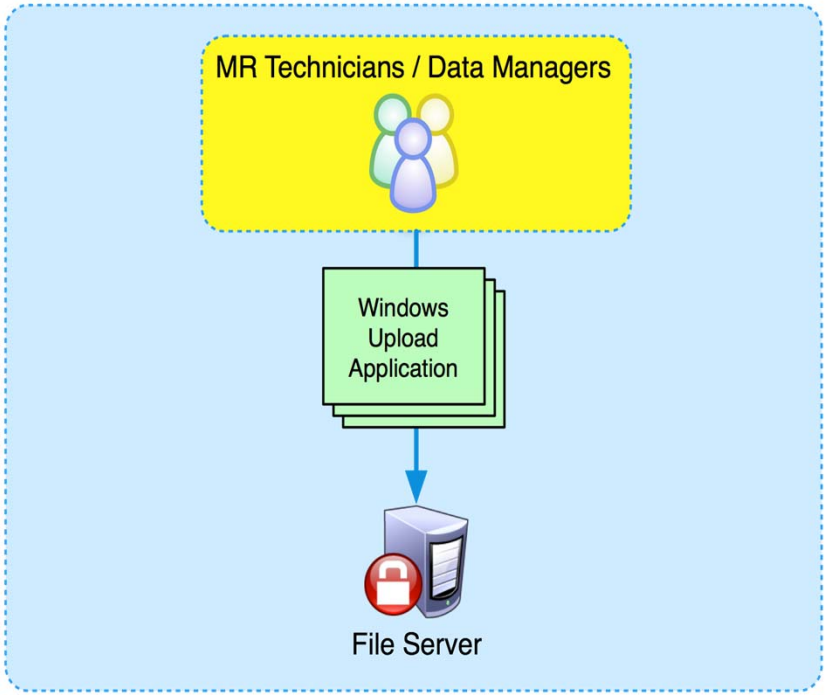


# Imaging & Raw Data Acquisition

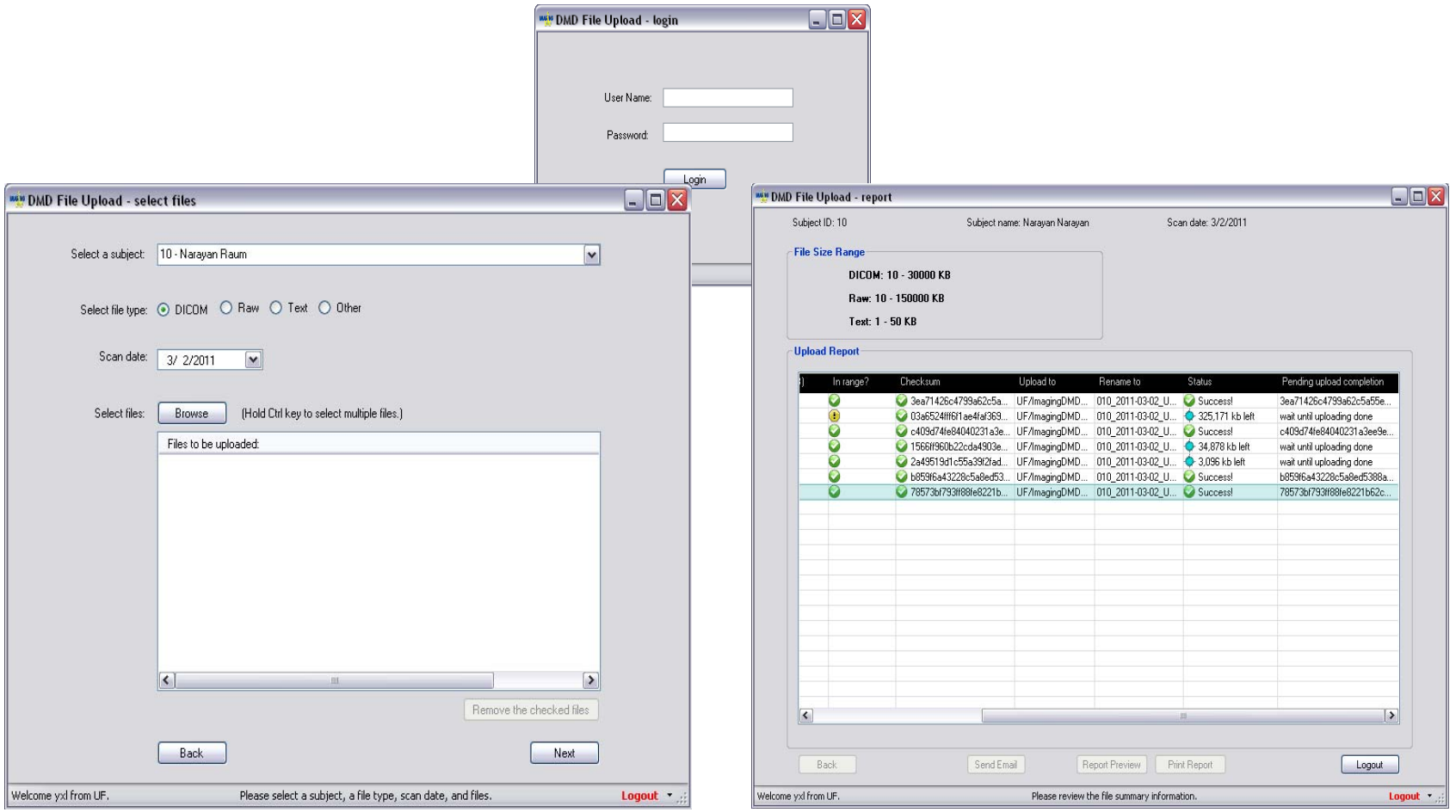


# File Server

- SFTP – Secure File Transfer Protocol
  - Direct shell access
  - Shared drive mountable
- Windows Upload Application
  - MD5 Checksum
  - Directory structure and file management
  - Email log upon completed transfer

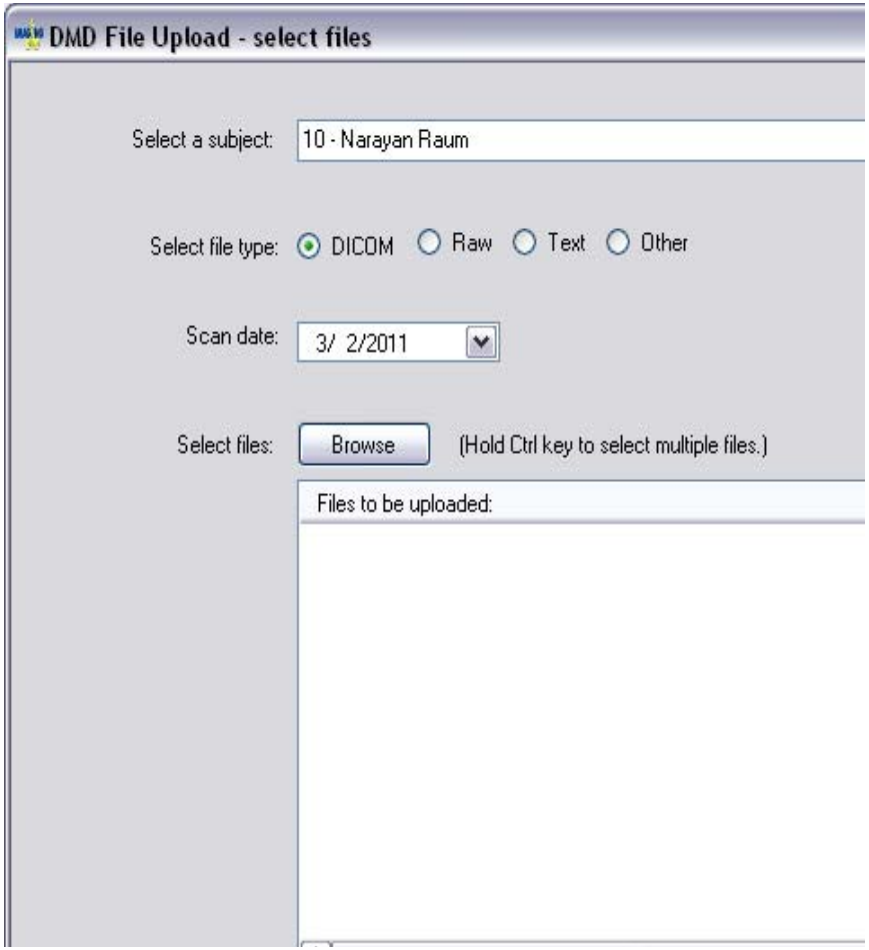


# Upload Application

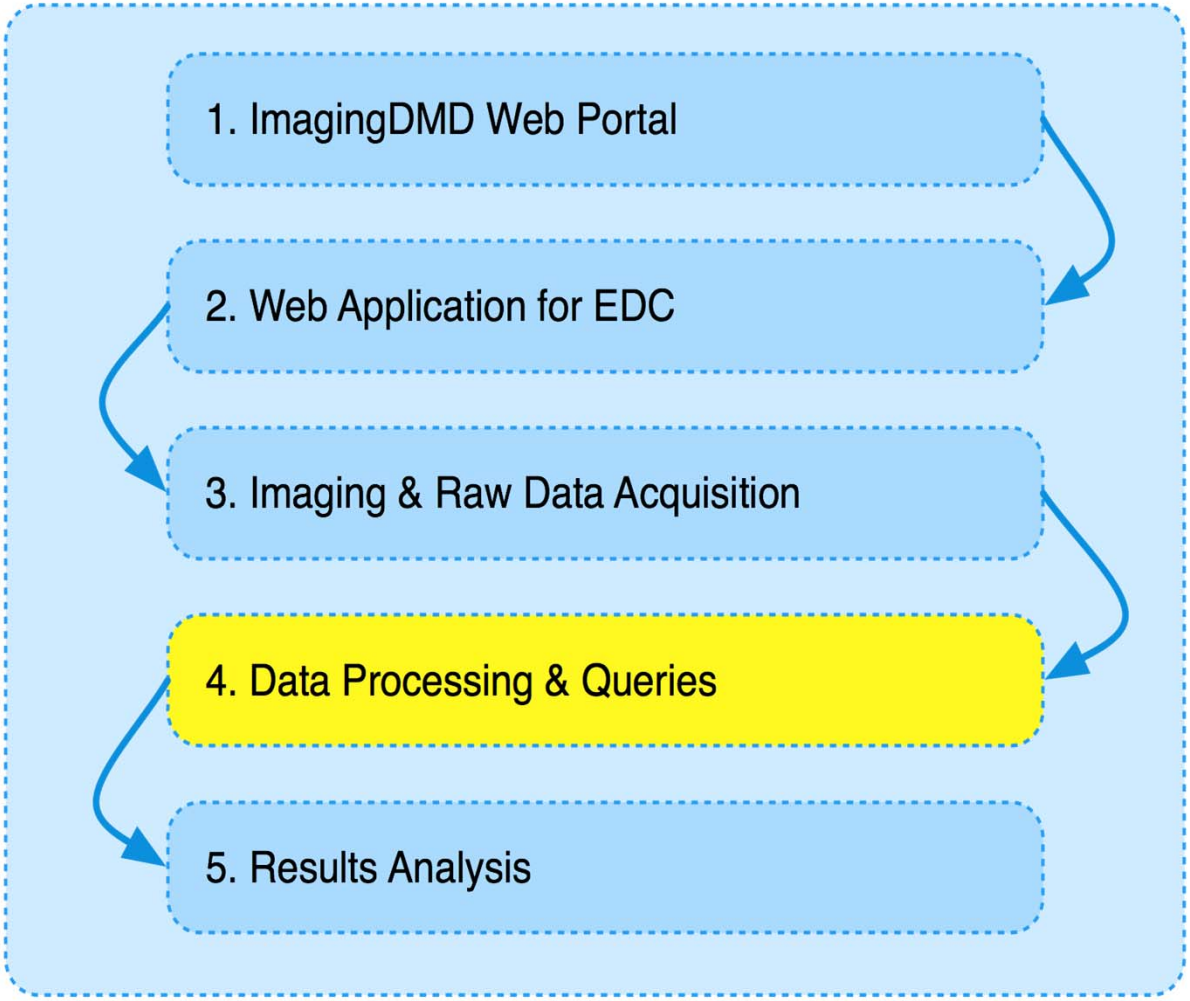


# Directory Structure Management

- Original file to upload named “abc123.txt”
- UF
  - 001
    - 001_2011-09-01
      - DICOM
      - Text
      - Raw
        - » UL
          - 001_abc123.txt

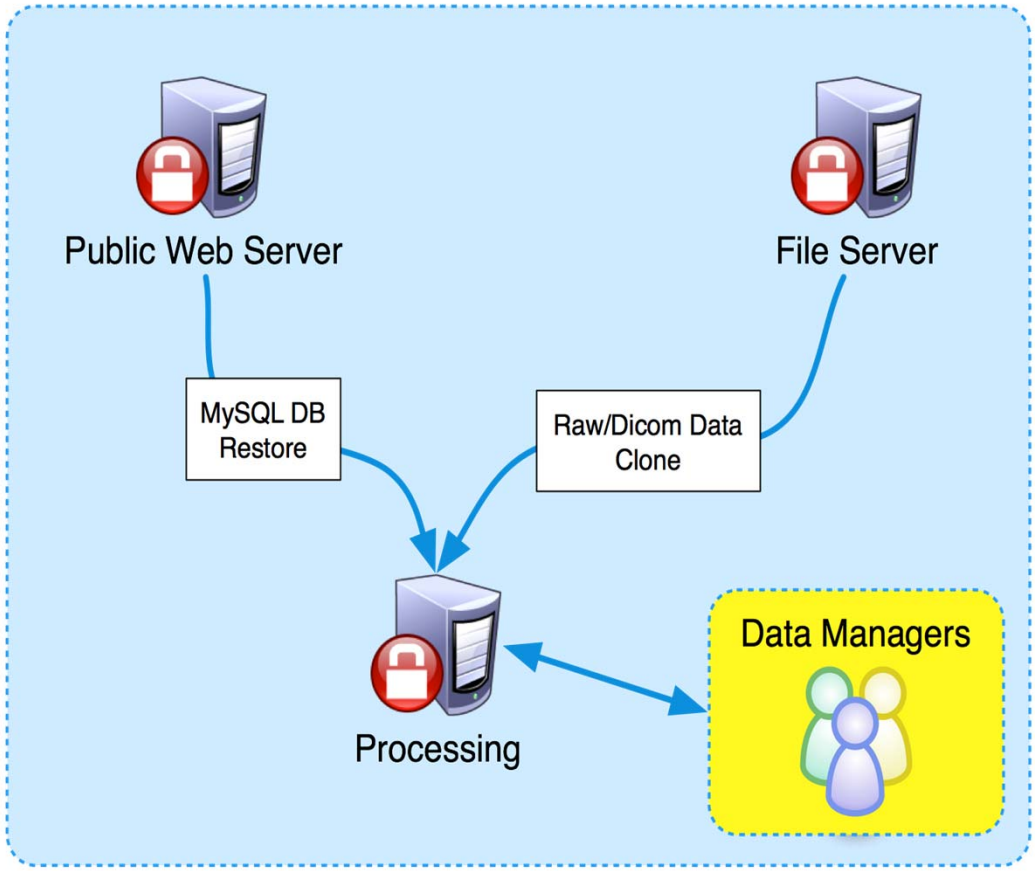


# Data Processing & Queries

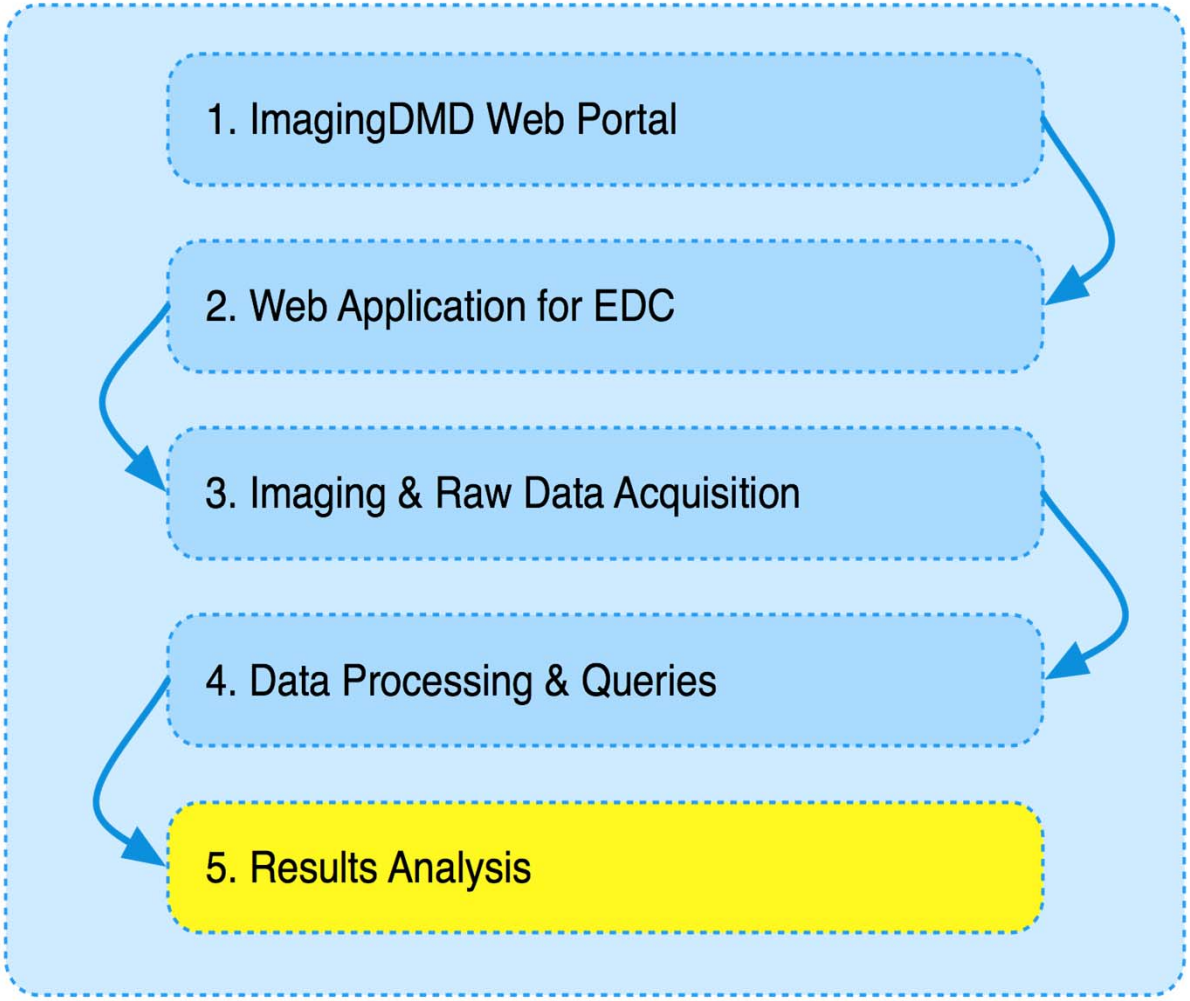


# Processing Environment

- Data immediately available
  - Raw
  - Dicom
  - Biodex
- EDC data queries
  - MySQL Instance
  - Database restored daily
  - Custom queries of data
- Software installed for analysis
  - IDL
  - Matlab



# Results Analysis



# Accepted Poster AMIA 2011

## Informatics System with Imaging and Touchscreen Devic

Narayan D. Raum, Christopher P. Barnes, Yang Li, Stephen Williams, Univ

### Abstract

Duchenne muscular dystrophy, a genetic muscle condition seen in boys, typically requires frequent muscle biopsies to monitor disease progression. CTRIP at the University of Florida assisted in a study aimed at monitoring disease progression through the use of magnetic resonance by implementing a complex informatics system, which is comprised of custom-developed and open source applications including touchscreen friendly EDC applications and MRI management solutions. This poster aims to outline the systems and infrastructure implemented to support the research aims.

The Clinical and Translational Research Informatics Program (CTRIP) at the University of Florida engineered an informatics system to support a national, multi-center NIAMS and NINDS funded research protocol, which is studying the potential of magnetic resonance imaging to, in a noninvasive manner, monitor disease progression in Duchenne muscular dystrophy. Many considerations, use-cases and decisions took place during planning and implementation of the Imaging DMD systems and infrastructure. Additional interfacing strategies and techniques were implemented to ensure user-friendliness and facilitate research. Emphasis was placed on the use of open source applications and solutions, which were instrumental in providing affordable solutions to facilitate the study needs.

### System Overview

#### Public Portal

The public-facing web site was implemented using Drupal, a popular open-source content management system. The portal serves as a gateway for all interests into the study, including activities and information for the young boys with DMD. Parents can obtain a login from study coordinators for patient self-reporting of data. Their access point to the database is through the public-facing web site. The site currently ranks first in a Google search for "imaging dmd". The site also contains links to a very active Facebook profile.

#### Electronic Data Capt

A touchscreen friendly web ap framework. It provides flexib self-reporting, and interfaces to

#### Screenshots

Homepage

Enrollment Information

About the Study

#### Screenshots

Subject Management

# Questions & Discussion

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