

Electronic Data Capturing Systems

Motivation, Design, and Implementation:
The University of Kentucky Experience



Prior to the New System (1989-2015)

- Data Collection
 - Paper forms
 - Data extraction via hand entry or TELEform OCR Scanner Software
- Data Storage
 - Various MS Access databases
- Reporting
 - MS Access Forms/Reports/Queries
 - Ad-hoc SAS queries

Challenges

- Data Collection
 - Paper forms filled out incorrectly and incompletely
 - Data QA was a significant burden
 - Scanning forms was very labor intensive, slow
 - Difficult to manage/track progress
- Data Storage
 - Data was not stored centrally on a single platform
 - Required significant effort to collate data
 - Lacked: audit tracking, UAC, sufficient redundancy, etc.

Challenges cont.

- Reporting
 - Significant delay between collection and ability to report
 - Datasets had to be stitched together from multiple sources
 - Preparation for NACC submission was resource intensive
 - No Business Intelligence/Enterprise reporting
 - No Real-time Operational reporting ability

New Data Systems Design

- Data Collection (Front-End)
 - MS SharePoint 2013
 - Forms7 (deprecated, now StratusForms)
 - SPServices (jQuery Library)
- Data Storage (Back-End)
 - MS SQL Server 2014
 - Centralize all data into Enterprise Data Warehouse (EDW)
- Reporting
 - MS SQL Server 2014 Reporting Services (SSRS)

Site Contents



Data Collection (Front-End)

- UDS 3.0 Forms
 - UDS forms constructed as individual HTML forms
 - Utilizing CSS & JavaScript
 - Used source code from NACC E-Forms hosted on NACC's website (UDS/FTLD Module Submission System)
 - Added additional JavaScript form logic for data quality control:
 - Cross-form checking
 - Form data input control
 - Pre/post form processing

Form A5: Subject Health History

ADC name: U Kentucky Subject ID: Form Date: / /
 VISIT #: Examiner's initials:

INSTRUCTIONS: This form is to be completed by the clinician or ADC staff. For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form A5. Check only one box per question.

1. History of cigarette smoking and alcohol use	
CIGARETTE SMOKING	
1a.	Has subject smoked within the last 30 days? <input checked="" type="radio"/> 0 No <input type="radio"/> 1 Yes <input type="radio"/> 9 Unknown
1b.	Has subject smoked more than 100 cigarettes in her/his life? (If No or Unknown, SKIP TO QUESTION 1F) <input checked="" type="radio"/> 0 No <input type="radio"/> 1 Yes <input type="radio"/> 9 Unknown
1c.	Total years smoked (99 = unknown): <input type="text"/>
1d.	Average number of packs smoked per day: <input type="radio"/> 1 cigarette to less than ½ pack <input type="radio"/> 2 ½ pack to less than 1 pack <input type="radio"/> 3 1 pack to less than 1½ packs <input type="radio"/> 4 1½ packs to less than 2 packs <input type="radio"/> 5 2 packs or more <input type="radio"/> 9 Unknown
1e.	If the subject quit smoking, specify the age at which he/she last smoked (i.e., quit) (888=N/A, 999=unknown): <input type="text"/>
ALCOHOL USE	
1f.	In the past three months, has the subject consumed any alcohol? <input checked="" type="radio"/> 0 No (SKIP TO QUESTION 2a) <input type="radio"/> 1 Yes <input type="radio"/> 9 Unknown (SKIP TO QUESTION 2a)
1g.	During the past three months, how often did the subject have at least one drink of any alcoholic beverage such as wine, beer, malt liquor, or spirits? <input type="radio"/> 0 Less than once a month <input type="radio"/> 1 About once a month

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Packet Progress for Participant Number 222222

Visit Number 2

Consent

- Consent Form: Complete ✓

Checklist

- Form Z1 - Form Checklist: Complete ✓

Nurse

- Blood Draw Form: Complete ✓

Physician: Subject

- Form B1 - Physical Evaluation: Not Started
- Form A5 - Subject Health History: Complete ✓
- Form B3 - UPDRS: Incomplete ✕
- Form B8-W - Neurological Exam: Complete ✓
- Form B8 - Neurological Findings: Complete ✓
- Form A4 - Subject Medications: Complete ✓

Physician

- Form B9 - Symptoms: Complete ✓
- Form B2 - Hachinski: Complete ✓
- Form B4- CDR: Complete ✓
- Form D1 - Diagnosis: Complete ✓
- Form D2- Medical Conditions: Complete ✓
- Diagnostic Impression: Complete ✓

Physician: Subject

- Form B1 - Physical Evaluation: Not Started
- Form A5 - Subject Health History: Complete ✓
- Form B3 - UPDRS: Incomplete ✕
- Form B8-W - Neurological Exam: Complete ✓
- Form B8 - Neurological Findings: Complete ✓
- Form A4 - Subject Medications: Complete ✓

Incomplete Packets



LINK	PTID	FirstName	LastName	VISITNUM	PACKET	VISITDATE	INITIALS
Check Participant Progress	111111	Timothy	Shannon	1	UDS	12/12/2015	SEP
Check Participant Progress	222222			2	UDS	11/10/2015	TPS
Check Participant Progress	1549			2	UDS	10/26/2016	DS
Check Participant Progress	82569			7	UDS	11/1/2016	DS
Check Participant Progress	540			17	UDS	9/21/2016	GAJ
Check Participant Progress	1409			3	UDS	12/8/2016	KCJ
Check Participant Progress	1424			3	UDS	1/3/2017	KCJ

Data Storage (Back-End)

- MS SharePoint 2013
 - Individual UDS Form data stored in SharePoint lists (tables)
 - Provides native audit tracking w/ version control
 - SQL Server Integration Services (SSIS) for migrating data
 - Automated integration packages import/update data into SQL Server
- MS SQL Server 2014
 - Serves as ADC Enterprise Data Warehouse (EDW)
 - Stores all UDS data collected (Past/Present)
 - SQL Views combine all UDS records
 - Provides additional audit tracking & UAC

Reporting

- MS SQL Server Reporting Services (SSRS)
 - Native reporting functionality packaged with MS SQL Server
 - Native UAC
 - Pulls data directly from EDW
 - Created reports for previous visit data, cohort statistics, participant status, neuropsych dashboards, etc.
 - Developed searchable reports based on Subject ID, etc.
 - Ability for users to subscribe to reports
 - Variety of options for viewing/exporting reports



Sanders-Brown Center on Aging: Reporting Services

Home



- [New Folder](#)
- [New Data Source](#)
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Administrative Core



Biostatistics Core



Clinical Core









Neuropath Core













Outreach and Education Core

 Sanders-Brown Center on Aging: Reporting Services
Clinical Core

 New Folder |  New Data Source |  Report Builder |  Folder Settings |  Upload File  Details View

- | | | |
|--|---|--|
|  Awaiting Consensus Report |  B9--B5 Discrepancy Report |  Clinical Cohort Summary |
|  Currently Active - Mailing List |  Form A2 Co-participant Demographics |  Impressions |
|  Last A1 Demographics |  Last A3 Family Health History |  Last A5 Subject Health History |
|  Last B9 Clinician Judgment |  Last Psychometrist |  Late List - 18 months plus |
|  MCI-CVD Physical |  Milestone Lookup |  Neuropsych Report |
|  Participants with UDS 3 Visits |  Patient Summary 2.0 |  Patient Summary 3.0 |

Post-Implementation

- Data Collection
 - Form logic reduced burden of data QA
 - Time to completion of packets improved significantly
 - Easy to manage/track progress
- Data Storage
 - Data centralized to Enterprise Data Warehouse
 - Longitudinal data is easily/automatically collated
 - Improved audit tracking, UAC, redundancy, etc.

Post-Implementation cont.

- Reporting
 - Real-time data
 - Immediate availability to Clinicians, Core Staff
 - Abundance of reporting options, formats, etc.
 - Faster preparation of datasets for researchers
 - Faster preparation of data for NACC submissions
 - Business Intelligence/Enterprise reporting for UK ADC Administrators
 - Real-time Operational reporting ability for all UK ADC Cores
 - Significantly reduced burden on DMS Core Staff

Summary

- Initial Development

- Two informatics systems architects/developers
 - With skills in MS SQL, HTML, JavaScript, MS SharePoint
- Timeframe
 - About 4 months from design stage to testing and implementation

- Future Development

- Continue to expand platform to collect Neuropath data
- Develop additional form input logic controls
- Develop additional cross-visit logic checks
- Develop additional reporting capabilities

Questions?