Designing and Implementing a Web-Based Data Management System for a Multi-Site Longitudinal Intervention Study

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Objectives:

- To discuss the design and implementation of a web-based data management system (DMS) for a complex, multi-site longitudinal study.
- To compare web-based DMS used currently, with PC-based DMS used previously.

Purpose of DMS:

- To assist field staff from multiple sites with managing participant activities efficiently for a longitudinal intervention study.
Background: NIH-DC Initiative

- **The NIH-DC Initiative (1993-2009)**
  
  To reduce infant mortality in minority populations in the District of Columbia.

- **Project DC HOPE (1998-2004)**
  
  To evaluate the effectiveness of a behavioral intervention targeting smoking, depression, and intimate partner violence in pregnant low-income minority women, with the goal of improving pregnancy outcomes.

- **GirlTalk for Teen Moms Study (2004-2009)**
  
  To evaluate the effectiveness of a community based intervention for minority teen mothers, with the primary purpose of increasing the inter-pregnancy interval to greater than 24 months.
GirlTalk Study Flowchart

Recruit Teens

Screening + Enrollment

Consent (Teen and legal guardian)

Baseline CAPI #1 (Teen + Mother)

Baby Delivered

Baseline CAPI #2 (Teen)

Randomize

Usual Care Group

Follow-up CAPI (every 6-mo)

Pregnancy Test/Check (every 3-mo)

Intervention Group

53 Intervention Sessions:
- Weekly (1-6mo)
- Bi-monthly (7-12mo)
- Monthly (13-18mo)
- Group (every 3-mo)

(N=340)
Goals of the DMS

- **Real-time data:** Data available anytime, anywhere
- **Reduce staff time/burden:** Record all data forms electronically; pre-populate using linked data forms.
- **Increase efficiency:** Allow multiple users to access data real-time; reduce the need to email/call sites.
- **Reduce staff error:** Manage 100+ possible activities for each participant over 2-yr study; staggered enrollment dates; provide reminders, trigger key events.
- **Increase Monitoring/QA:** Reports allow for continual review of process indicators
Developing the DMS

- Finalize the procedures; create detailed flow chart
- Assign roles and responsibilities
- Develop data collection forms
- Develop reports
- Decide if reminders are needed for events
- Define event windows (time allotted to complete events)
Lessons Learned from Design

- Manage client and user expectations
- Keep it simple (e.g. minimize # of data forms)
- Finalize procedures in advance to reduce labor/time
- Expect changes to occur in first 6-mo of study—pilot test if possible
- Balance flexibility for staff vs. automated DMS control
- Remember, always need a human to think!
Implementing the DMS
Objective

- To describe the efficiencies obtained by moving from a PC-based data management system (DMS) to a Web-based system
All transmissions were initiated by the central server at the RTI DCC.

Required successful nightly data transmissions to and from each site via point to point modem transmission.

Physical security of Central PC had to be addressed.
PC-Based System - Pros

- Users could continue working if an Internet connection was not available.
- Modem connections at each site allowed developers to dial directly into the machines to remotely control the desktops for support.
- Application development tool (MS Access) and environment (Windows) were familiar.
PC-Based System - Cons

- Telephone connections were slow and somewhat unreliable.
- There was no real-time synchronization of the data between the sites and the DCC. At best there was a one day delay.
- Software updates had to be transmitted to each PC and installed.
- Users could access the system only from PCs where the software had been installed.
Web-Based System  
(GIRL TALK)

- Web-based model eliminates the problems of delayed data transmission.
- Data are stored in a secure SQL Server database at the DCC.
- All data are available as soon as they are entered or after a laptop transmits.
Web-Based System - Pros

- **Real-Time Data Access:** All data are instantly available as soon as they are entered in the DMS.
- **Simplified Software Updates/Fixes:** The DMS application files are housed and managed at the DCC.
- **Data Security:** Data is not stored on study PCs. Users enter data directly into the Web application, and data is stored in a secure database at the DCC.
- **Anytime / Anywhere Access:** Users can access the DMS from any computer with an Internet connection and the Internet Explorer browser.
Web-Based System - Cons

- An Internet connection is required to access the DMS.

- The Web interface is not as smooth as an application that runs on PCs (e.g. Word, Outlook).
  - Smaller user interface toolset
  - Performing one simple task per screen vs. navigating through all tasks on a complex screen
  - Responsiveness (excessive server roundtrips)

- There was a learning curve for the chosen Web development technology (ASP.NET version 1.1).
Web DMS Features – Role-Based Menu

- Access to features is controlled through roles assigned to menu items. This means we can develop and maintain one application for all users.

Counselors in clinics see this:

Interviewers at call center see this:
Users at both locations use the same Events feature. User’s location determines the subset of events to be displayed.
Web DMS Features – Appointment Calendar

- Each location has its own appointment calendar. Appointments can be filtered by staff member.
Web DMS Features – Appointment Calendar

- Clicking on an appointment link pops up a second window showing details about the appointment, including a MapQuest link to the appointment location.

![Appointment Details Window]

**APPOINTMENT DETAILS**

- **Teen ID:** G10254
- **Teen Name:** Test Teen
- **Appt Type:** Home Visit - Teen Only
- **Date and Time:** 05/01/2006 4:30 PM
- **Place:** 1600 Pennsylvania Avenue NW
  Washington DC 20500
- **Counselor:** TAA
- **Notes:** This appointment is tentative.
- **MapQuest:** [Map This Appointment Location](#)
Web DMS Features – Report Generation

- Reports are generated in the DMS using real-time data from all sites.
Study documents are stored centrally in the DMS. This ensures that users across the sites access the most recent version.
Study staff use the DMS to upload ACASI/CAPI data files to the DCC server. A separate transmission system is not needed.
Cost Considerations for Web-Based System

- Size of study – Number of cases, number of study activities, amount of data being collected
- Duration of study
- Multiple sites – Number of centers and staff in the field
- Infrastructure – Technical support costs associated with maintaining Web server, database server, Internet connections
Implementation Lessons Learned

- A phased approach to implementing a system works well when time frame is short.

- Sometimes a system can give users too much flexibility. Make it rigid enough to minimize user errors.

- Avoid re-inventing the wheel. If a software tool with the desired functionality already exists, consider using it.
  - For example, use MS Outlook to maintain appointment schedule.

- Often users will “ask for the moon.” Keep an open mind and view their requests as an opportunity to explore features previously thought to be too difficult to implement.
Using a Web-based DMS alleviated many of the problems encountered with the PC-based system.

- Transmission difficulties
- Sharing data between sites and the DCC

The Web environment allows for new features that are difficult or not possible to implement with stand-alone PC systems.

- Centralized events tracking, appointment scheduling, document storage
Questions? Contact Us

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