

DATA ACQUISITION,
DATA MANAGEMENT AND
SUBJECT TRACKING IN
CLINICAL AND
TRANSLATIONAL RESEARCH

Seeking solutions to
persistent challenges

Data Acquisition, Management and Tracking

Symposium Moderators:

Bruce A. Barton, PhD

Research Professor

UMMS Dept. of Quantitative Health Sciences

Director, Quantitative Methods Core

Mary E. Costanza, MD

Professor of Medicine, UMMS Dept. of Medicine

Data Acquisition, Management and Tracking

Bruce Barton: Disclosure

I have no actual or potential conflict of interest in relation to this program/presentation.

Data Acquisition, Management and Tracking.

Mary Costanza: Disclosure

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Data Acquisition, Management and Tracking

Background

Clinical studies involving recruiting and observing human subjects over time requires

- Data of many types to be collected from many sources
- Data must be integrated into 1 system, using a variety of data interfaces
- This system must track subjects, generate management reports & develop analytic reports

HOW IMPORTANT
IS
DAMT ANYWAY?

Why DAMT is Important

- Without GOOD Data Management, you risk:
 - Not getting funded
 - Not able to use for analysis
 - Not able to publish
 - Not able to verify results
 - Not able to sleep at night
- Without GOOD Tracking, you risk:
 - Losing specimens
 - Losing patients
 - Losing your mind

Why DAMT is Important

- Funding agencies now want Data Management Plans
- Badly designed data capture systems may produce data that is uninterpretable
- Journals are frequently now requesting data that went into analysis (and sometimes the programs)
- If someone questions results, you may not be able to reproduce them from scratch – part of QC and Reproducible Research
- You think that you have insomnia now? Just wait!!!

Why DAMT is Important

- Without specimen tracking, easy to lose specimens in freezers and in transit
 - Picture specimens sitting on a loading dock in Dallas in July – not pretty
- Without patient tracking, lose patient visits, create protocol violations, lose data for analysis
 - Data may not be fully missing at random – so cannot impute
- Without tracking systems, you have no control of the study or project

Bottom Line

- Without reliable data, cannot do reliable statistical analysis
- Without reliable analysis, why did you do your study?



Research Conveyor Belt

DAMT: Definitions

- In the following presentations and slides, the definition of “data management” varies:
- QMC: research data management for research studies, such as clinical trials, and research endeavors, such as animal labs
- IT: clinical data management using EHR/EMR systems
- Library: data management for organizing data files for long-term access, storage, archiving

Data Acquisition, Management and Tracking

Specific problems

- Designing effective and complete field naming conventions
- Handling potentially conflicting data from various sources
- Designing routines for updating data fields in real time
- Developing customized applications to support complex DAMT tools

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Symposium purpose

- To begin a dialogue among faculty and staff involved in addressing the clinical data challenges of DAMT
- To identify & characterize important and recurring challenges
- To identify local resources that could facilitate DAMT system design and implementation
- To explore potential solutions to common DAMT problems

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Symposium Format

Case study presentation:

Roger Luckmann, MD, MPH, UMMS Dept. of Family
Medicine and Community Health

Panel discussion:

Rebecca Gore, PhD, Biostatistician Programmer, UML
Dane Netherton, Database Administrator, UMMS QHS/QMC
Paul Ranauro, UMMS Information Services

Audience Participation

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Audience and Panel Discussion

- What are the important & recurring problems?
- What local resources are available?
- What can we do to improve DAMT?