Data Quality: Lessons Learned

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Disclosures for ATHN for Anne Neff

- Project specific funding
  - LFB Biotechnologies consultant
  - Research studies:
    - NovoNordisk
    - PTC Therapeutics
    - CSL Behring
- Chair, Data Safety Monitoring Board, NHLBI Transfusion Medicine and Hemostasis Network
- Chair, Data Monitoring Committee, Pfizer rVIIa study

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Our Story: Data Quality

- HTCs want to use and reuse data collected to
  - create ATHNready Personal Health Reports and give USB drives to their patients
  - produce HDS and UDC reports and
  - conduct research projects
- The question that must be answered: Is the data's quality (presence and correctness) fit for use for these purposes?

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Improving Quality of Data

Patient	Hemostasis Diagnosis		Baseline Lab Value		Severity or Type Classification*		Errors Corrected	
	Present	Correct	Present	Correct	Present	Correct	All Correct	Errors Corrected
1	X	X	X	X	X	X	X	
2	X	O	X	X	O	-	O	X
...								
20	X	X	X	X	X	X	X	
# Present or Correct (X's)	3	2	3	3	2	2	2	
# Not Present or Correct (O's)	0	1	0	0	1	0	1	
% Error	0%	33%	0%	0%	33%	0%	33%	
Source Document		Paper Chart		Lab Report		Paper Chart		

- Compares 10% of cases to source documents
- Data quality plan to reduce systematic errors

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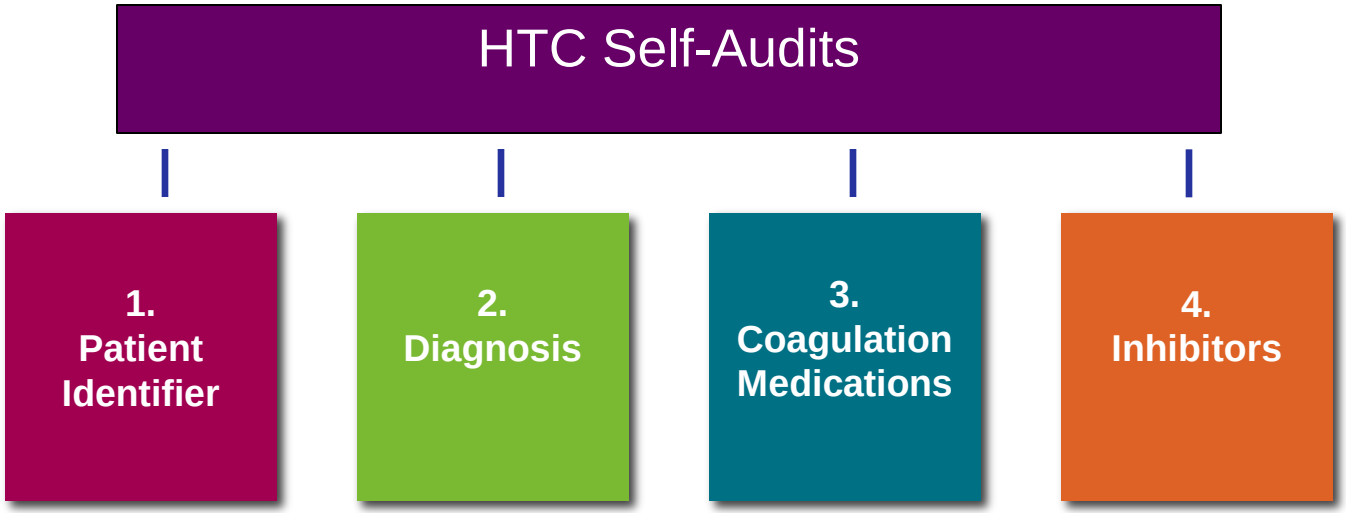
Self-Audits to Ensure Data Quality



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ATHN Data Quality Counts Audits

- Audited over 500 records
- To Validate WebTracker conversions and/or other patient data
- Compares source documents (EMRs, paper charts, lab reports, etc) to WebTracker database entries
- Error analysis
  - Recorded on Quality Plan summary sheet
  - ?Transcription errors; ?Data never collected
  - Propose Action Plan to correct current errors AND prevent future errors

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Patient Identifier Audit

- ATHN ID#
- Address
- Phone #
- Gender
- Race
- Ethnicity
- DOB
- Place of Birth
- Last 4 SSN’s

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What We Have Learned - Patient Identifier Audit

- We’re good at ID#’s, Addresses, Phone #’s, gender and DOB
- We’re not as good with Ethnicity, Place of birth, and last 4 of SSN’s.
- Race & Ethnicity are self-reported
  - Do EMRs handle mixed-race well?
  - Do most clinics even ask for ethnicity?
- All in all, this audit usually goes well

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Diagnosis Data Audit

Patient	Hemostasis Diagnosis		Baseline Lab Value		Severity or Type Classification*		Errors Corrected	
	Present	Correct	Present	Correct	Present	Correct	All Correct	Errors Corrected
1	X	X	X	X	X	X	X	
2	X	O	X	X	O	-	O	X
...								
20	X	X	X	X	X	X	X	
# Present or Correct (X's)	3	2	3	3	2	2	2	
# Not Present or Correct (O's)	0	1	0	0	1	0	1	
% Error	0%	33%	0%	0%	33%	0%	33%	
Source Document		Paper Chart		Lab Report		Paper Chart		

- Hemophilia – dx OK
  - severity & baseline labs iffy
- Von Willebrand disease
  - precise type often missing

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Coagulation Medication Audit

Present/Correct

- CURRENT factor medication/DDAVP
- Med Reconciliation
- WebTracker & Med reconciliation match
- Start date
- Treatment type
  - Prophy, on-demand, pre-surgical
- Dosage
- Frequency
- Patient Weight
- Error correction

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Coagulation Medication Audit- Lessons Learned

- Oops! We DO want you to put all patients on the same audit page
  - Added a column for Pt identifier
- List primary hemostatic medicine(s)
  - Some may have one med for ITT; a second one for bleeds
- If none currently, then put none and stop there

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Inhibitor Audit

	Current Inhibitor				Historical Inhibitor					
Patient	Current Inhibitor Titer		Current Inhibitor Start Date		Historical Inhibitor Titer		Historical Titer Start Date		Historical Inhibitor Endt Date	
	Present	Correct	Present	Correct	Present	Correct	Present	Correct	Present	Correct

- Enter ALL inhibitor patients; past & present into this audit
- Magenta bar over Current Inhibitor columns
- Blue bar over Historical Inhibitor columns
- Patients will have one or the other

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Currently Active Inhibitor

- Complete the first 4 columns under magenta header
- If applicable, complete the 10 ITT columns
  - IT med, start date, dose, frequency, end date
  - Can be on-going or failed
- ***Insert a dash into Historical columns***

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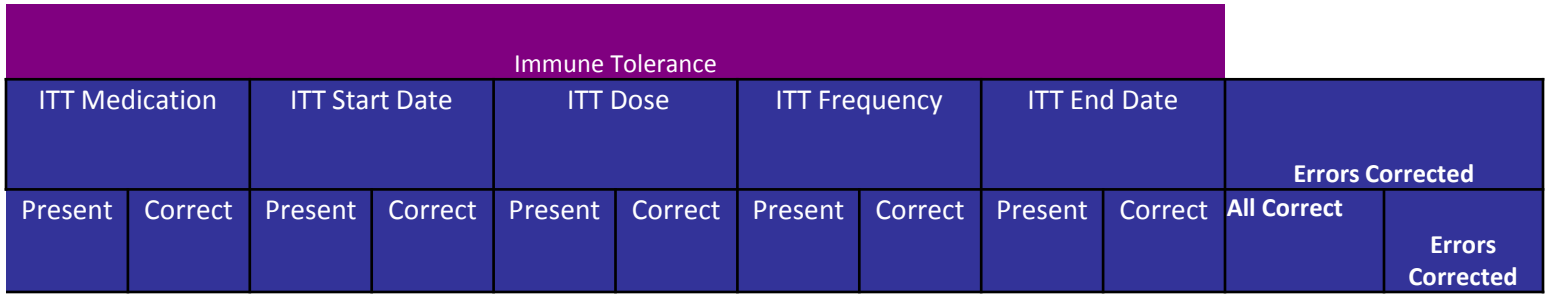
Historical Inhibitor; Currently Zero Titer

- Inhibitor is gone
  - Transient
  - Tolerized; ITT has finished and pt is on routine prophylaxis
- Complete 4 columns under dark blue header
- Complete 10 ITT columns, if applicable.
- Current Inhibitor (level of zero) recorded as present in Current Columns

Inhibitor Audit



- Immune Tolerance data entered under the second magenta heading
- Determine presence/absence and then correctness of data entered into WebTracker for all categories listed
- Some older patients may not have this data recorded

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Inhibitor Examples - Various Inhibitor Scenarios

Current Inhibitor

- Current Titer and start date
- Historical Inhibitor-dashes
- IT
  - If not on IT and never was, fill in with dashes
  - If currently on IT, complete up to End date (dash)
  - If IT tried & failed; complete all columns for IT

Historical Inhibitor

- Transient
  - No IT ever done-dashes
- Tolerized successfully
  - Complete entire magenta-headed columns of IT
- Current inhibitor columns completed (assuming recent levels checked, recorded in WebTracker)

Inhibitor Audit - Lessons Learned

- Confusion abounds on what columns need completion in the various scenarios
- Many patients will not have the old records to complete the ITT section
- Collect these data points moving forward in WebTracker
- No need to supply reasons for absences/zeros
- REMEMBER-ALL inhibitor patients are included in this audit, not just a sample

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Some General Points about Audits

- Audit 10% or at least 20 records, whichever is *greater*
  - Patient Identifier
  - Diagnosis
  - Medications
- Inhibitor audit should include ALL patients with inhibitors so may be more or less than 20
- Auditor is not the person who populates the database
- Develop Preventive Quality Plan for errors found
- Re-Audit to assess efficacy of Quality Plan

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Breakfast Training Session

- Hands-on training to navigate around the Excel spreadsheet audit files
- Ask questions!
- Be on your way to breezing through your audits at home

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Goals of Audits

- Quality check on data transfer to WebTracker
- Identify barriers to quality data and change processes to break down those barriers
- CLEAN and ACCURATE data which we can access for meaningful research studies

- *Ultimate goal*: Better Care for bleeding disorder patients

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ATHN Data Quality Committee

- Anne Neff, Chair, Vanderbilt University
- Natalie Duncan, Indiana Hemostasis & Thrombosis Center
- Ann Forsberg, New England Hemophilia Center
- Jeffery Hord, Children's Hospital Medical Center of Akron
- Pat Mancini, New England Hemophilia Association
- Cindy Su, Centers for Disease Control and Prevention
- Betsy Wilson, Vanderbilt University

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ATHN Data Quality Counts Grant Recipients – Round 1

- Yale Hemostasis Center
- Mount Sinai Reg. HTC with
  - Newark Beth Israel
  - Albany Medical college
  - Mary M Gooley HTC
  - Hemophilia Ct.r of Western NY
  - Weill Cornell Medical college
- Charleston Area Med Ctr.
- Backus Children's Hospital
- Univ. of Miami
- Vanderbilt HTC
- Wake Forest UHS
- Akron children's Hospital HTC
- Hemophilia Clinic of Western MI Cancer Ctr. with;
  - Pediatric Ctr. at Bronson
- Northwest Ohio HTC
- Ohio State University HTC
- Univ. of MI HTC
- Bleeding and Clotting Disorders Institute, Peoria
- Children's Hospital of Orange County
- Children's Hospital of MI
- Helen DeVos Children's Coagulation Disorders program

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Thank you!

ATHN Data Quality Counts Grant Recipients – Round 2

- Vermont Regional Hemophilia Ctr
- Central VA Ct for Coag Disorders/VA Commonwealth
- Med Coll GA Pediatric HTC
- Univ MS Med Ctr
- Univ. AL/Birmingham
- Palmetto Health
- East TN HTC
- Northern Reg Bleeding Dis Ctr at Munson Medical Ctr
- West Central Ohio Hemophilia Ctr
- MI St Univ Ctr for Bleeding & Clotting Disorders
- Stroger Hospital of Cook Cty (Adults and Pediatrics)
- AR Ctr for Bleeding Disorders
- TX Children's HTC/Baylor
- HTC of Hawaii
- Univ of CA/Davis HTC
- HTC of Las Vegas
- City of Hope
- Providence Sacred Heart Med Ctr and Children's Hospital
- Duke Univ Health System

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Thank you!

ATHN Data Quality Counts Grant Recipients – Round 3

- New England Hemophilia Ctr./UMASS Memorial Hospital
- Mount Sinai Reg. Comprehensive HTC with SUNY/Syracuse (Peds & Adults)
- Children's National Hemophilia Ctr.
- Johns Hopkins Univ. HTC
- UNC/Chapel Hill HTC
- Detroit Receiving Hospital and Univ. Med Ctr./Comprehensive Ctr. for Bleeding Disorders and Thrombosis
- Henry Ford Health System HTC
- Nationwide Children's Hospital
- Univ. Hospitals Case Med Ctr.
- Cincinnati Children's Hospital HTC
- Fort Worth Bleeding Disorders Program
- Iowa Hemophilia & Thrombosis Ctr.
- Intermountain HTC
- Children's Hospital of Los Angeles
- Stanford University

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Thank you!

Remember:
It's all about the data

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