

ATHN DATA SUMMIT 2016

A Look to the Future for ATHN and You! Hematologist's Perspective

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What ATHN Offers the Hematologist

Securing Data-Advancing Knowledge-Transforming Care

- Clinical Manager
 - Tracking and reporting the HTC population
 - Data for research feasibility
- Research Opportunities
 - Participation in national research and surveillance
 - Development of investigator initiated research
 - Support for early career investigators (DREAM award)
- Quality Improvement
 - Training in quality improvement

Clinical Manager

Adaptability for Innovations in Care

- Bleeding Disorders
 - Novel therapeutics
 - beyond factor replacement therapy
 - Focus on transition and transfer of care
 - Focus on the aging population
- Thrombotic Disorders
 - Novel therapeutics
 - beyond warfarin and heparin
 - Focus on anticoagulation safety
 - Focus on prevention of venous thromboembolism

Clinical Manager

Adaptability for Evolving Reporting Requirements

- Local
 - HTC growth
 - Clinical outcomes

- Regional/National (HRSA)
 - Annual reporting
 - Healthy People initiatives
 - Quality Improvement

ATHN's Research and Surveillance

Existing portfolio

- ATHN Dataset and Data Quality Counts
- CDC Community Counts
 - Registry
 - Population Profile
 - Mortality Reporting
- My Life Our Future

ATHN's National Research and Surveillance Challenges

- Prioritizing research studies at HTC
 - Competing demands
 - ATHN-X; DREAM award projects
 - Industry sponsored
 - Investigator initiated (outside of ATHN)
- Funding
 - Current funding may not align with personnel effort
 - Regulatory
 - Recruitment
 - Specimen collection and processing
 - Data collection, abstraction, entry and auditing

Investigator Initiated Research with ATHN

Example: ATHN-X

- Development of US PUPs Registry
 - Collaboration: Blood Center of Wisconsin, PedNet, Children's Mercy Hospital, Rady Children's Hospital San Diego and ATHN
 - Initial phase: test feasibility of enrolling PUPs into Registry and collecting all treatment, bleed and inhibitor testing data for the first 50 exposure days
 - Utilizing ATHN's Strengths
 - Clinical Manager and Studies Manager infrastructure
 - Question Library
 - Flexibility with funding flow
 - Existing subcontracts with HTC's

Investigator Initiated Research with ATHN

Challenges

- Data to Guide Site Selection (8-10 sites for feasibility phase)
 - Birth rates
 - ATHN data
 - #patients in ATHN Dataset with birth year 2010-2016; need permission from HTCs to get site data
- CRF and Dataset Build
 - Study specific modules using existing questions + customized questions to align with PedNet Registry
 - \$\$\$\$
 - ATHN priority #X ---> timeline for build and testing

Quality Improvement Needs Assessment

- Training
 - The Dartmouth Institute Microsystems Academy
 - Time intensive
- Quality Improvement Resources
 - Guidelines and Policies (e.g. Got Transition)
 - Transition Readiness Assessments (e.g. HEMO-Milestones Tool)
 - Educational Tools (e.g. NHF Steps for Living)
- Baseline Data for QI
 - Clinical Manager Query (e.g. #patients 18-25y with annual visit)

Recommendations for ATHN

A Hematologist's Perspective for the Future

- Stay on top of changes in clinical care and reporting requirements
 - Update Clinical Manager
- Understand time commitments for research and surveillance at HTC's
 - Fund accordingly
- Increase accessibility of data to investigators
- Develop novel strategies to reduce costs and time for Database changes
- Continue to promote QI training and sharing of QI resources