

ATHN DATA SUMMIT 2016

ATHN Data Matters

Norma Wolf

ATHN Data Matters

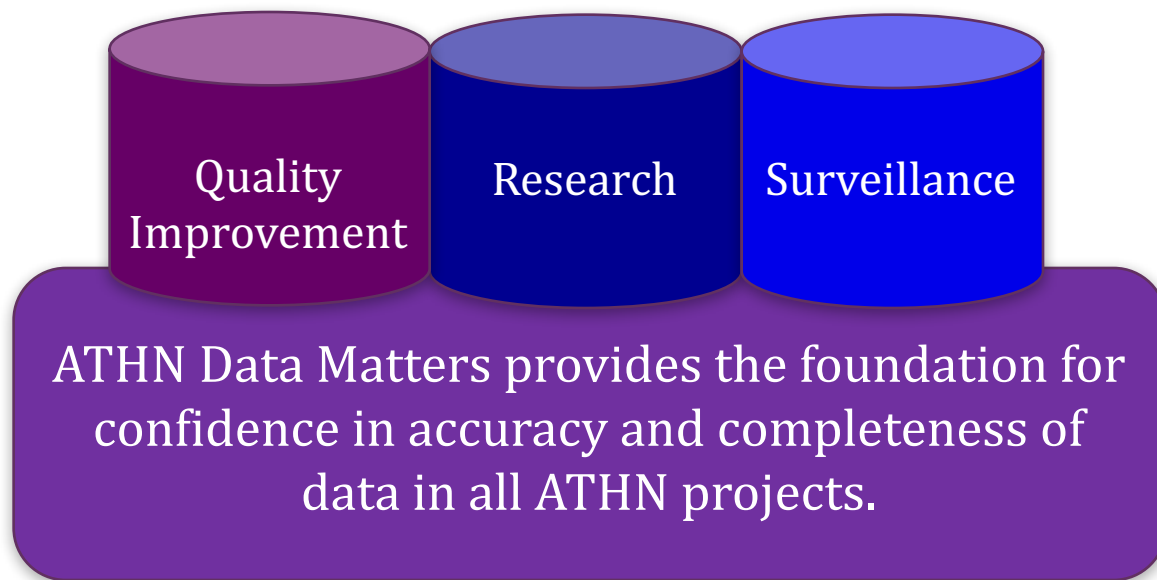
- Introduction
 - Brief program overview
 - Specific program details
 - Program timeline
 - Questions
-
- Please note that ATHN Data Matters training will be presented to Data Managers during Track 1 this afternoon.

Special Acknowledgement:

ATHN Data Matters is the next generation of the previous work completed by the ATHN Data Quality Committee and incorporates portions of the Reference Report and ATHN self-audits developed through their work.

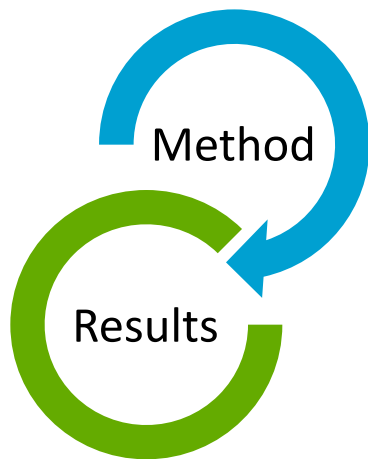
Introducing Our New Program

ATHN Data Matters



How We Developed Our Program

We took all of the following into consideration:



- Core data elements
- Healthy People 2020 Indicators
- National Quality Metrics
- Previous ATHN self-audits
- ATHN Reference Reports
- Information valuable to our partners (i.e. CDC and HRSA)

Literature Review

What is everyone else doing?

- Reviewed over 60 articles
 - Software systems
 - Other registries
 - Informational articles
 - Research studies



Components of Our Program

To assure data integrity

- Automated validations
- Annual reviews
- Biennial audits
- Special ATHN Data Matters initiatives
- Ongoing education

ATHN Data Matters

Program Details

Automated Validations

- Automated edit checks/validations
- At the time data is entered
- Clinical Manager and Study Manager



Annual Review

- Completed manually by HTC and ATHN staff
- ATHN Data Matters Report generated by HTC
 - Represents 10% of HTC's active patients (20/50)
 - ATHNdataset and/or Community Counts HTC Population Profile
 - Different patients each year
 - Reviewed by Medical Director/ Nurse Coordinator
- Submitted electronically during scheduled time
 - Submissions through support@athn.org
- Follow-up for corrections/completeness
- Resubmit report with updates



ATHN Data Matters Report

	A	B	C	D	E	F	G	H	I	J	K	L
1												
2												
3	ATHN Data Matters ID	Patient's Zip Code	Gender	Race	Ethnicity	Age	Education Level	Primary Diagnosis	Diagnosis Baseline	Inhibitor Diagnosis	Inhibitor Diagnosis Status	Primary Treatment Medication
4	5932451-2016	41783	Male	White	Not Hispanic, Latino/a, or Spanish origin	26	2-year college degree (Associates)	Factor VIII, hereditary	< 1.0% (Severe)	Inhibitor, Factor VIII, Human	no history of	ADVATE
5	6742120-2016	40126	Male	White	Not Hispanic, Latino/a, or Spanish origin	38	Primary / Secondary	Factor IX, hereditary	< 1.0% (Severe)	Inhibitor, Factor IX, Human	active	Alprolix
6	2481585-2016	40680	Male	White	Not Hispanic, Latino/a, or Spanish origin	37	Primary / Secondary	Factor VIII, hereditary	< 1.0% (Severe)	Inhibitor, Factor VIII, Human	no history of	Helixate FS
7	2842292-2016	40052	Male	White	Not Hispanic, Latino/a, or Spanish origin	22	Some college	Factor VIII, hereditary	5.9% (Mild)	Inhibitor, Factor VIII, Human	no history of	ADVATE
8	5178584-2016	40145	Male	White	Not Hispanic, Latino/a, or Spanish origin	46	4-year college degree (Bachelors)	Factor VIII, hereditary	< 1.0% (Severe)	Inhibitor, Factor VIII, Human	no history of	Helixate FS
9	4512856-2016	40157	Male	White	Not Hispanic, Latino/a, or Spanish origin	16	2-year college degree (Associates)	Factor VIII, hereditary	< 1.0% (Severe)	Inhibitor, Factor VIII, Human	history of	Helixate FS
10	3233568-2016	40055	Male	White	Not Hispanic, Latino/a, or Spanish origin	59		Factor IX, hereditary	37.0% (Mild)	Inhibitor, Factor IX, Human	no history of	
11	4577820-2016	40135	Female	White	Not Hispanic, Latino/a, or Spanish origin	12	Primary / Secondary	vWD, type 1	VWF Activity: 22.0%, FVIII: 111.0%, VWF Ag: 31.0%			

Biennial Audit

- Completed every 2 years
- ATHN Data Matters Audit Report generated by HTC
 - Audit should be performed by someone other than the person entering data into Clinical Manager
 - Includes 20 patients of current year's Annual Review
 - Report includes blank columns to record comparison
 - HTC to compare data entered to source data such as EMR
 - HTC to complete corrections as appropriate
- Completed report submitted electronically
 - Submission should include a statement of error correction completeness
 - Submissions through support@athn.org

Special ATHN Data Matters Initiatives

- Address data elements that could benefit from further validation and data clean up
- Based on overall program findings or HTC specific findings

Education

- Initial Kick-off training
 - Data Summit Track 1 session
 - Webinar
 - Informational email
- Ongoing training
 - Informational and training webinars
 - Based on data review findings or best practices
 - Approximately twice per calendar year
 - Recorded and on support website



Timeline

- HTCs will be divided into Groups 1, 2, & 3
- All submissions and/or questions to support@athn.org
- Regional Coordinators copied on email communications
- Participation is mandatory
- Non-compliance will be escalated as appropriate
- Annual report of findings shared at ATHN Data Summit

Timeline

Annual Reviews

- Group 1
 - ATHN Data Matters Report due – 11/1/2016
 - Summaries sent to HTC – 11/30/2016
 - Resubmission of report with corrections made due – 12/31/2016
- Group 2
 - ATHN Data Matters Report due – 2/1/2017
 - Summaries sent to HTC – 2/28/2017
 - Resubmission of report with corrections made due – 3/31/2017
- Group 3
 - ATHN Data Matters Report due – 5/1/2017
 - Summaries sent to HTC – 5/30/2017
 - Resubmission of report with corrections made due – 6/30/2017

Timeline

Biennial Audits

- Will begin Quarter 4 of 2017
- Will follow same grouping as Annual Reviews
- Will follow same timeline as Annual Reviews
- All submissions and/or questions to support@athn.org
- Detailed training beginning Quarter 3 of 2017

Conclusion

As you can see, ATHN Data Matters is a program for assuring accuracy and completeness of data collected as part of ATHN projects and studies. This program will continue to evolve as we review program findings annually.

Thank You!

“A healthier overall population will maximize patient satisfaction and minimize resource consumption. Getting there requires complete, accurate patient data and meaningfully using that data to engage individuals at all times, exchange information between providers and ultimately drive better outcomes.”

http://www.cerner.com/solutions/population_health/

Securing Data.
Advancing Knowledge.
Transforming Care.

