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.

The ATHN Quality Committee has an ongoing vital role in this new program and the work to assure quality data is available for all ATHN projects. Their expertise and insight are greatly appreciated.
Introducing Our New Program

ATHN Data Matters

Quality Improvement
Research
Surveillance

ATHN Data Matters provides the foundation for confidence in accuracy and completeness of data in all ATHN projects.
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
We hear you!
Trying to reduce your workload while still getting the job done.

• ATHN Data Matters replaces current self-audits
• New format – consolidated for ease of use
• All reports are generated in Clinical Manager
• HTCs run & submit annual ATHN Data Matters reports for review
• Biennial audits every other year – only specific data points are audited
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)
  - ATHN dataset 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
<table>
<thead>
<tr>
<th>ATHN Data Matters ID</th>
<th>Patient's Zip Code</th>
<th>Gender</th>
<th>Race</th>
<th>Ethnicity</th>
<th>Age</th>
<th>Education Level</th>
<th>Primary Diagnosis</th>
<th>Diagnosis Baseline</th>
<th>Inhibitor Diagnosis</th>
<th>Inhibitor Diagnosis Status</th>
<th>Primary Treatment Medication</th>
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<tbody>
<tr>
<td>5992451-2016</td>
<td>41783</td>
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<td>White</td>
<td>Not Hispanic, Latinoa, or Spanish origin</td>
<td>26</td>
<td>2-year college degree (Associates)</td>
<td>Factor VIII, hereditary</td>
<td>&lt; 1.0% (Severe)</td>
<td>Inhibitor, Factor VIII Human</td>
<td>no history of ADVATE</td>
<td></td>
</tr>
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<td>6742120-2016</td>
<td>40126</td>
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<td>White</td>
<td>Not Hispanic, Latinoa, or Spanish origin</td>
<td>38</td>
<td>Primary / Secondary</td>
<td>Factor IX, hereditary</td>
<td>&lt; 1.0% (Severe)</td>
<td>Inhibitor, Factor IX Human</td>
<td>active</td>
<td>Alprolix</td>
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<td>Primary / Secondary</td>
<td>Factor VIII, hereditary</td>
<td>&lt; 1.0% (Severe)</td>
<td>Inhibitor, Factor VIII Human</td>
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<td>22</td>
<td>Some college</td>
<td>Factor VIII, hereditary</td>
<td>5.9% (Mild)</td>
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<td>4-year college degree (Bachelor)</td>
<td>Factor VIII, hereditary</td>
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<td></td>
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<td>2-year college degree (Associates)</td>
<td>Factor VIII, hereditary</td>
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<td>history of Heksele F3</td>
<td></td>
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<td>Factor IX, hereditary</td>
<td>37.0% (Mild)</td>
<td>Inhibitor, Factor IX Human</td>
<td>no history of ADVATE</td>
<td></td>
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<td>4577820-2016</td>
<td>40135</td>
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<td>White</td>
<td>Not Hispanic, Latinoa, or Spanish origin</td>
<td>12</td>
<td>Primary / Secondary</td>
<td>VWD, type 1</td>
<td>VWF Activity: 22.0%; FVIII: 111.0%; VWF Ag: 31.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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 of limited data elements
  – 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
Teamwork

• Together we can do this!
• Overall program findings will be shared
• Work considered an important part of Community Counts and Data Quality Counts grants
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

Through ATHN Data Matters, we will all work together to verify the quality of the reported data and improve consistency and reliability of data collected in Clinical Manager. Using data we collect can lead to better care of people in the bleeding disorders community.

THE DATA REALLY DOES MATTER!
“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.