

ATHN DATA SUMMIT 2011

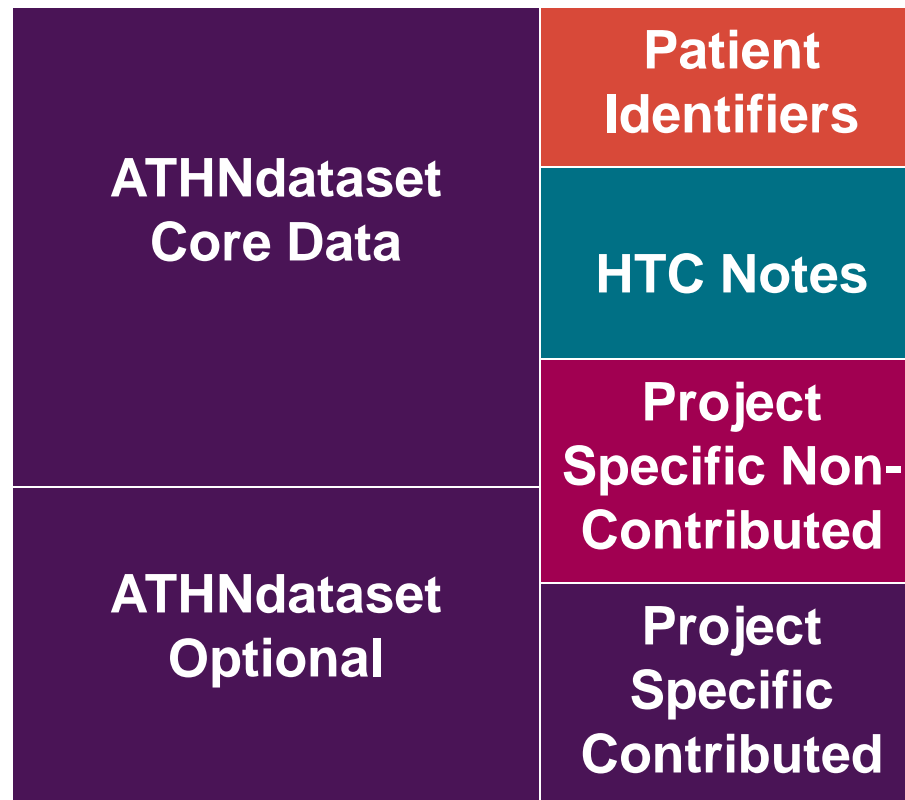
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ATHNdataset: Proposed Core Data Elements

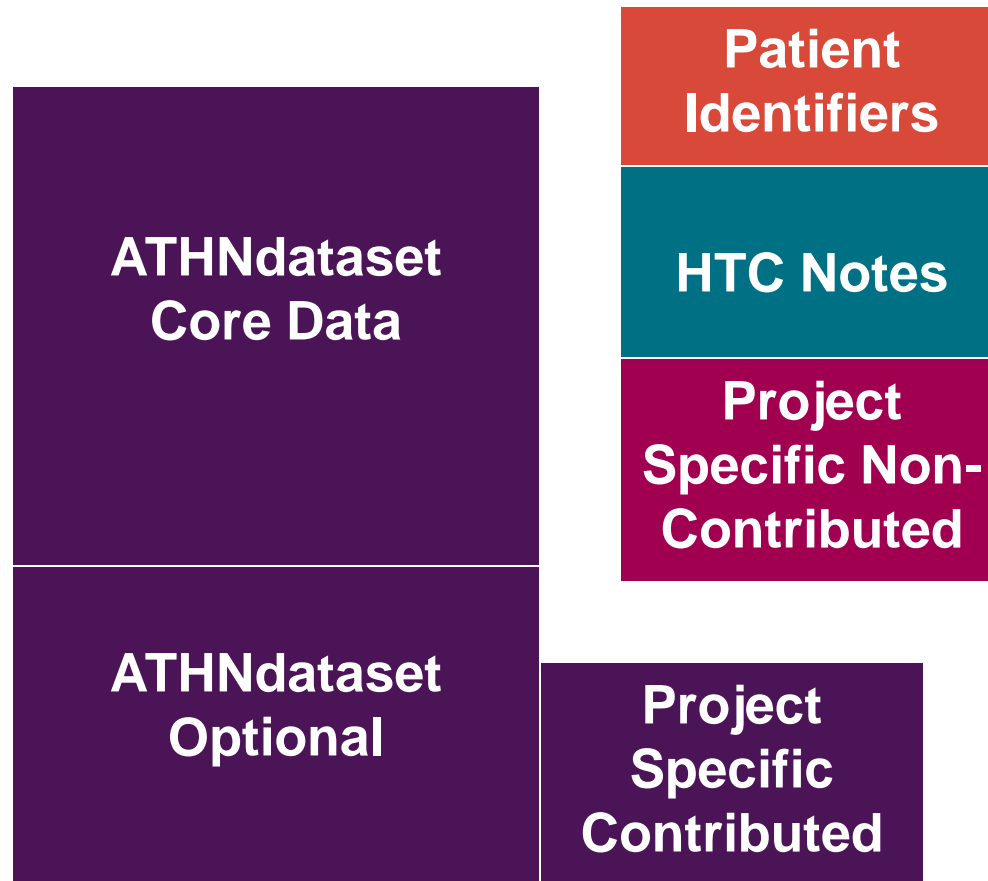
Ann Forsberg, MA MPH
UMASS Memorial Hospital
Worcester, MA

HTC Data in WebTracker Compared to ATHNdataset



Authorized Data is Used by ATHN

All Data is Available to HTC



Core ATHNdataset

- A robust core ATHN dataset for national research, program evaluation, quality improvement.
- Relevant data.
- Draft by the ATHN Quality Working Group.
- MD, RN and researcher input regarding the elements and historical data.

WebTracker Fields/ATHNdataset Data Elements*	Data Quality Committee Recommendations 07 11	HDS	UDC	ATHNready PHR
Unique Patient Identifier, Patient Status and Mortality Data				
Unique Patient Identifier	Yes			
Patient Status -Active vs. Inactive	Yes	X		
Date made Inactive	Yes (auto fill)	X		
Reason for Change in Status	Yes			
Date of Death	Yes	X	X	
Primary Cause of Death	Yes	X	X	
Contributing Cause of Death	Category of Primary Cause			

WebTracker Fields/ATHNdataset Data Elements*	Data Quality Committee Recommendations 07 11	HDS	UDC	ATHNready PHR
Demographic Information				
Date of Birth	Yes	X	X	X
Race/Ethnicity	Yes	X	X	
Sex	Yes			X
Student Status	No		X	
Education Level	No		X	
Employment Status	No		X	
Marital Status	Yes		X	
Primary Language	Yes		X	
Second Language	No			
Medical Alert Use and Type	Yes (keep for ATHNready_			
PCP	No	X		
Insurance Information				
Payer and Type	Yes	X	X	

WebTracker Fields/ATHNdataset Data Elements*	Data Quality Committee Recommendations 07 11	HDS	UDC	ATHNready PHR
History				
Family History of Bleeding Disorder	Yes		X	
> 1 in Household with Bleeding Disorder	No		X	
Reproductive History	No			
HTC Services Utilized	Maybe - wait for HRSA		X	
Age at First HTC Visit	Age at Date of First HTC Visit		X	
Visit Information				
Type of Visit	Yes			
Date of Visit	Yes	X		
of Related Diagnosis (From list of Diagnoses	No			
Disposition	No	X		
In-patient admission and Discharge Diagnoses	Yes			
HTC services provided at visit	No			
Referral Information	No			

WebTracker Fields/ATHNdataset Data Elements*	Data Quality Committee Recommendations 07 11	HDS	UDC	ATHNready PHR
Joint Range of Motion Measurements	Yes or No answer			
Vital Signs				
Weight	Yes		X	
Height	Yes		X	
Head Circumference	No		X	
Temperature	No			
Pulse Rate	No			
Blood Pressure	No			
Respiratory Rate	No			
Pain Index Score	No			
Length	No		X	
Diagnoses				
Primary Bleeding or Clotting Disorder	Yes	X	X	X
Start Date	Yes		X	
Age at Diagnosis	Yes		X	
Reason for Diagnostic Testing	Yes			
Complications of Bleeding or Clotting Disorder	Yes			
Anemia Details	No			

WebTracker Fields/ATHNdataset Data Elements*	Data Quality Committee Recommendations 07 11	HDS	UDC	ATHNready PHR
Inhibitor Information	Yes	X	X	X Hx/Current
Indication for Diagnosis	Indication for Inhibitor Diagnosis			
Assay Method	Yes			
Product at Time of Appearance	Yes			
End Date	Yes (for inhibitor)			
Other Diagnoses and Co-Morbidities	Yes			
HIV	Yes	X	X	X
Hepatitis	Yes		X	X
Other Diagnoses	No			
Allergy Information	No (yes for ATHNready)			X
Allergy Type / None Known	No			
Allergen	No			
Reaction Type	No			
Start Date	No			
End Date	No			

WebTracker Fields/ATHNdataset Data Elements*	Data Quality Committee Recommendations 07 11	HDS	UDC	ATHNready PHR
Immunizations	for Hepatitis A & B			
Immunization Type	Yes		X	
Immunization Reporting Method	Yes			
Immunization Status	Yes			
Finish Date	No			
Last Updated	No			
Dose Information	No			
Dose Number	No			
Injection Date	No			
Vaccine	No			
Route	No			
Lot Number	No			
Immunization Booster	No			
Booster number	No			
Injection Date	No			
Vaccine	No			
Route	No			
Lot Number	No			

WebTracker Fields/ATHNdataset Data Elements*	Data Quality Committee Recommendations 07 11	HDS	UDC	ATHNready PHR
Surgeries/Procedures	Yes			
Date	Yes			
Surgery / Procedure Type	Yes			
Surgery / Procedure Anatomical Location	Yes			
Related Diagnosis (From list of diagnoses)	Yes			
Related Hospital Visit (From list of visit types)	Yes			
Outcome	Yes		CVAD complication	
Complications	No			
CVAD	No		X	
Medications				
Medication Name (Generic or Brand)	Yes (for coag)			X
Related Diagnosis (From list of diagnoses)	Yes			
Start Date	Yes			
Treatment Type (e.g., Prophylaxis, Immune Tolerance)	Yes		X	X
Dosage and Schedule	Yes			X
End Date	Yes			
Reason for Discontinuation	Yes			

WebTracker Fields/ATHNdataset Data Elements*	Data Quality Committee Recommendations 07 11	HDS	UDC	ATHNready PHR
Devices	No			
Device Type	No			
Device Anatomical Location	No			
Date of Issue	No			
End Date	No			
Images	No			
Date	No			
Image Type	No			
Image Anatomical Location	No			
Interpretation	No			

WebTracker Fields/ATHNdataset Data Elements*	Data Quality Committee Recommendations 07 11	HDS	UDC	ATHNready PHR
Laboratory				
Laboratory Test Results	Yes (coagulation labs)	X	inhibitor	X INHIBITOR and FACTOR LEVEL
Test name	Yes			
Date/Time	Yes			
Collection method	Yes			
Assay Method	Yes			
Lab Values and Test Interpretation	Yes			
Laboratory Detail	Yes			
Phenotype	No			
Molecular Defect	(Yes or No answer)			
Polymorphisms	(Yes or No answer)			

WebTracker Fields/ATHNdataset Data Elements*	Data Quality Committee Recommendations 07 11	HDS	UDC	ATHNready PHR
Bleed/Infusion Data				
Product Usage	Yes			
Exposures	Yes			
Date of First Exposure	No			
Method of Logging Product Usage	Yes			
Treatment Setting/Type	No			
Start Date	Yes			
Medication Name	Yes			
Infusion Dosage and Schedule	Yes			
Time between Treatment and Bleed	No			
Bleed Events	No			
Start and End Date (Duration)	No			
Time	No			
Method of Logging Bleeding Events	No			
Anatomical Location of Bleed	No			
Associated Events	No			
Method of Confirmation of Bleeding	No			

WebTracker Fields/ATHNdataset Data Elements*	Data Quality Committee Recommendations 07 11	HDS	UDC	ATHNready PHR
Bleed/Infusion History				
Date of First Bleed	Yes			
Date of First Product Exposure	Yes			
Product Information First Exposure	Yes			
Anatomical Location of First Bleed	Yes			
Associated Events	No			
Patient Use of Home Infusion	Yes			
Age at First Home Infusion	Yes			
Person Home Infusing Patient	No			
Consents	Yes			
ATHNdataset	Yes			
Universal Data Collection for CDC	Yes			
Other	No			
Contact Info				
Patient	Yes (For ATHNready)			X
Emergency Contacts	Yes (for ATHNready)			X

Historical Data or Prospective Data

- Historical data that should be entered
 - Surgeries
 - Inhibitor
- Data that should be entered prospectively
 - Labs
 - Medications