

# ATHNdataset Core Data Elements

DATA CATEGORY	CORE DATA ELEMENT
<b>Record Status</b>	Record Status - Active vs. Inactive
	Date Made Inactive
	Inactive Reason
<b>Mortality Status</b>	Mortality Status - Alive vs. Deceased
	Date of Death
	Primary Category of Death
<b>Demographics</b>	Primary Cause of Death
	Date of Birth
	Gender
	Race
	Ethnicity
	Education Level
<b>Consents</b>	Employment Level
	ATHNdataset Patient Authorization
<b>Insurance Information</b>	Zip Code
	Category
	Start Date
	Payer Name
<b>Diagnoses</b>	Type
	Primary Bleeding or Clotting Disorder Diagnosis Name
	Status
	Primary Diagnosis Indication
	Start Date
<b>Complications and Co-Morbidities</b>	Reason for Diagnostic Testing
	History of Other Diagnoses
	Inhibitor
	HIV
	Hepatitis A
<b>Surgeries/Procedures</b>	Hepatitis B
	Hepatitis C
	Date
	Surgery/Procedure Type

DATA CATEGORY	CORE DATA ELEMENT
<b>Medications</b>	Primary Bleeding or Clotting Disorder Medication Names
	Start Date
	Primary Regimen Indication
	Treatment Type
	Dose
	Frequency
<b>Immune Tolerance Regimen</b>	End Date
	Reason for Discontinuation
	Start Date
<b>Immunizations</b>	End Date
	Response
<b>Bleed/Infusion Data</b>	Immunization Type
	Immunization Status
	Product Usage
	Bleed Events
	First Product Exposure
	Historical Product Exposure
	First Bleed Information
<b>Visit Information</b>	Infusion Administration History
	Target Joint History
	Type of Visit
<b>Vital Signs</b>	Date of Visit
	Visit Disposition
	Report sent to PCP
	Weight
<b>Laboratory Tests</b>	Height (length for children)
	Baseline Diagnoses and Co-Morbidities
	Test Name
	Draw Date
	Lab Results

\* ATHN Affiliates determine the data that is collected, managed and securely stored and transmitted using the Clinical Manager system. The ATHNdataset Core Data Elements that are listed above may change over time. ATHNdataset is a HIPAA-defined Limited Data Set stripped of all 16 categories of identifiers set forth in the HIPAA Privacy Rule. Data shared with ATHN as part of the ATHNdataset will be made available to ATHN and to approved researchers for research into the specific causes, prevention, treatment and social and economic impact of blood disorders, in compliance with all laws and regulations protecting the security of electronic health information and patient privacy.