

ATHNdataset Core Data Elements

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

DATA CATEGORY	CORE DATA ELEMENT
Medications	Primary Bleeding or Clotting Disorder Medication Names
	Start Date
	Primary Regimen Indication
	Treatment Type
	Dose
	Frequency
	End Date
	Reason for Discontinuation
Immune Tolerance Regimen	Start Date
	End Date
	Response
Immunizations	Immunization Type
	Immunization Status
Bleed/Infusion Data	Product Usage
	Bleed Events
	First Product Exposure
	Historical Product Exposure
	First Bleed Information
	Infusion Administration History
Visit Information	Type of Visit
	Date of Visit
	Visit Disposition
	Report sent to PCP
Vital Signs	Weight
	Height (length for children)
Laboratory Tests	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.

