

ATHN DATA SUMMIT 2011

Securing Data.
Advancing Knowledge.
Transforming Care.

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The InterContinental
Michigan Avenue — Chicago

The ATHNdataset: What's In? And What's Not?

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Our story: What's in? What's not?

- ATHN Development Committee has begun exploring the use of the ATHNdataset for research
 - type of studies
 - the kinds of questions
 - whether the dataset is robust enough
- The issue this raised: What's in the database? What's not?
- The development committee began working with ATHN Operations group to explore the data contained in the ATHNdataset.

HTC
Full Access
& Reuse of
HTC Data



**WebTracker
Central Server**



**ATHNdataset
(16 identifier
removed)**



**HDS, UDC
Surveillance
or Study dataset**



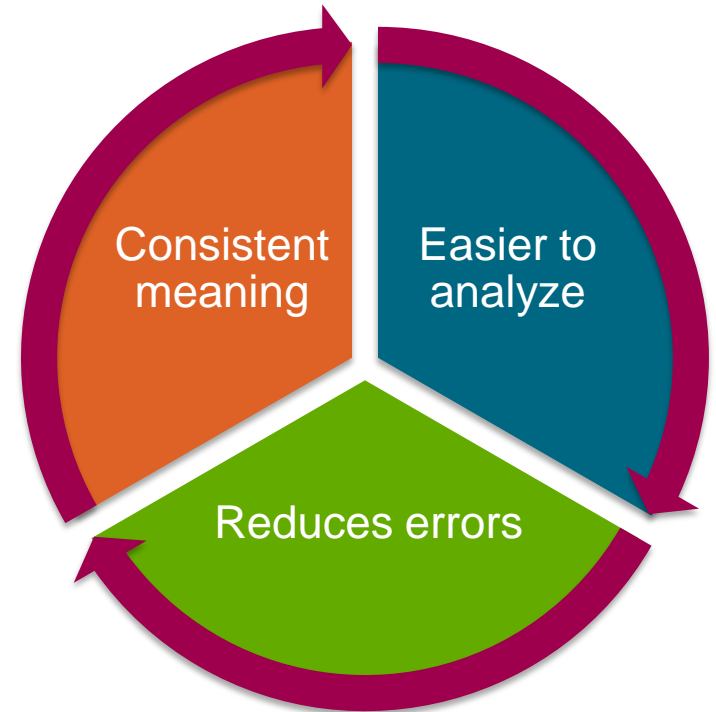
ATHNdataset

- Brings together standardized data elements into one national dataset
- Is a “Limited Data Set” as defined by Privacy Rule
 - Stripped of 16 specified direct identifiers
 - Used or disclosed for public health, research or health care operations
 - Disclosure covered by data use agreements with researchers
- Patients choose to “opt in” and authorize use of the data for research – not legally required

Standardized Data Elements

Use SNOMED CT, LOINC and First DataBank's NDDF

- Primary blood disorder
- Family history
- Laboratory test results
- Treatments
- Inhibitors
- Routine care and trauma
- Allergies
- Types of bleeds/infusions



What's not in the ATHNdataset?

- Data of patients who did not sign the authorization
- 16 identifiers to be excluded from a limited data set (HIPAA)

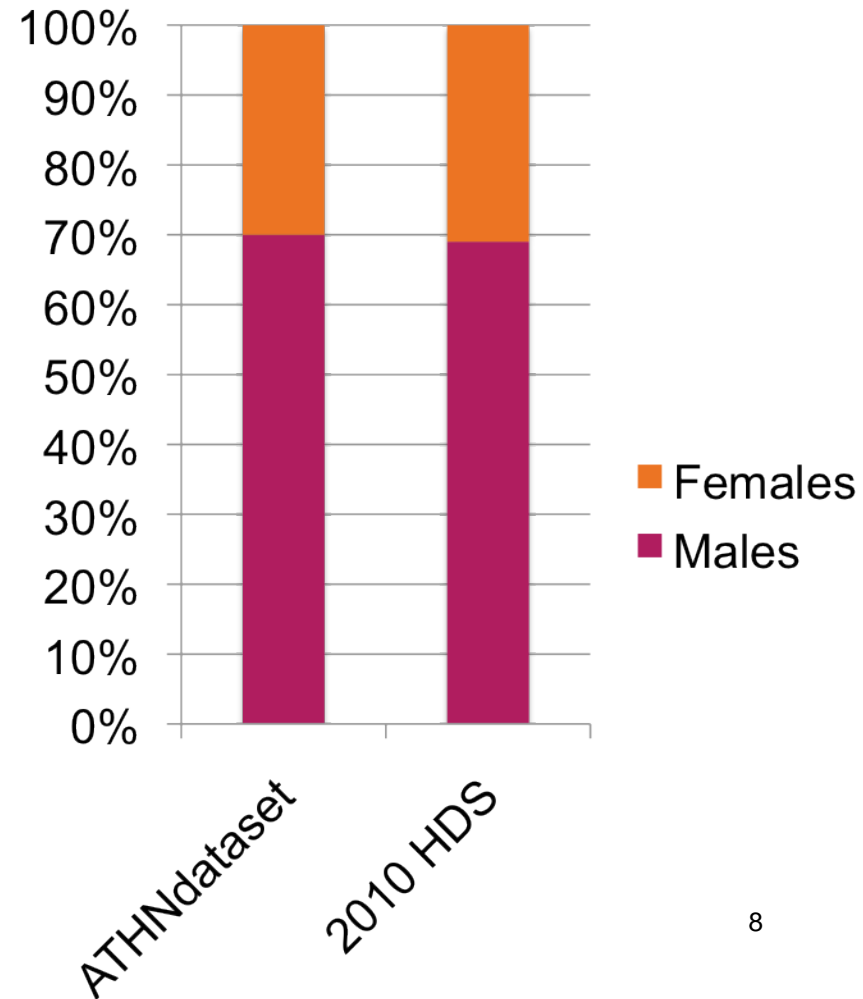
Identifiers NOT in the ATHNdataset, which Is a limited data set		
Name	Social security #	Certificate/license #
Postal address	Medical records #	Vehicle ID/serial#
Telephone #	Health plan beneficiary #	Device ID/serial #
Fax #	Account #	Web URL
Email address	Full faced photos	IP address
	Biometric identifiers	

Patient Gender

ATHNdataset (as of September 1, 2011) vs.
2010 Hemophilia Data Set (HDS)

ATHN Gender	# Patients	% Patients
Male	3,588	70%
Female	1,553	30%
Total	5,141	100%

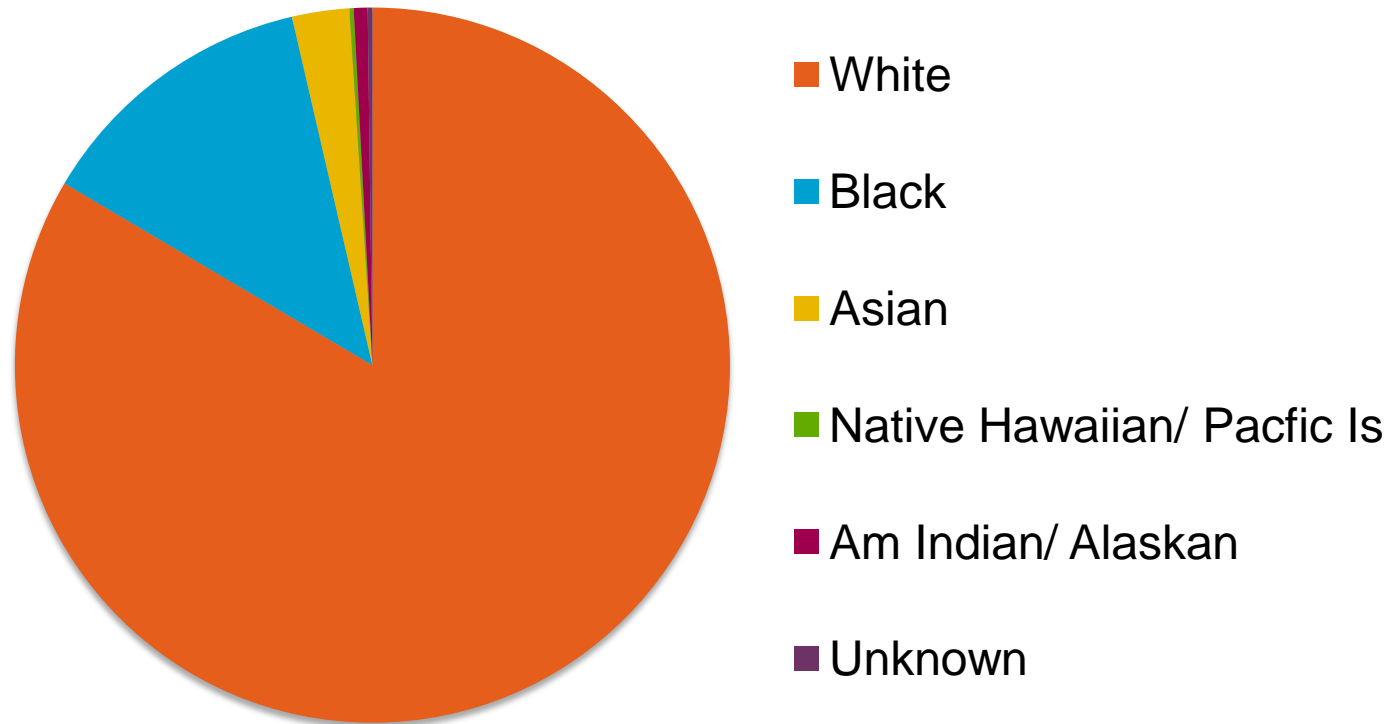
HDS Gender	# Patients	% Patients
Male	22,411	69%
Female	10,201	31%
Total	32,612	100%



Patient Race

(5,141 Authorized Patients as of September 1, 2011)

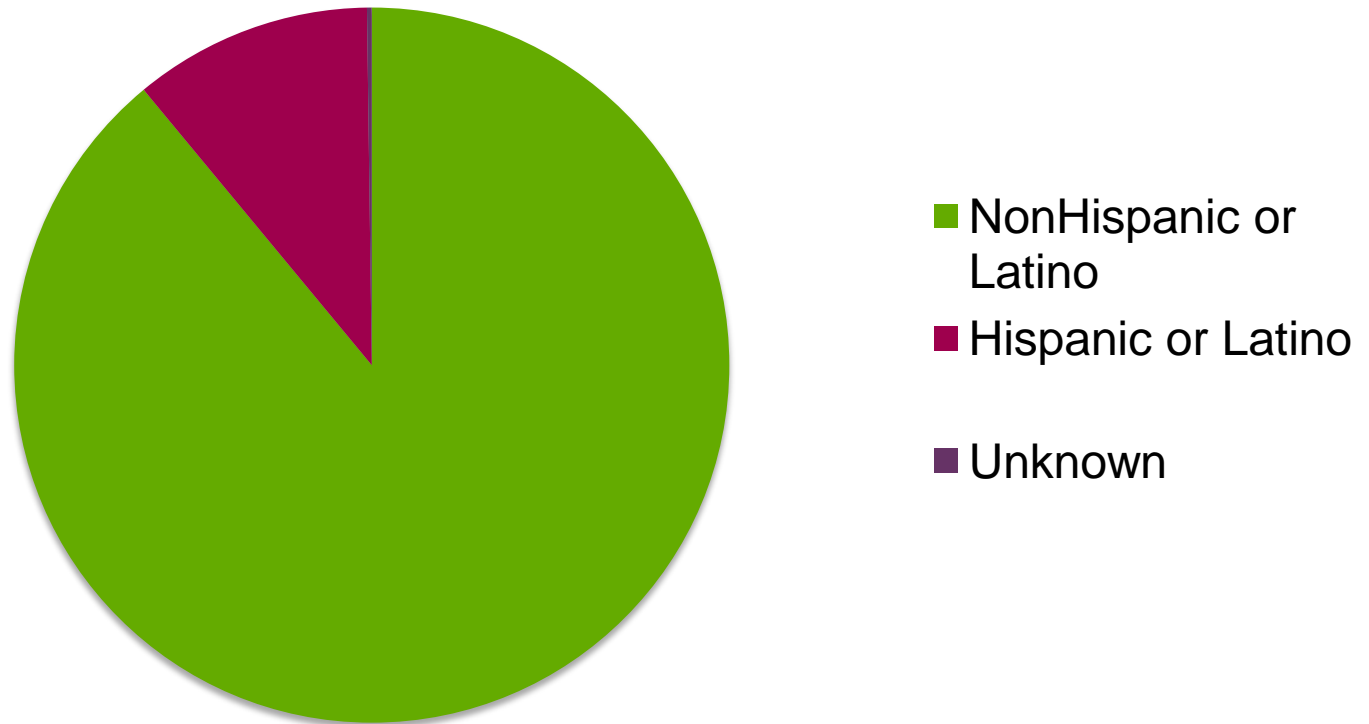
Racial Mix



Patient Ethnicity

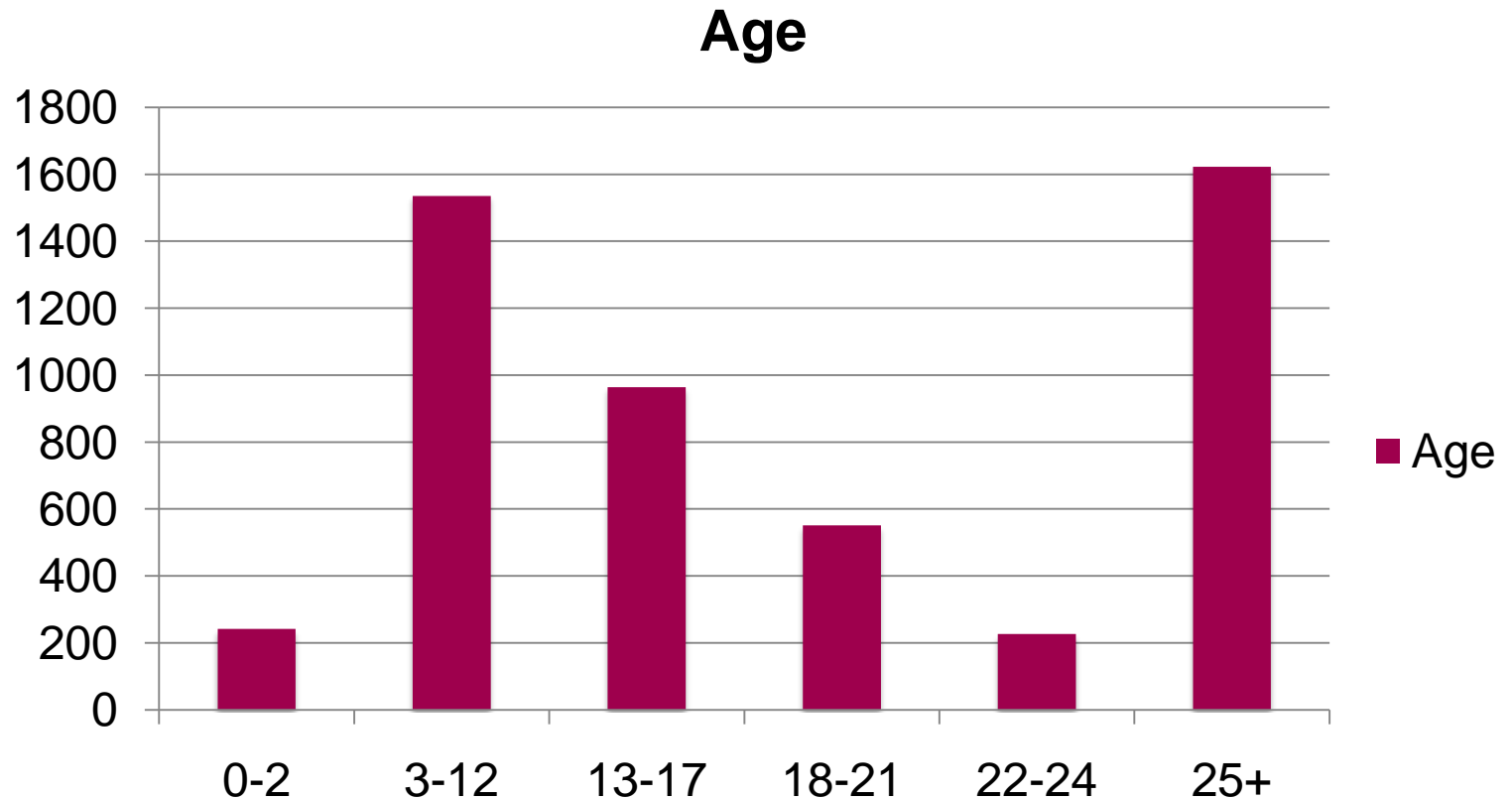
(5,141 Authorized Patients as of September 1, 2011)

Ethnicity



Patient Age Distribution

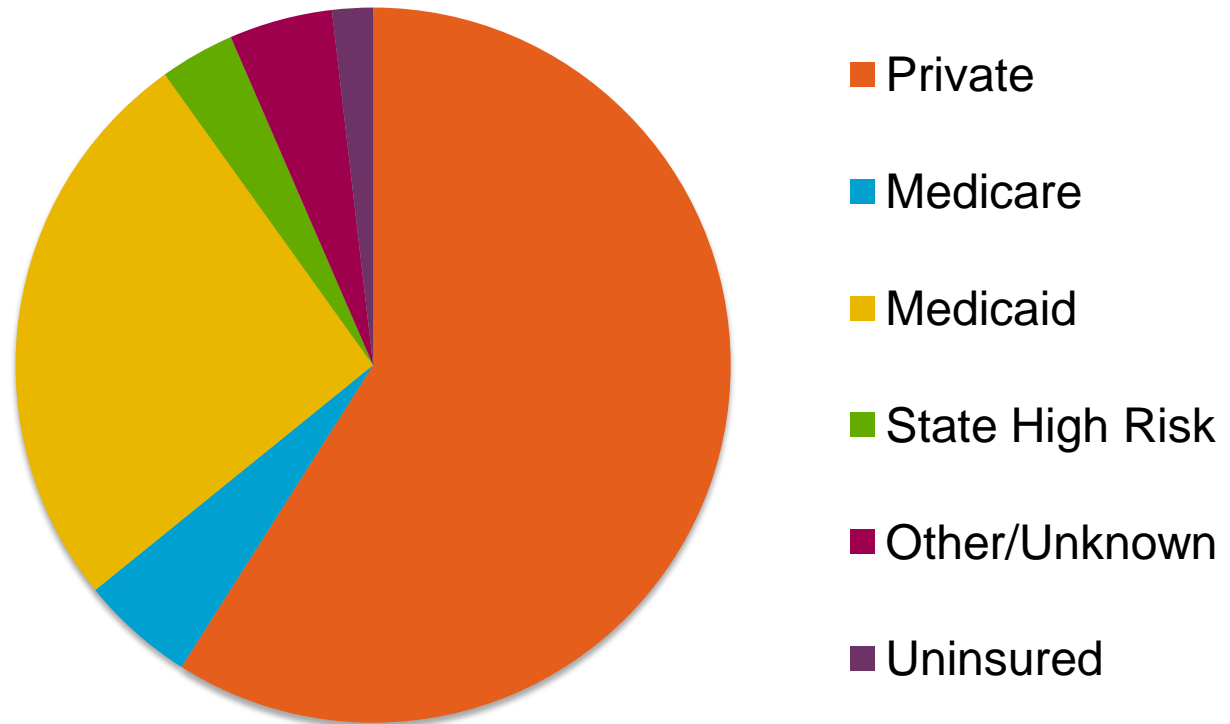
(5,141 Authorized patients as of September 1, 2011)



Payer Type: Primary Factor Payer

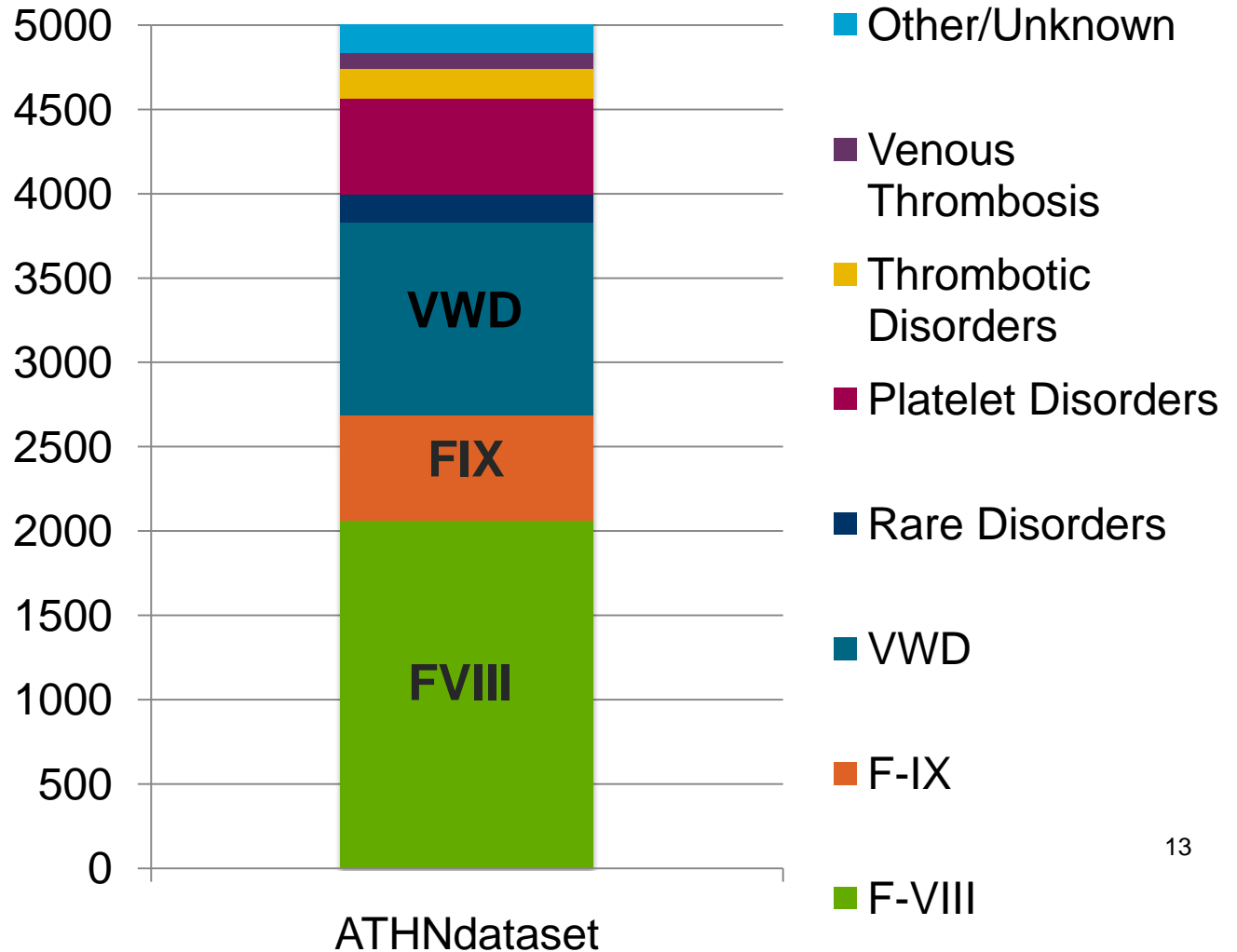
(1,627 of 5,141 Authorized Patients as of September 1, 2011)

Payer Type



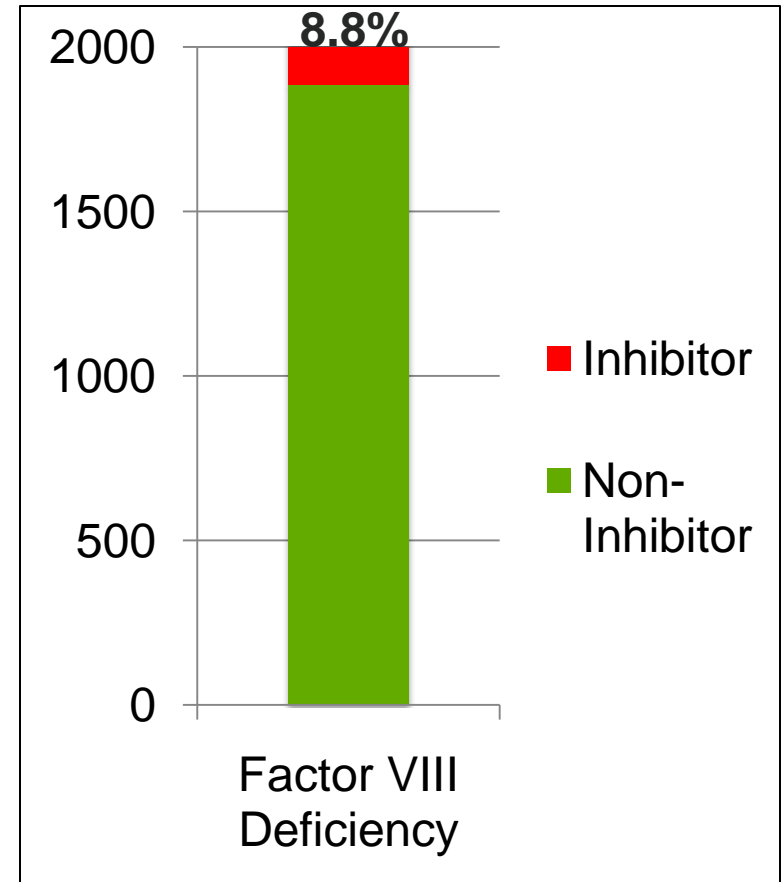
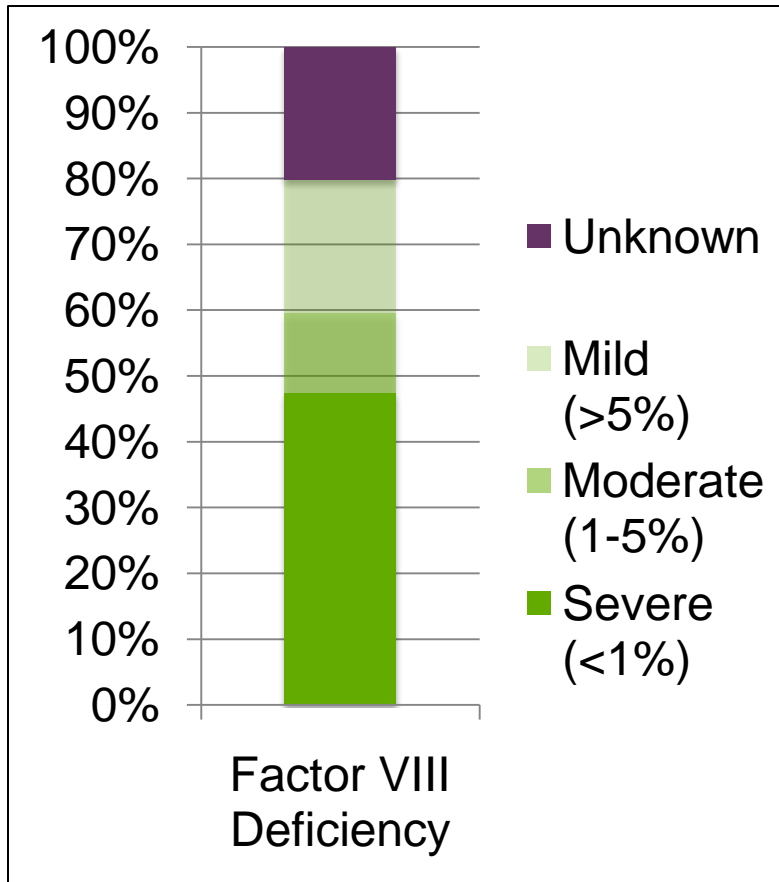
Patients By Primary Diagnosis

(5,141 Authorized Patients as of September 1, 2011)



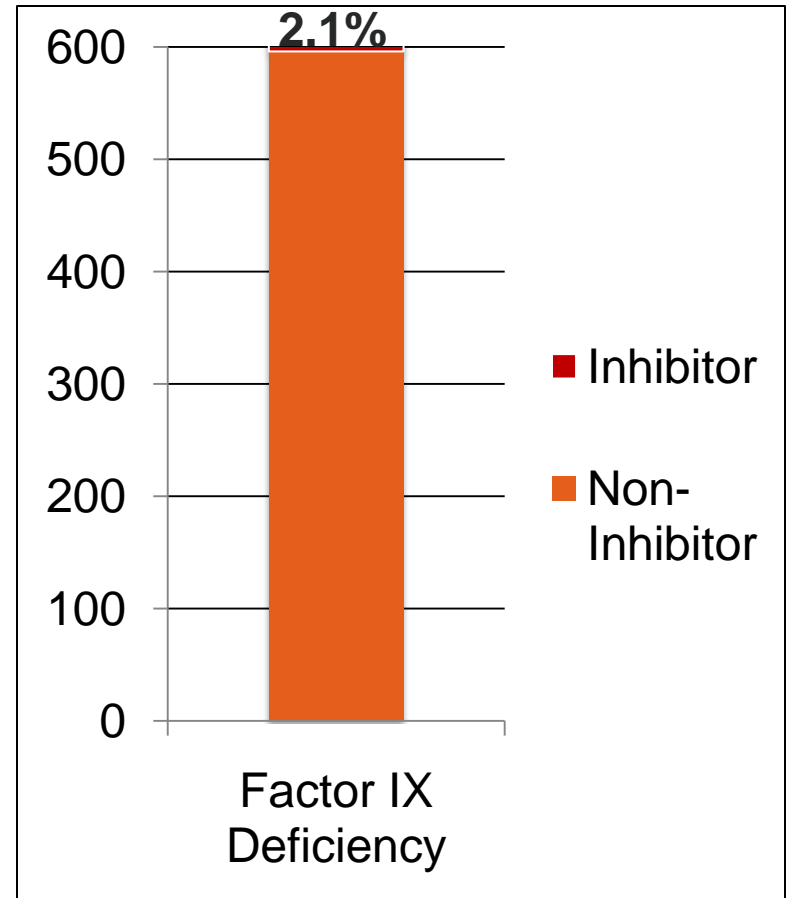
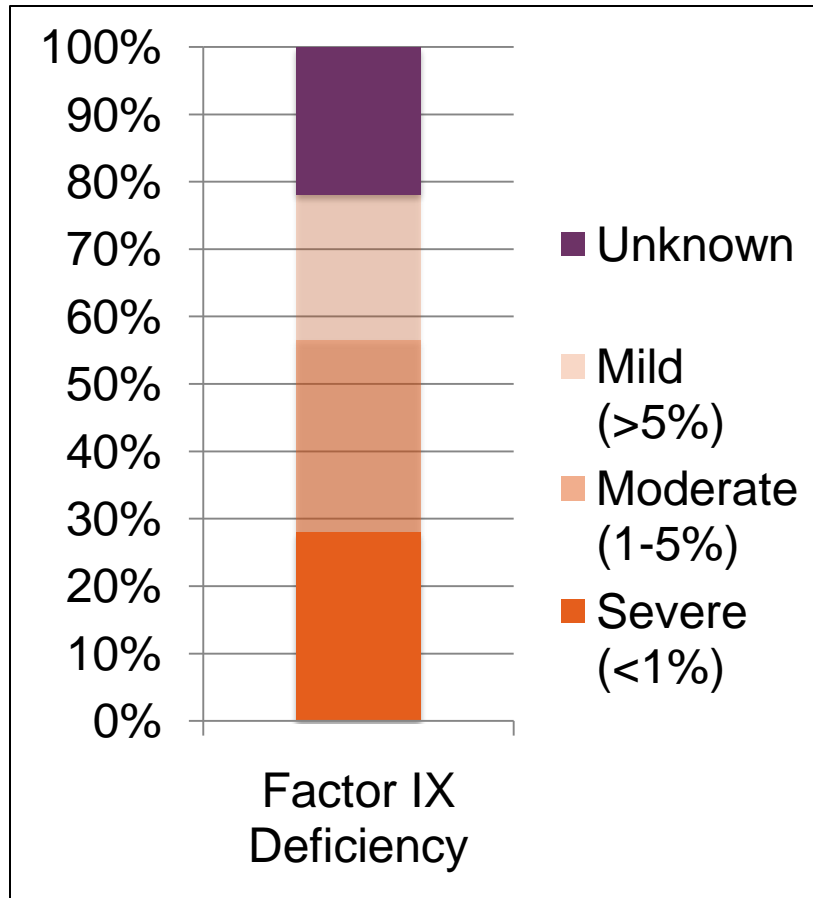
Patient Disease Severity & Inhibitors

(2,035 Hemophilia A Authorized Patients as of September 1, 2011)



Patient Disease Severity & Inhibitors

(609 Hemophilia B Authorized Patients as of September 1, 2011)

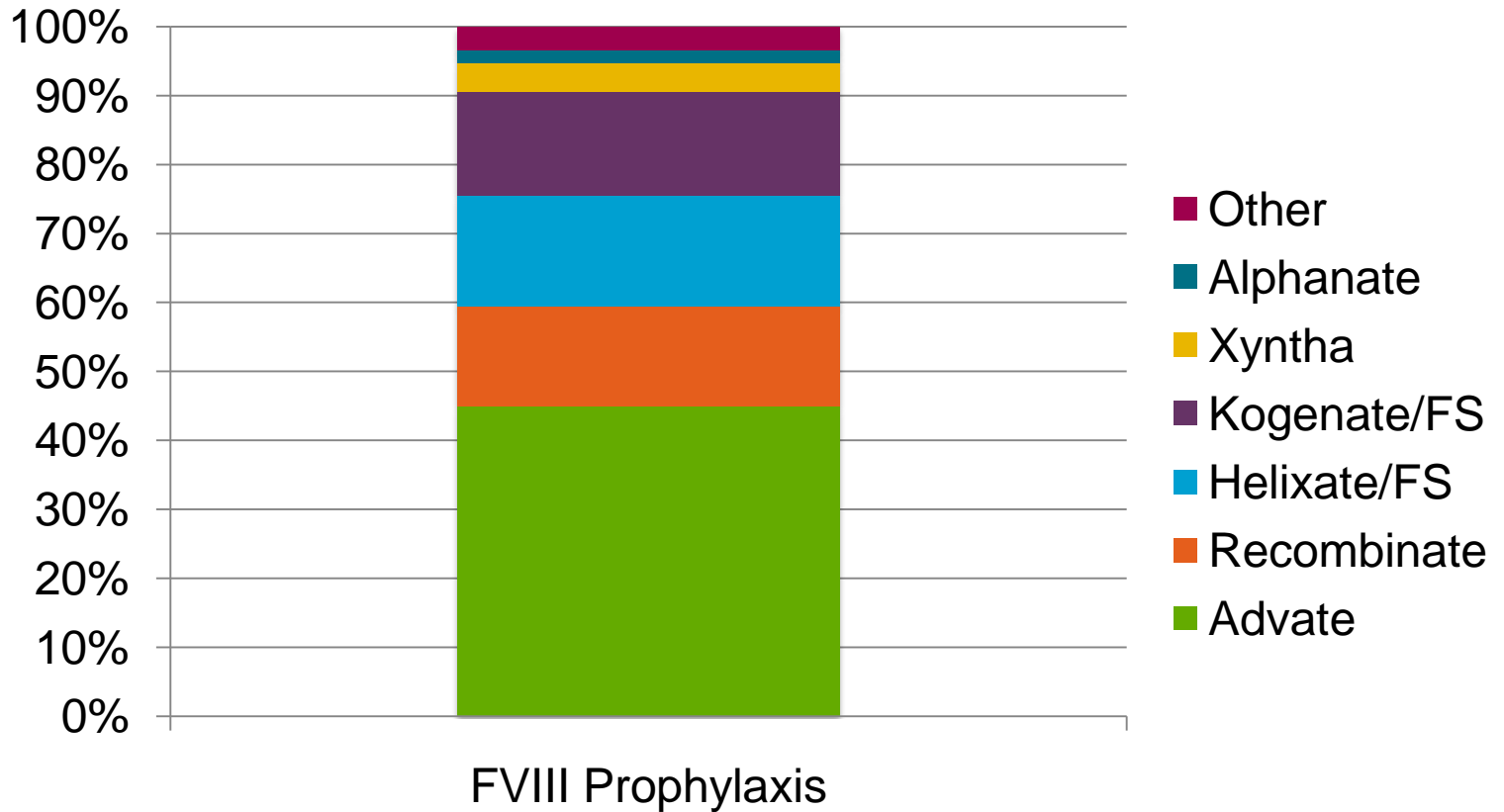


Factor Products Used for Prophylaxis

Products Currently Used for Factor VIII Deficiency

(5,141 Authorized Patients as of September 1, 2011;

2035 FVIII Patients 25% Identified* as Prescribed Prophylaxis)

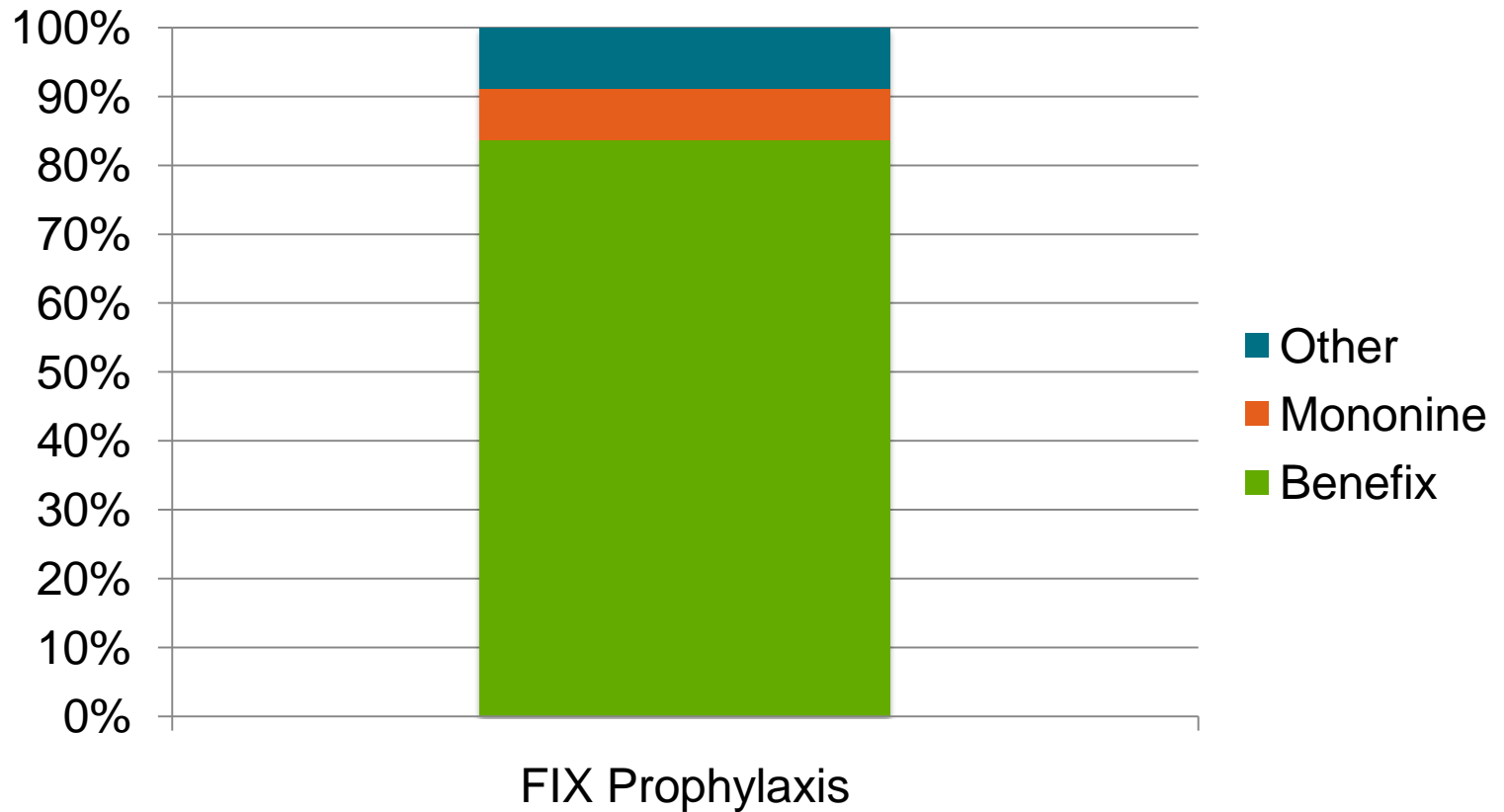


Factor Products Used for Prophylaxis

Products Currently Used for Factor IX Deficiency

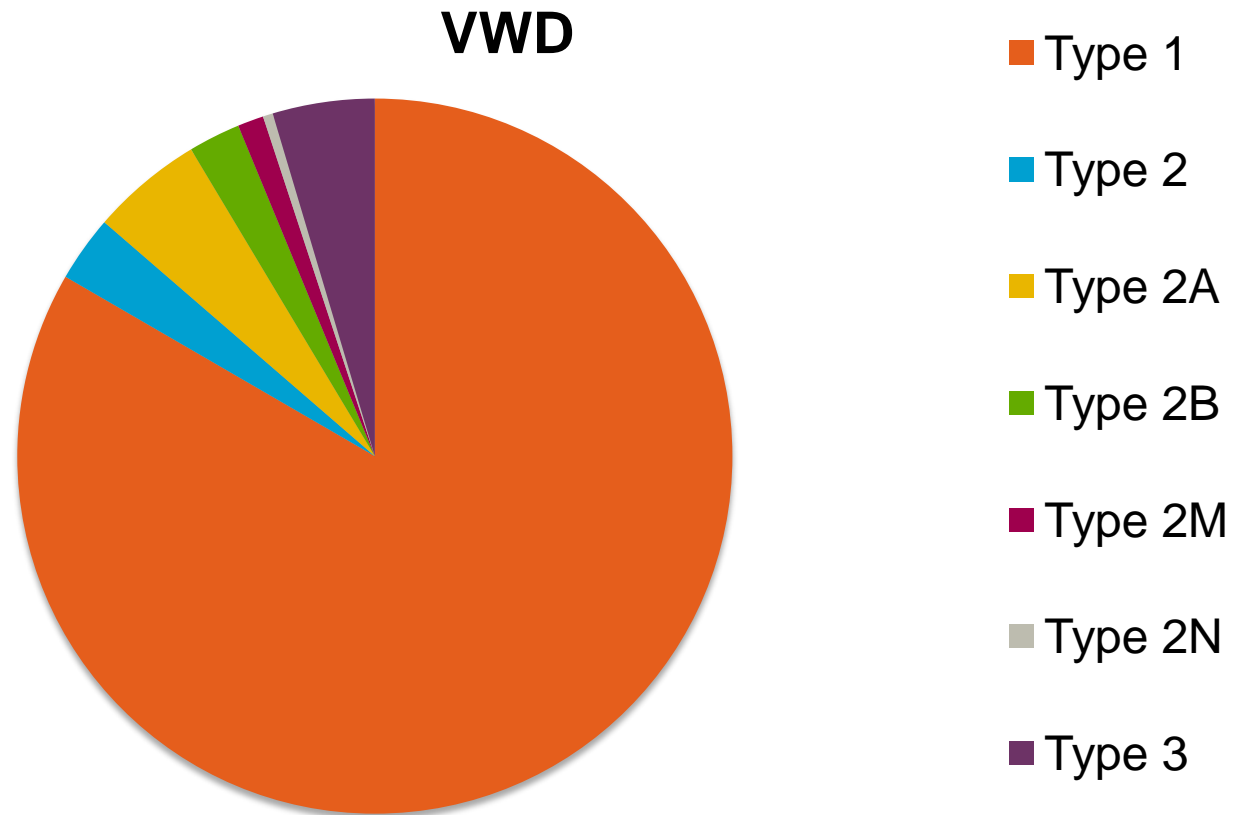
(5,141 Authorized Patients as of September 1, 2011

609 FIX Patients 13% Identified* as Prescribed Prophylaxis)



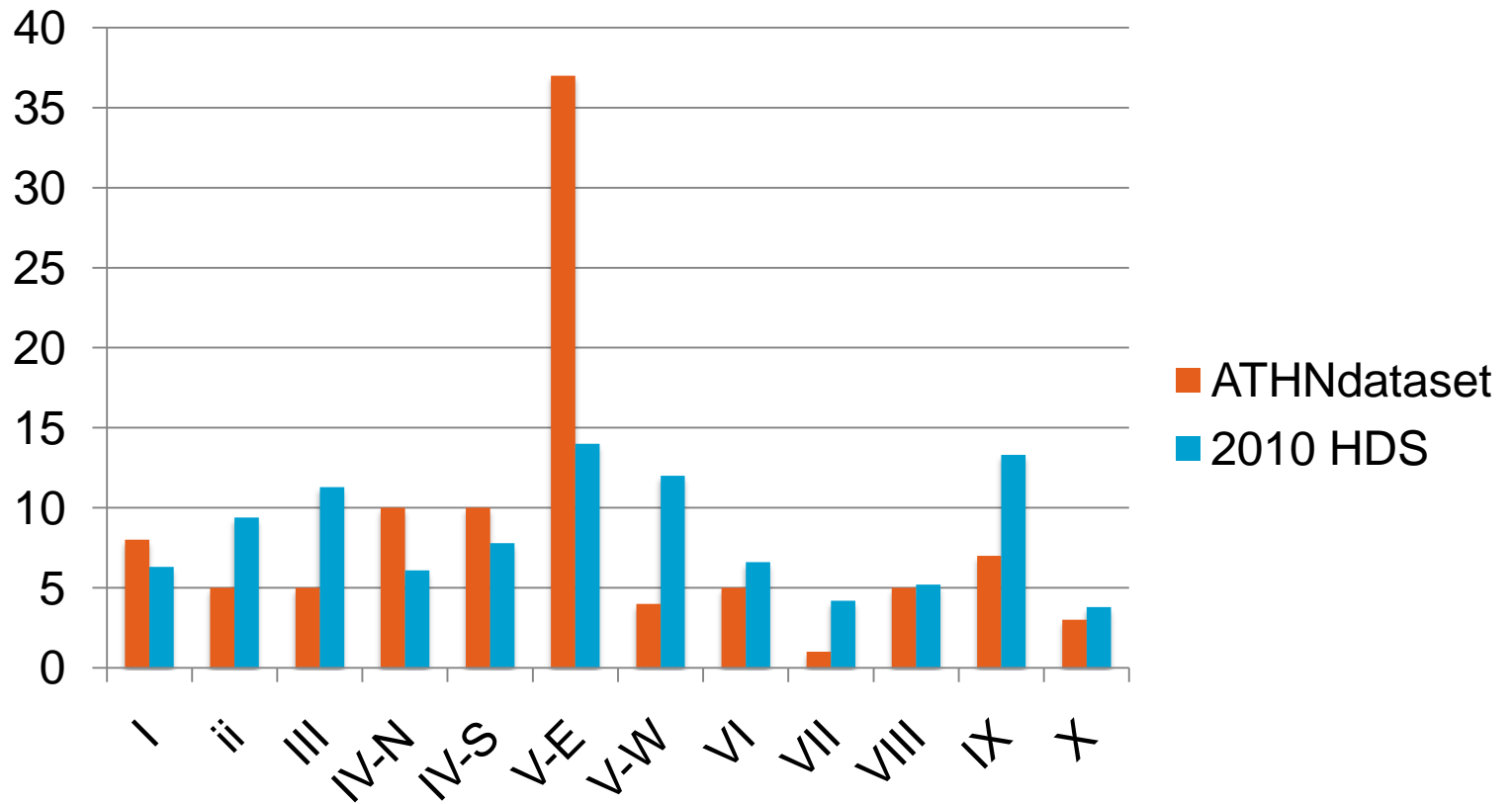
Von Willebrand Disease Patients

(1146 VWD Authorized Patients as of September 1, 2011)



Geographic Distribution of Patients

Percent of Patients in ATHNdataset vs. 2010 HDS by Region



How to Utilize ATHNdataset

Reuse Standard Building Blocks Across Research Projects

Feasibility Studies

- Site selection
- Hypothesis generation
- Power calculations

Observational

- Leverages a quality dataset

Cohort Studies

- Study data enriches the dataset

Controlled Trials

- Case control studies and randomized trials