

ATHN DATA SUMMIT 2011

Securing Data.
Advancing Knowledge.
Transforming Care.

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The InterContinental
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Patient Reported Outcomes: ATHNadvoy

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Our story:

Patient Reported Outcomes

- Patient reported outcomes are important measures but can be difficult to measure. Following the donation by Baxter (July 2010), the ATHNadvoy data can be analyzed with other clinical data
- The issue this raised:
 - What's in the database?
 - What can we do to ensure that the data enhances our understanding at the patient and population level?

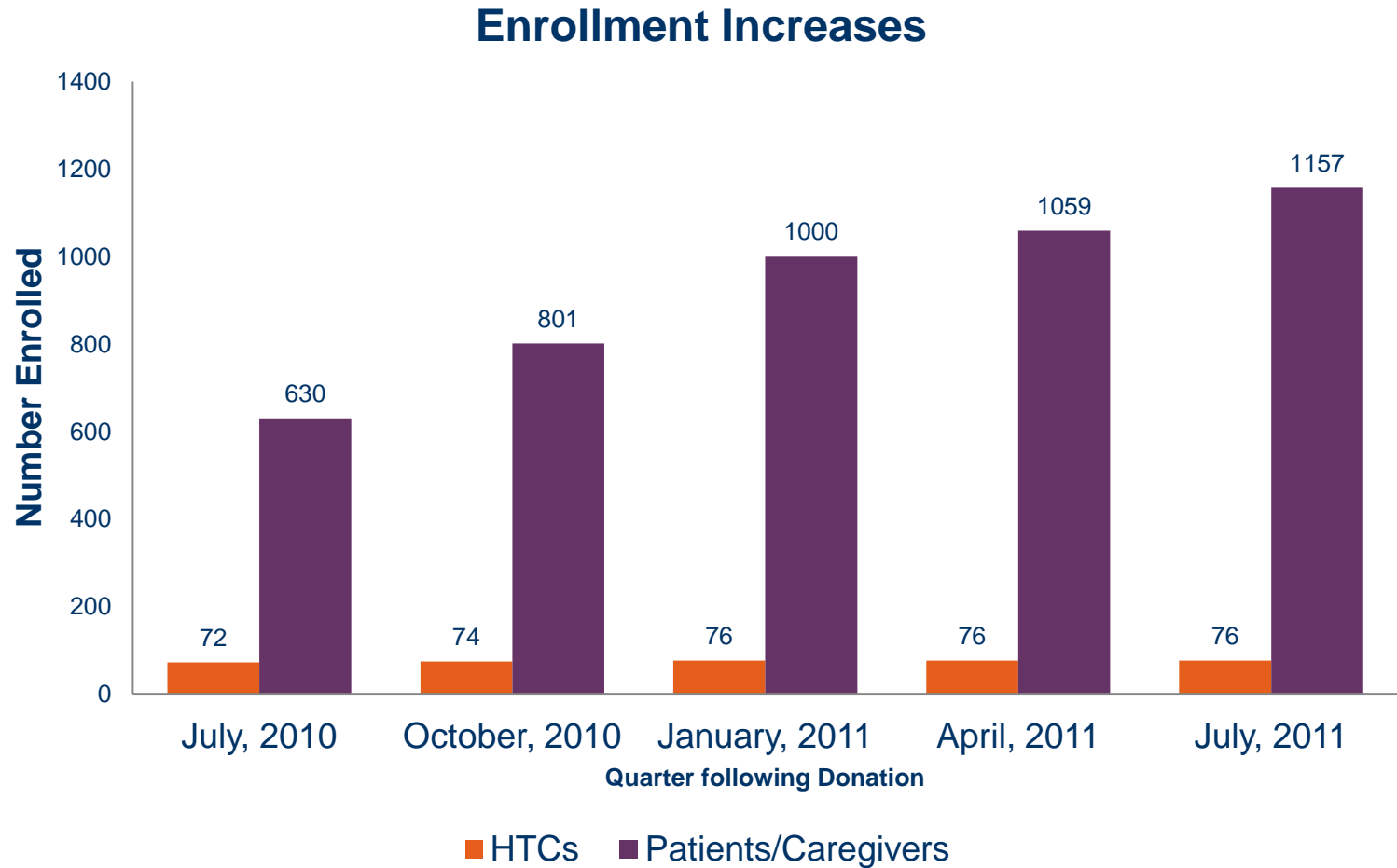
ATHNadvoy

- What's in it?
 - Patient's diagnosis and severity
 - Non-denominational
 - Details of bleed treatment/prophylaxis
 - Reason for infusion
 - Location of bleed
 - Product
 - Dose, frequency
 - Pain assessment

ATHNadvoy Bleed and Infusion Logs

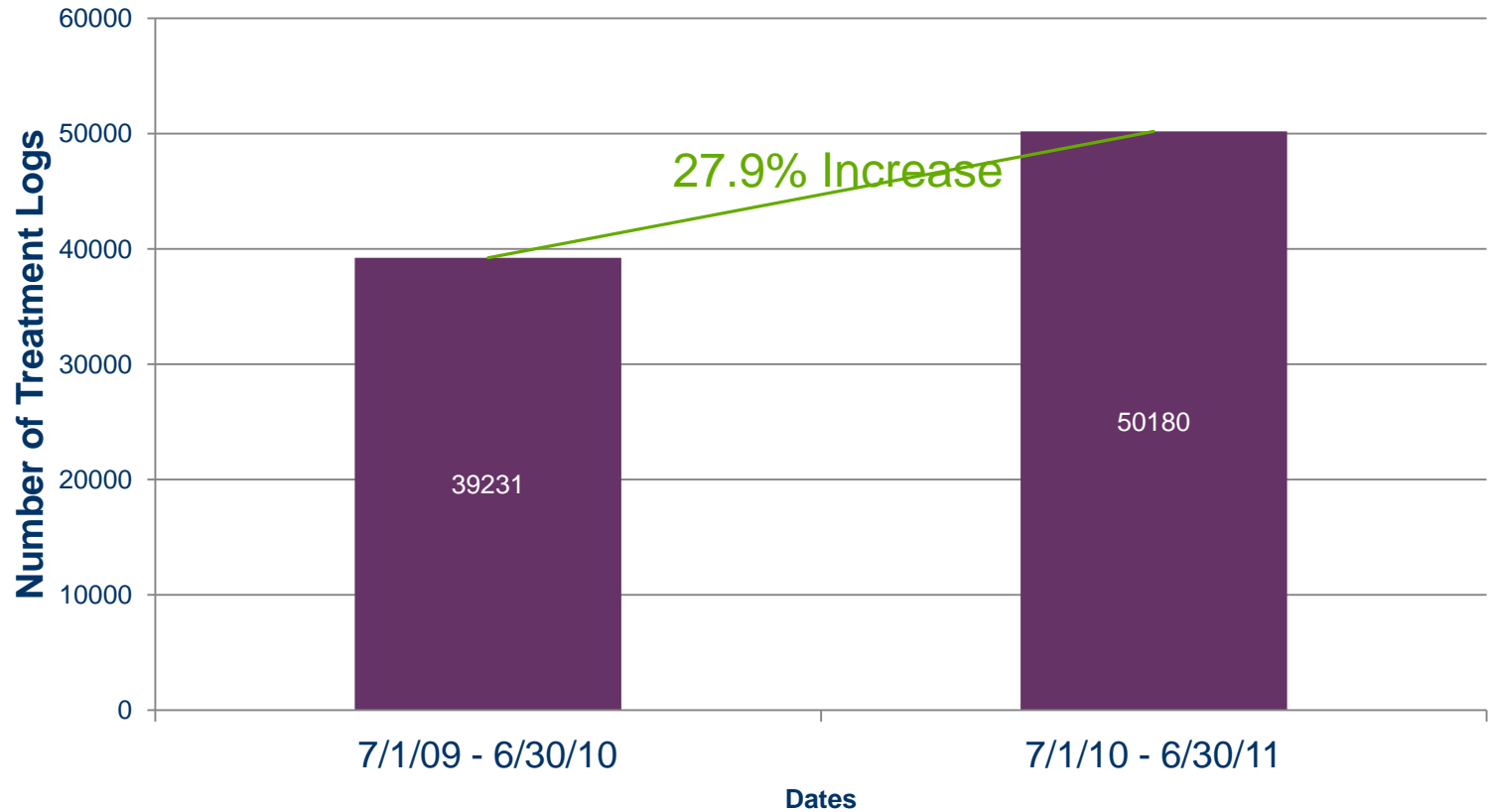
- Measure of clinical outcome for studies/care
 - Patient self-reported
- Indicator of treatment success
 - Document adherence
 - Monitor target joints and non-responsive bleeds
 - Individualize treatment regimens
 - Payer justification
- Easy to use web-based ATHNadvoy tool
 - Now under ATHN stewardship

Patient & HTC Enrollment Increases

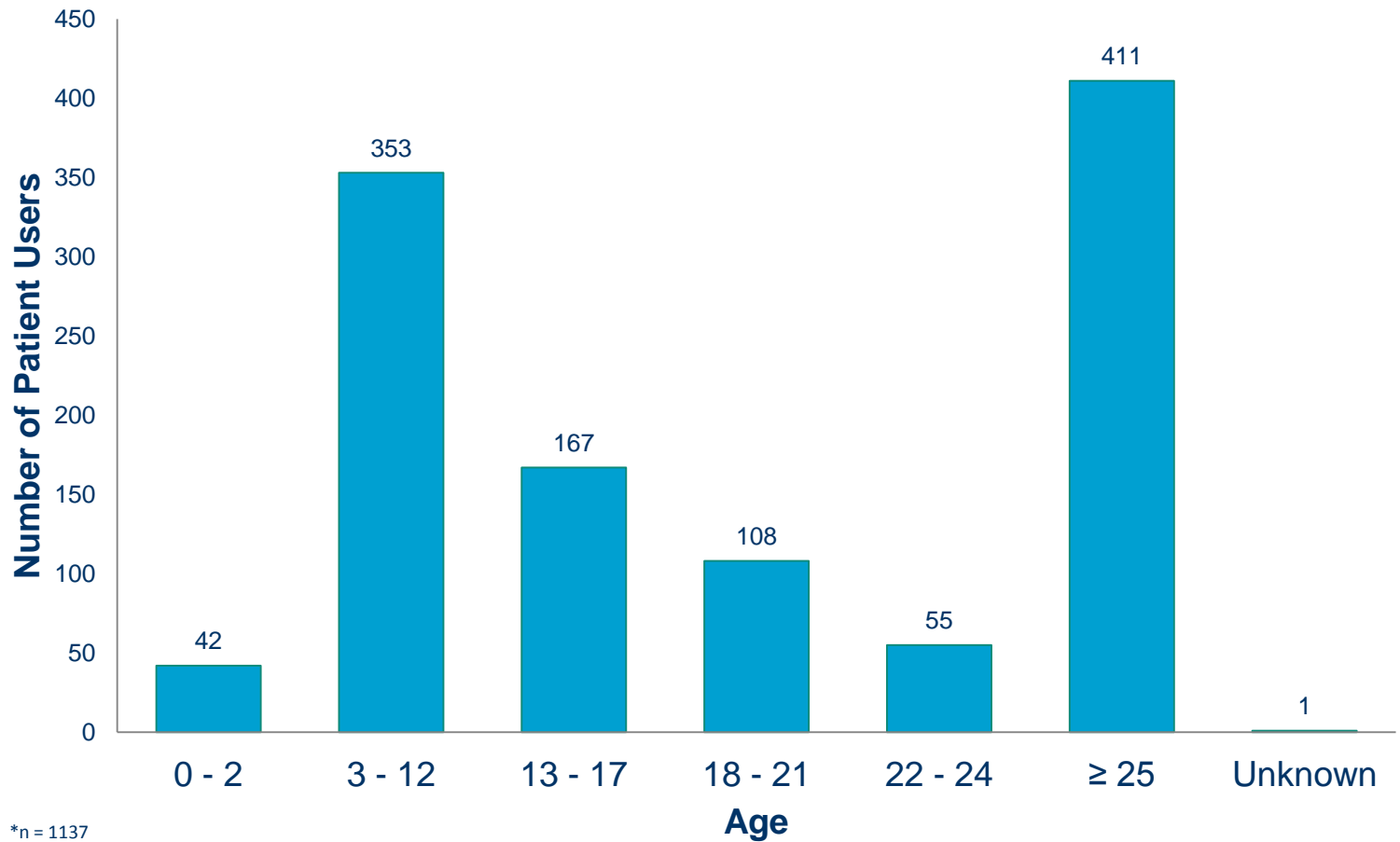


Growth in Treatment Logs

ATHNadvoy Pre/Post Donation to ATHN, July 2010

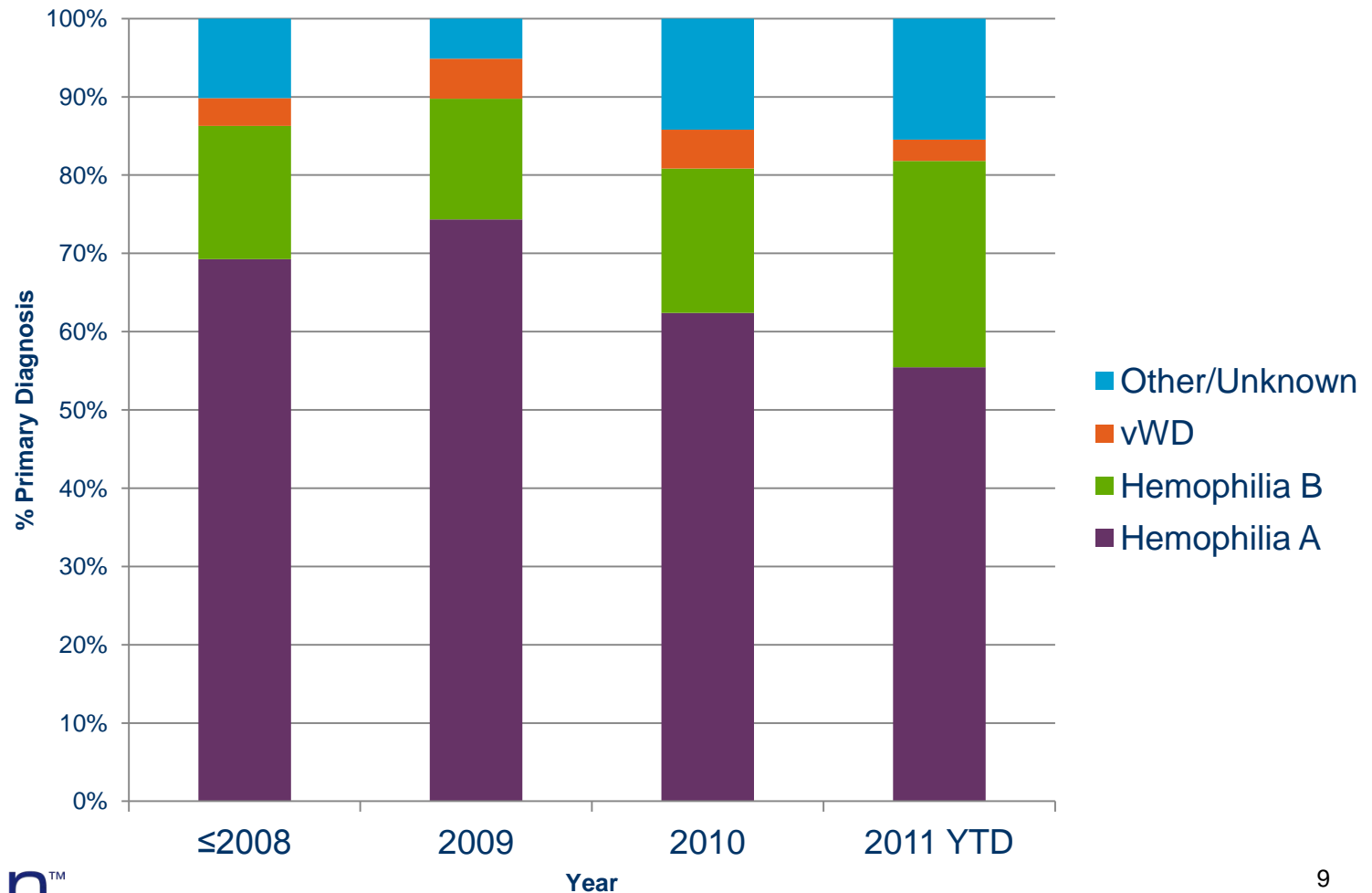


Age of Patient Users (ATHNadvoy as of July, 2011)



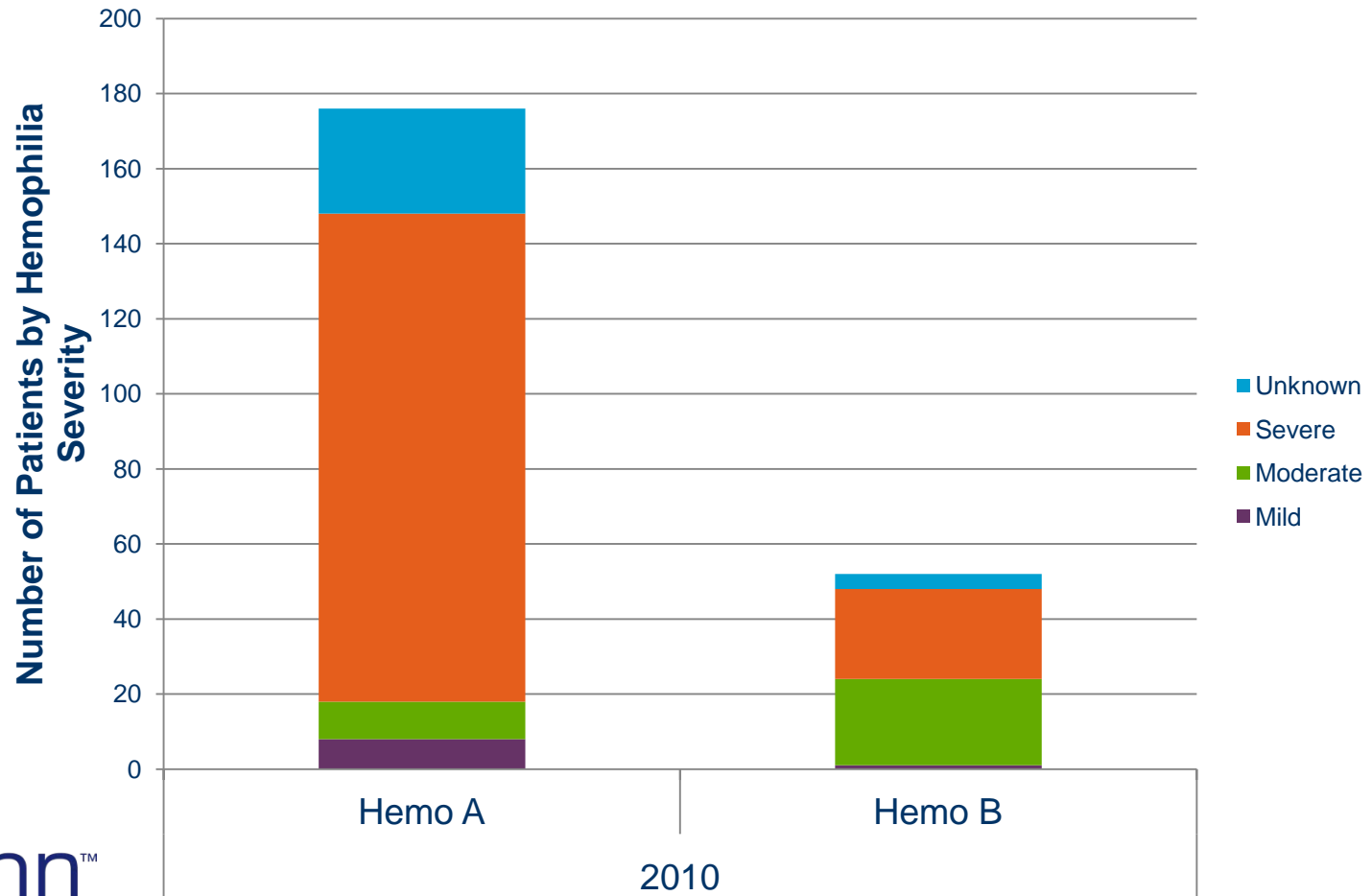
*n = 1137
†As of 7/12/11

Primary Diagnosis of Patients by Year (ATHNadvoy ≤ 2008 – July 2011)



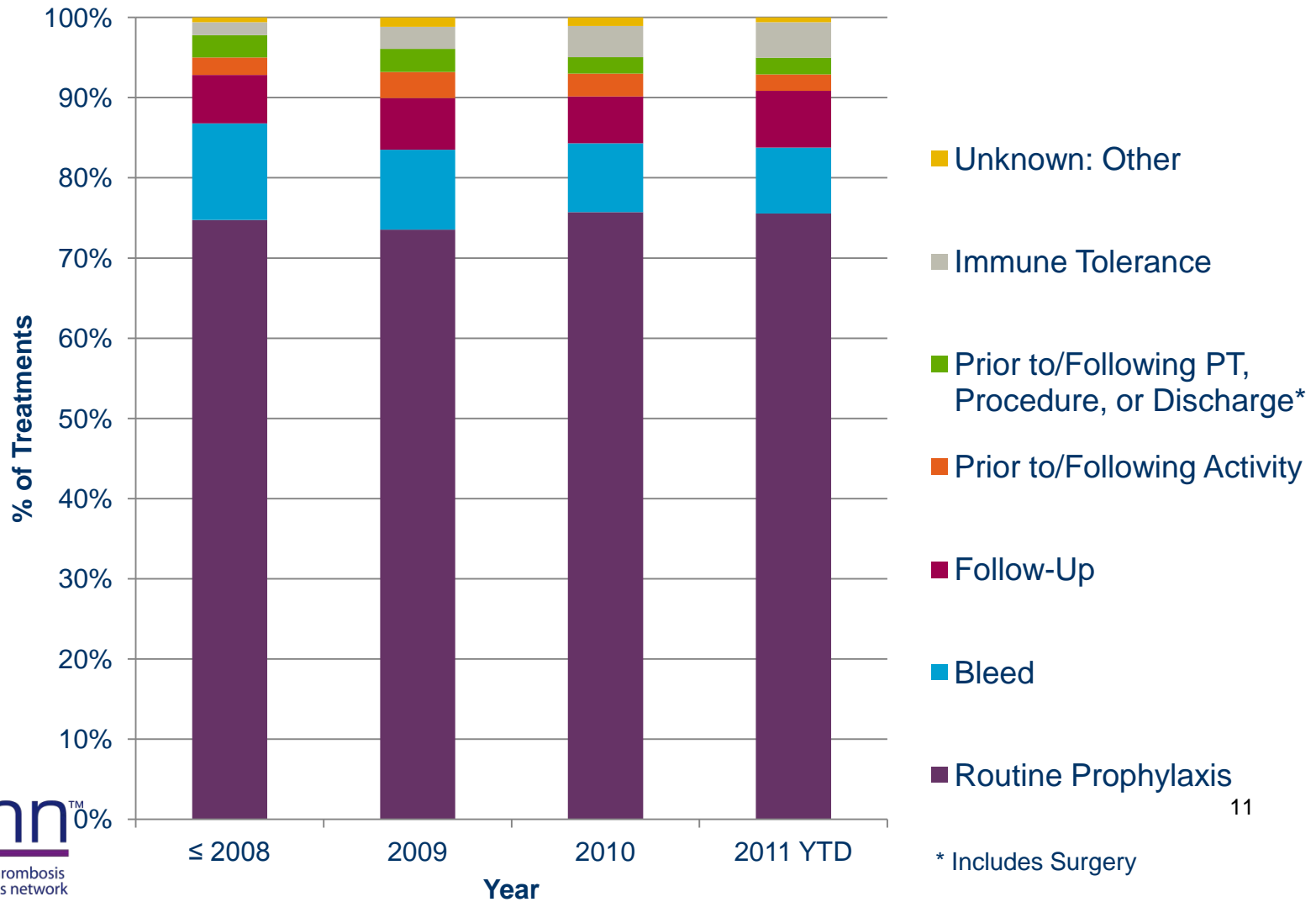
Patient Severity by Diagnosis

Comparison of Hemophilia A and B
(ATHNadvoy 2010)



Reasons for Treatment

(ATHNadvoy treatment logs ≤ 2008 – July 2011)



Treatment Logs by Bleed Location

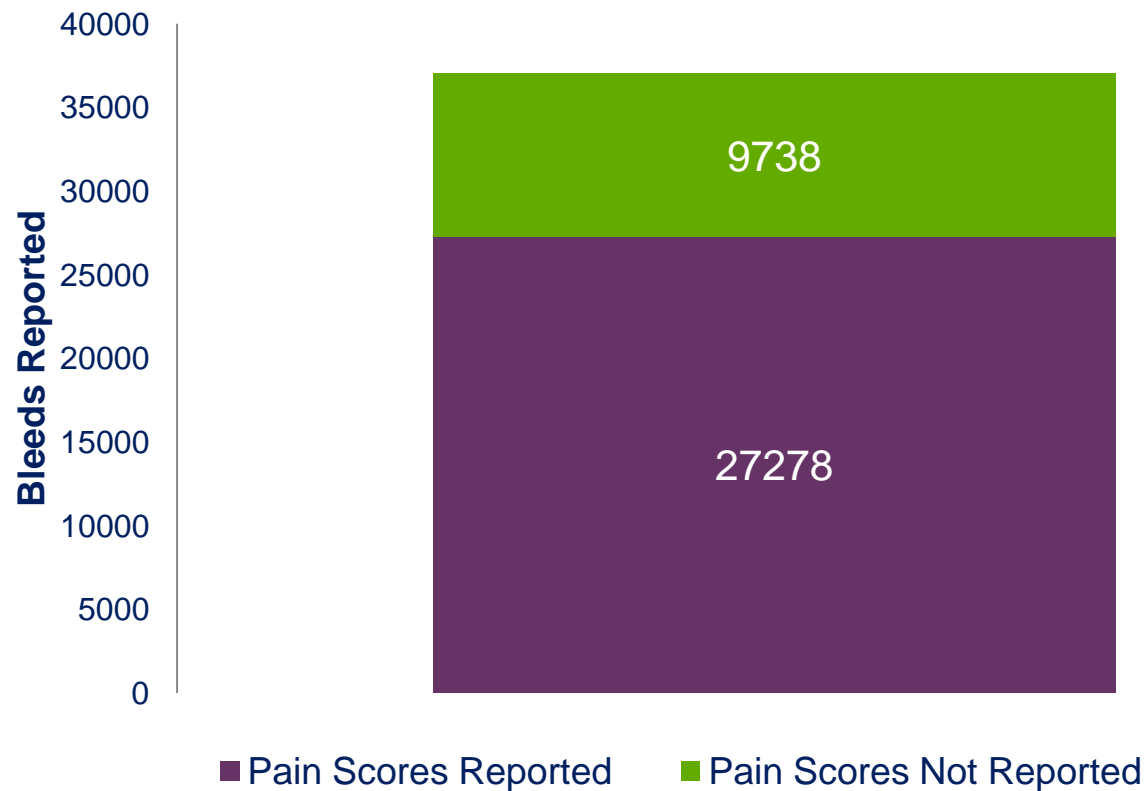
(ATHNadvoy \leq 2008- July 2011)

Bleed Location	Number of On Demand Treatment Logs	% of On Demand Treatment Logs
Elbow (L & R)	3820	16.11
Ankle (L & R)	3529	14.88
Knee (L & R)	2854	12.04
Other Sites	13509	56.97
Total	23712	100.00

- Across all years, elbows, ankles, and knees account for over 40% of logged bleeds






Pain Reports Associated with Bleeds

(ATHNadvoy \leq 2008- July 2011)



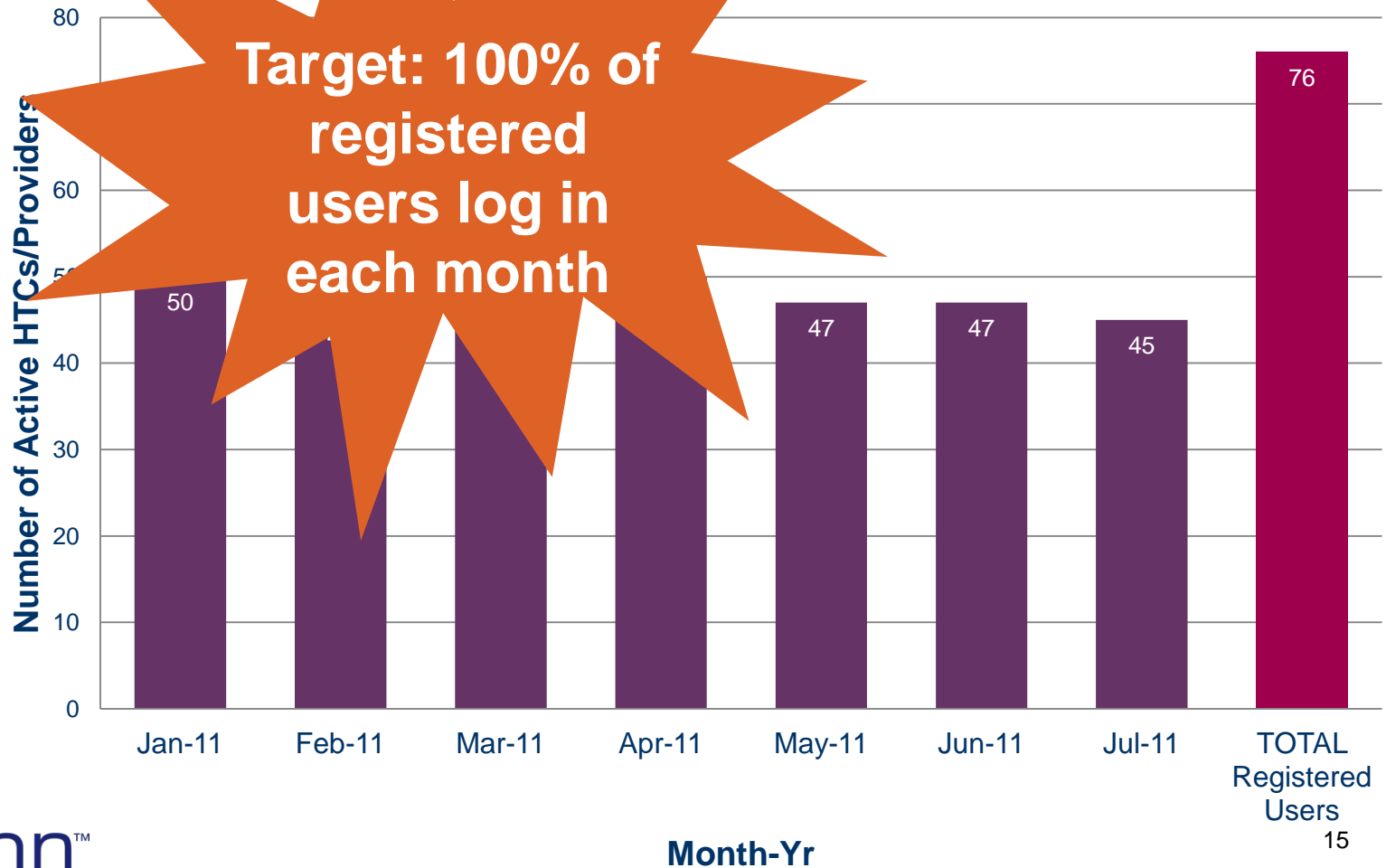
Level of Pain Associated with Bleeds

(ATHNadvoy \leq 2008- July 2011)

Year	 0 NO HURT	 1 HURTS LITTLE BIT	 2 HURTS LITTLE MORE	 3 HURTS EVEN MORE	 4 HURTS WHOLE LOT	 5 HURTS WORST	Not Specified	Yearly Total*	% of Yearly Overall Total*
\leq 2008	1615	3276	4295	2689	1379	784	3862	14038	51.46
2009	543	1394	1485	1135	573	194	1405	5324	19.52
2010	519	984	1658	1212	547	335	2492	5255	19.26
2011 YTD	279	568	859	519	251	125	1979	2661	9.76
Pain Scale Total*	2956	6222	8297	5615	2750	1438	9738	27278	
% of Pain Scale Overall Total*	10.84	22.81	30.42	20.58	10.08	5.27			

* "Not Specified" not included in calculations

HTC/Providers: Active Users by Month



Getting the Most from ATHNadvoy

- Patient that refuses to keep logs
- Patient that fills in log sheets in the HTC parking lot on the day of the Comp Care visit
- Patient regularly logs into ATHNadvoy. HTC regularly logs in to ATHNadvoy.

Inefficient.....sl less inefficient....more efficient

Getting the Most from ATHNadvoy

- Promote credibility and potential impact that ATHN can have to your HTC team.
- Foster support for ATHNadvoy in your language and actions during interactions with patients of the HTC
- Use the data from ATHNadvoy for your patients
 - Regularly log in to ATHNadvoy for all your patients
 - Close surveillance of infusion activity will enhance care
 - Bleed location, bleed frequency, pain data