

A National Infrastructure for Rare Blood Disorders: An Evaluation of Staffing, Training and Services in the US Federally-Supported Hemophilia Treatment Centers

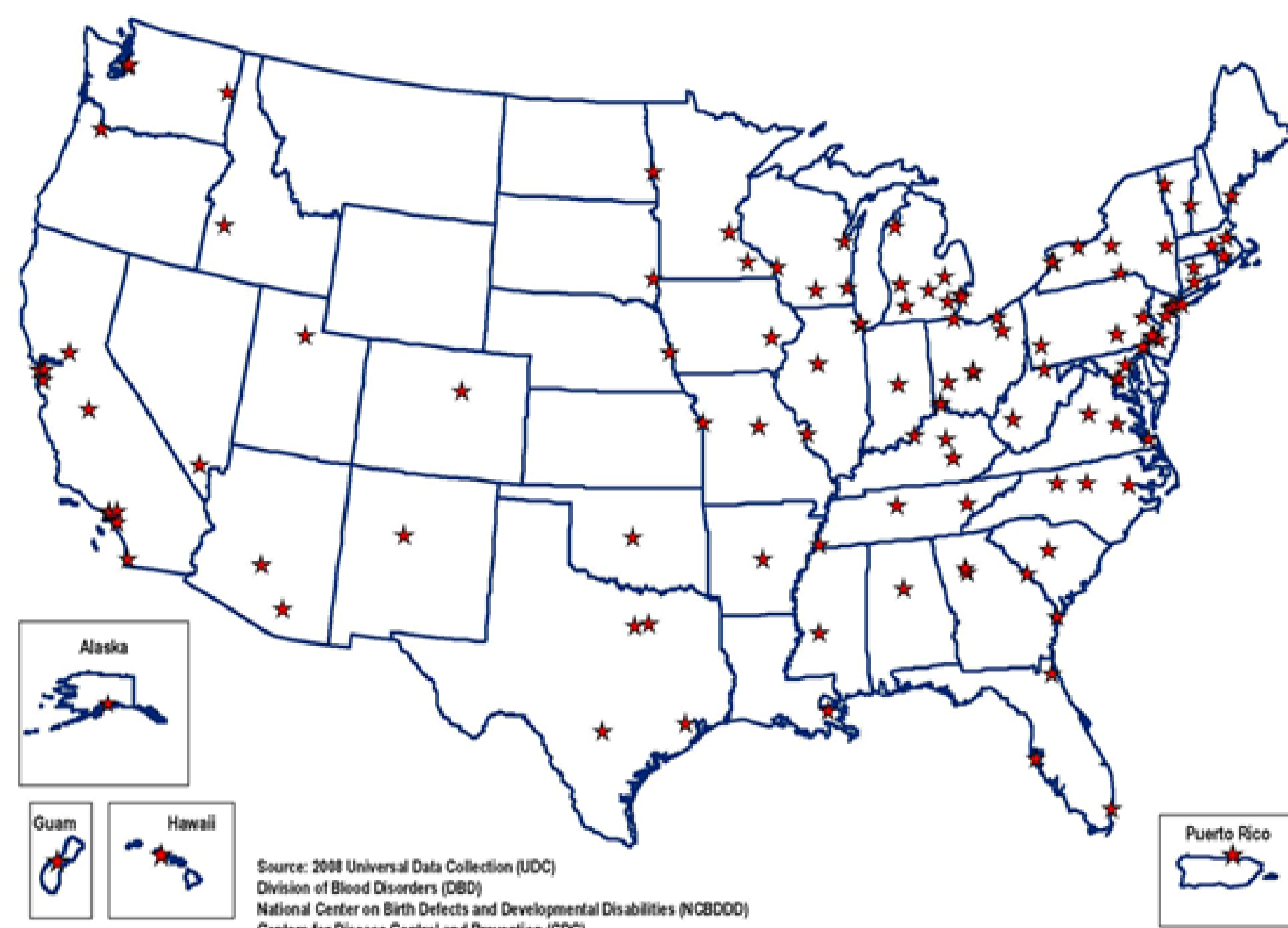
Ann Forsberg,¹ Susan Cutter,² Brenda Riske,³ Mariam Voutsis,⁴ Brian Wicklund,⁵ Judith Baker,⁶ and John Drake.⁷

¹New England Hemophilia Center, Worcester, MA, ²University of Pennsylvania Medical Center-Presbyterian, Philadelphia, PA, Hemophilia and Thrombosis Center, Denver, CO, ⁴Mount Sinai School of Medicine, New York, NY, ⁵The Children's Mercy Hospital, Kansas City, MO, ⁶Children's Hospital Los Angeles, CA, ⁷Gulf States Hemophilia and Thrombophilia Center, Houston, TX.

BACKGROUND

Over the past 35 years a regional network of 129 federally-funded (Health and Human Services and the Centers for Disease Control and Prevention) hemophilia treatment centers (HTCs) has been established to provide multidisciplinary comprehensive care services nationwide to persons with bleeding disorders. Although all HTCs provide core services including medical, nursing, physical therapy and social work, the HTC infrastructures are diverse due to center variance in demographics and resources.

UDC Hemophilia Treatment Centers (HTC)



PURPOSE

A nationwide study was conducted in 2009 to provide the first systematic review of HTC variability in the US along three constructs.

HTC size and characteristics
Staff
Resources

METHODS

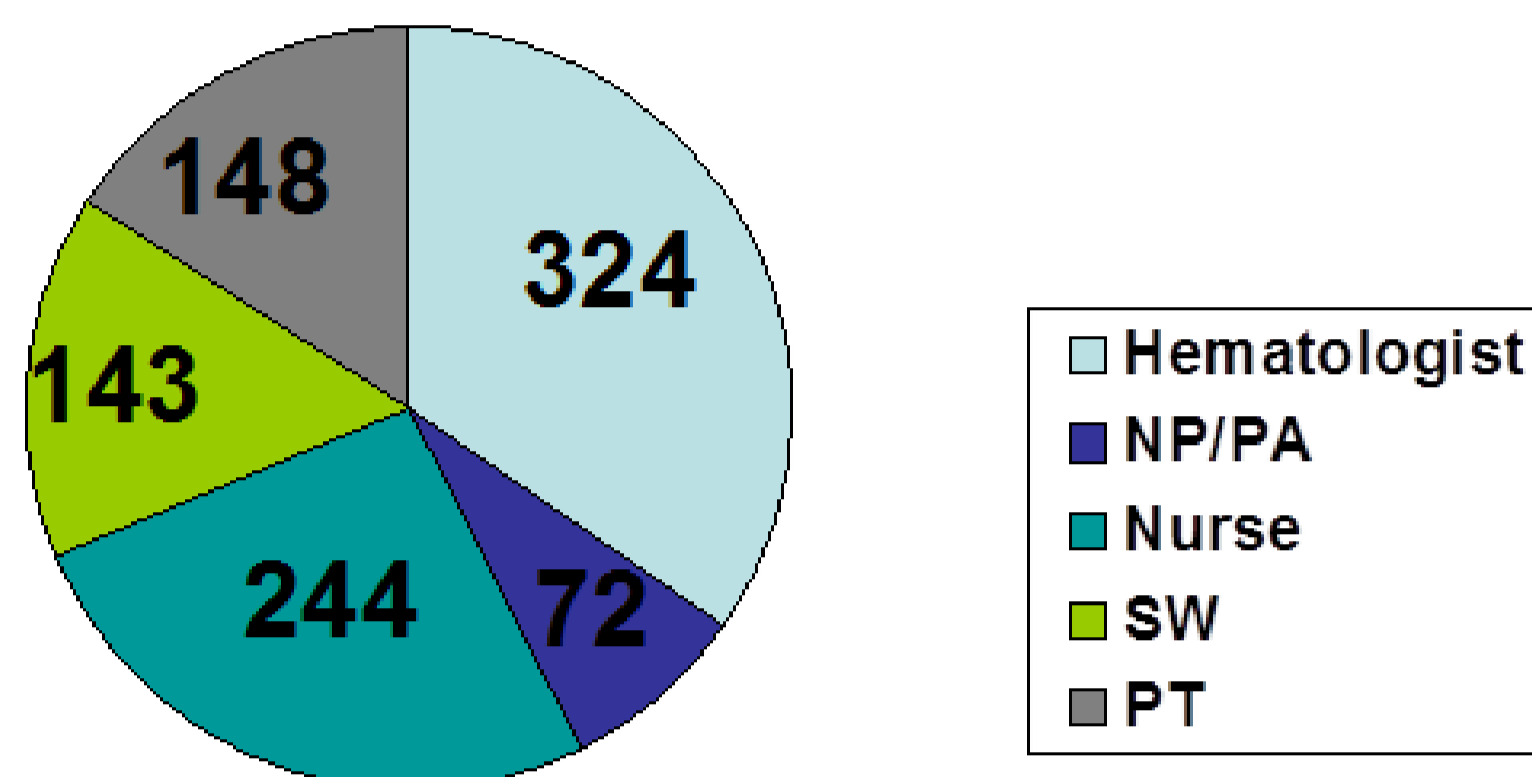
An e-survey was conducted at 129/129 centers to collect data on staffing, services and resources. This was combined with the Hemophilia Data Set (HDS), an annual aggregate data set of patient demographics.

Differences in infrastructure were analyzed by comparing small, medium and large centers.

Size and Number of HTCs in Each Analysis Group					
Size	# HTCs	Number of Patients			
		Min	Max	Mean	ST Dev
Small (Quartile 1)	32	10	114	78	28
Medium (Quartile 2,3)	65	115	289	196	49
Large (Quartile 4)	32	295	1312	479	238
All	129	10	1312	237	192

STAFF CHARACTERISTICS

Breakdown of Core Staff (n=931)



120/129 (93%) have complete core team

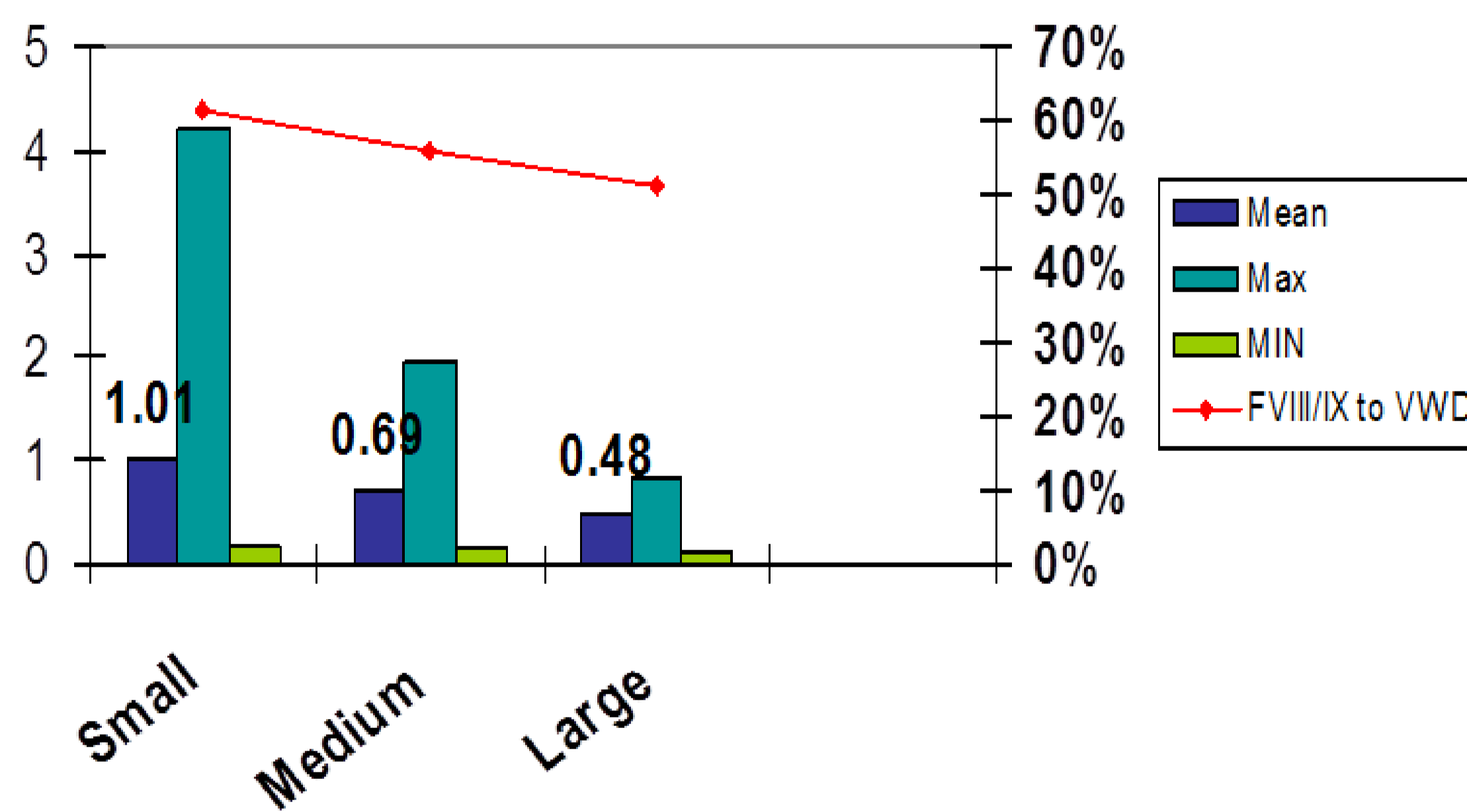
Staff Experience

- There was a correlation between years experience and discipline with 66% MDs, 46% of RNs, 42% SW and 37% PTs had >10 years experience (p=.01, Chi square)
- No significant difference in experience by center size.
- 96% of staff <4 years experience reported participation in orientation training

Core Staff Hours/Patients/Week

- Core staff hours/patient/week was significantly decreased as the size increased p<.005).
- The ratio of VWD to hemophilia significantly increased with center size

Staff Hours/Patient/Week vs Hemophilia/VWD



RESOURCES

Laboratory Services

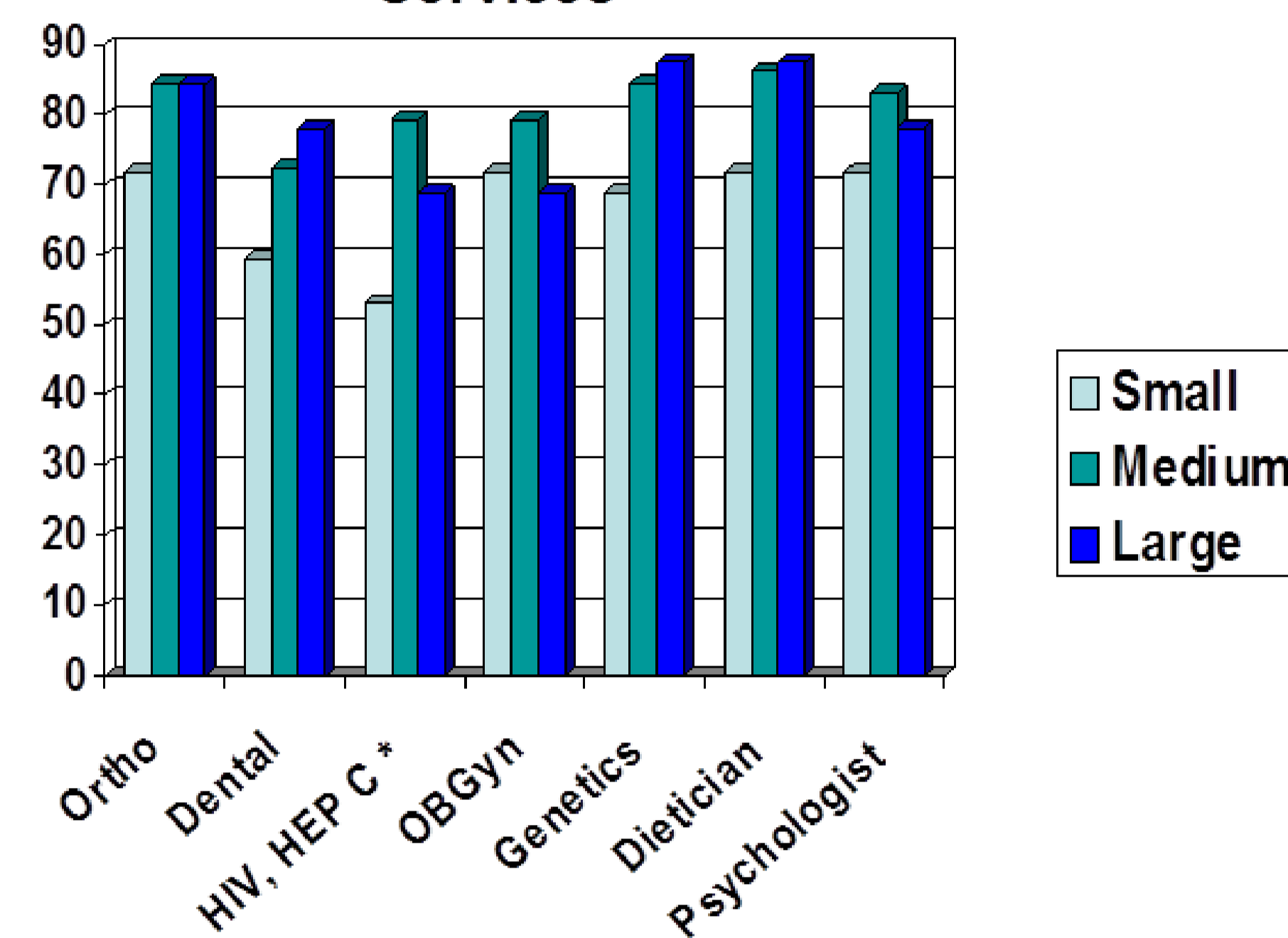
There was no significant difference in laboratory capacity to perform in house factor levels or time to obtain a stat level by center size.

	Small	Medium	Large
In House Factor Levels	84.4%	93.8%	93.8%
Factor Level at <1%	84.4%	86.2%	84.4%
Time for Stat Level	2.56 (4.51)	2.26 (3.27)	1.67 (1.49)

Coordination with Specialists

- The majority of HTCS had formal affiliations with multiple specialty providers
- There was a significant difference between small and large centers in percent of HTCs with subspecialty services but not between medium and large centers (P<.01).

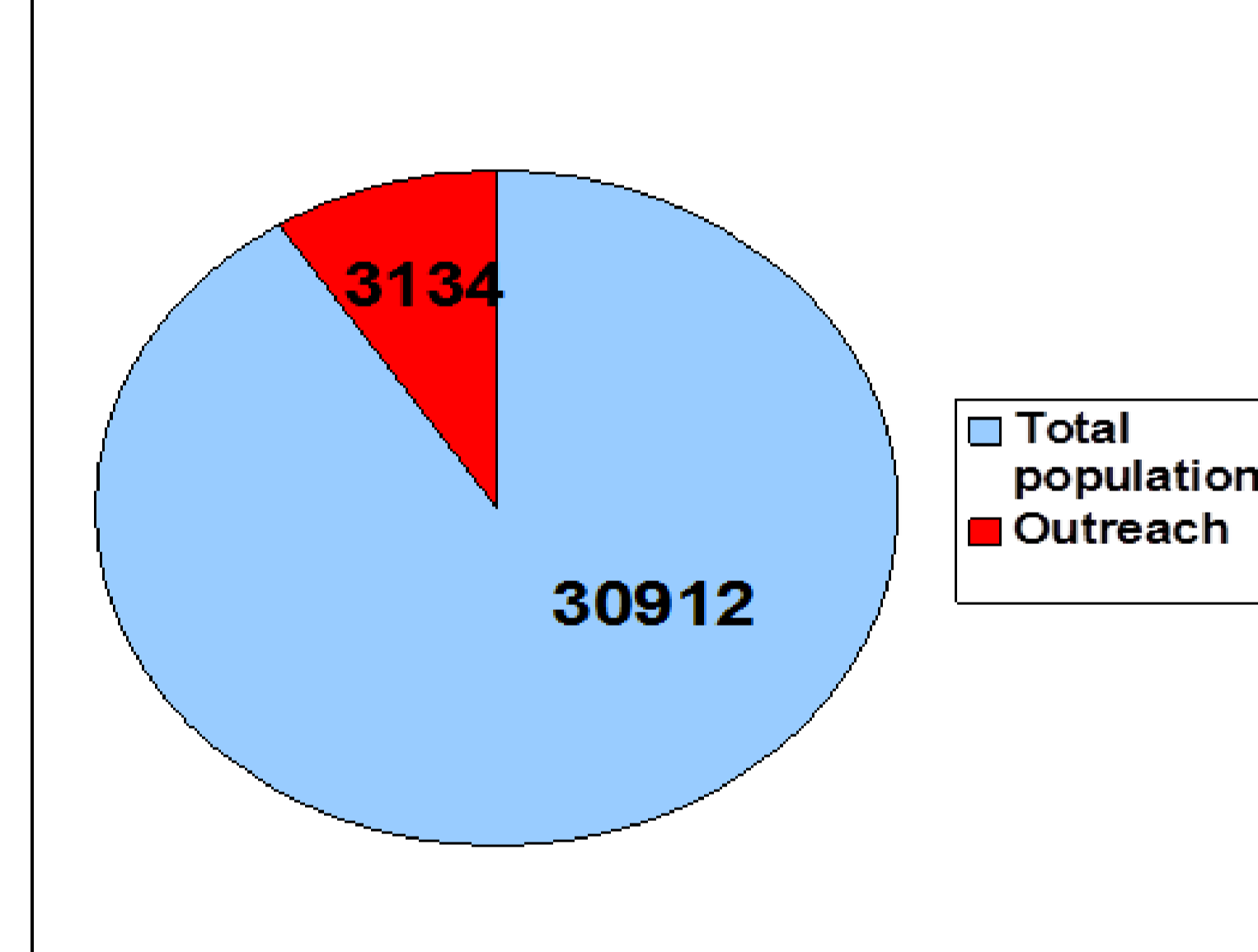
Per Cent of HTCs with Subspecialty Services



Outreach

Patients who are geographically distant from HTCs have access to care through outreach clinics. Medium and large centers are significantly more likely to offer these clinics. (p,.01).

Outreach vs Total Patients



CONCLUSION

- The infrastructures of the HTCs vary but all maintain core teams that have years of experience, participate in blood disorder education programs and coordinate care with subspecialists.
- The majority of HTCs offer in house laboratory coagulation services
- Staff hours/patient/week decreases with center size possibly due to increased efficiencies or decreased acuity.
- Centers have outreach clinics to improve access to care.
- This first systematic study of variation in HTCs lays the groundwork for future studies to link HTC characteristics with clinical

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Regional Coordinators

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