

Bleeding Disorder Patient Perspectives on Information and Service Needs in a Remote US Pacific Island

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Introduction

The Commonwealth of the Northern Mariana Islands (CNMI) is a remote United States Pacific territory with an underserved bleeding disorder population. Comprehensive hemophilia treatment center (HTC) care and clinical/patient education was initiated in 2014. A nationally uniform patient needs assessment was required to obtain a baseline, guide local priorities, monitor trends over time, and compare to US HTCs in the Western States/Region 9 (California, Guam, Hawaii, Nevada) where the CNMI HTC obtains technical assistance.



Methods – Medical and Educational Interventions

A Pediatric Hematology fellow (MD) affiliated with the HTC at the University of California San Francisco in US HTC Region 9, resided in CNMI in 2014-2016. MD partnered to improve care with CNMI's longstanding hemophilia champion – a CNMI physical therapist who developed bleeding disorder knowledge -- via linkage to the US Region 9 Public Health Director and clinician mentors.

December 2014

- The CNMI MD and PT with consultation from Region 9 leadership and California HTC mentor PT created a week-long clinical educational seminar series. Two hundred health care professionals and athletic coaches attended
- A weekend Family Bleeding Disorder Camp provided basic education, and introduced CNMI's bleeding disorder team: MD, PT, and Social Work
- MD reviews and corrects diagnoses on identified patients, consults regarding inpatient hematology treatment, diagnoses new patients
- Annual comprehensive care evaluations. More frequent clinic visits with MD for patients on active therapy
- Collaboration with dental care team occurred with dental care provided
- Conduct 2nd Family Bleeding Disorder Camp, providing individualized patient care binders to equip families to advocate medically and socially (April 2016)

Methods – Patient Needs Assessment

The 2013 US Bleeding Disorder Needs Assessment Survey ("NA Survey"), sponsored by the Federal Health Resources and Services Administration, that was used throughout the US HTC Network, was offered to all patients at CNMI's first family educational conference in December 2014.

Data analysis characterized trends in 8 categories of information and 11 types of HTC clinical services needed or received. We compared CNMI results to results from the 14 HTCs comprising the US' Region 9.

The NA Survey was re-administered at the 2nd CNMI family educational conference (April 2016) 16 months after implementing the first island-wide patient and provider education series and initiating comprehensive hemophilia care.

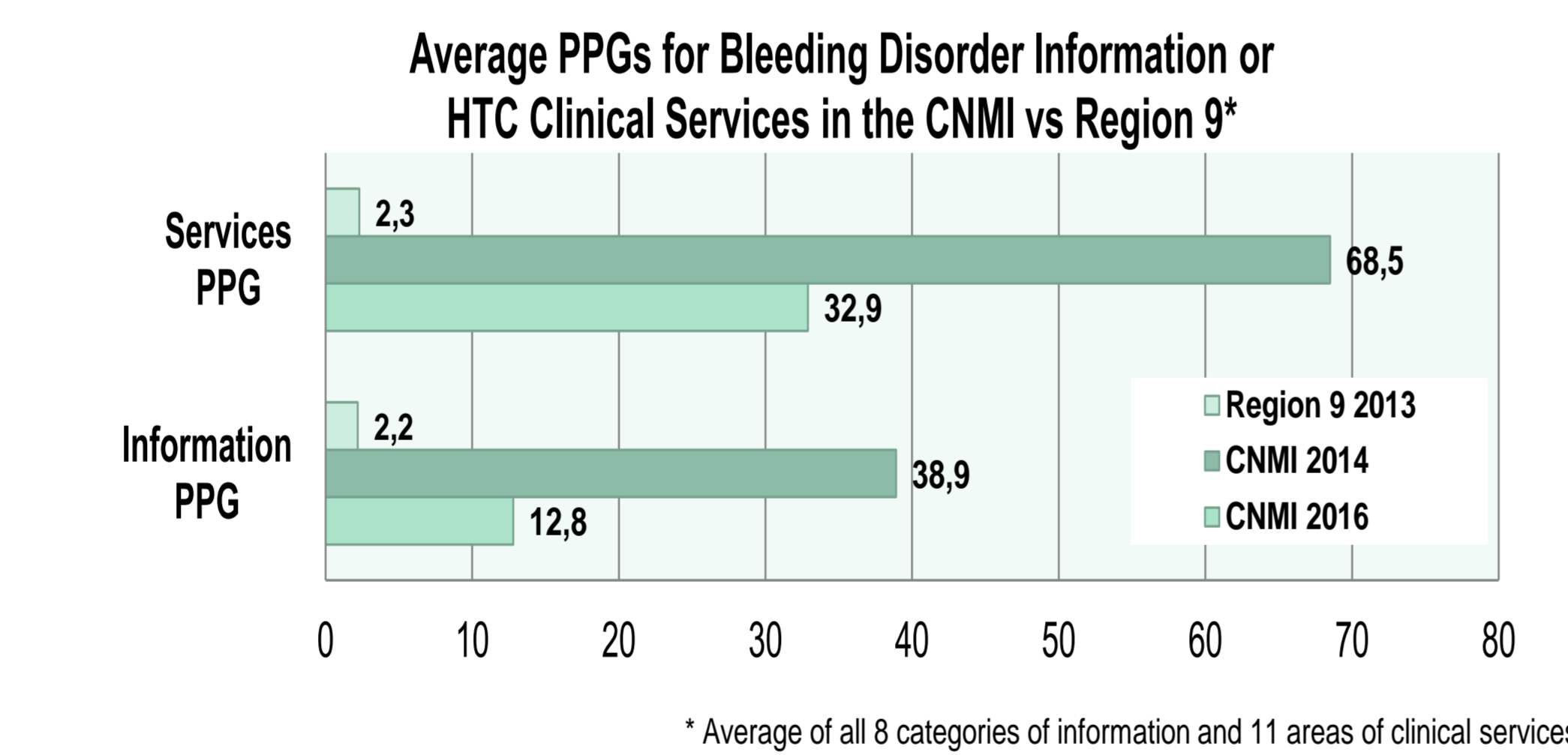
Findings

Table 1: CNMI Patient Population

	Severe Hemophilia A	Severe Hemophilia B	Von Willebrand type 2A	Von Willebrand type 2B	Von Willebrand type 2N	Hemophilia A carrier	Hemophilia B carrier
2014 Cases	3 (age 16, 39, 43)	1 (age 6)	2 (age 9, 32)	3 (age 17, 19, 25)	1 (age 9)	7	1
2016 Cases	2 (age 17, 45)	1 (age 8)	2 (age 10, 34)	3 (age 19, 21, 27)	2 (age 1 and 11)	7	1

Figure 1: Patient Needs Assessment - Percentage Point Gaps in CNMI vs. Western States/Region 9 HTCs, 2014 - 2016

- NA Survey response rates: CNMI 2014 and 2016 (100% or n=13 both years) versus 12.8% Region 9 HTCs in 2013 (n= 298)
- Percentage Point Gaps (PPG) were calculated by subtracting rates that NA Survey participants reported that information or HTC services were 'received' from the rates that information or HTC services were 'needed.' Larger PPGs suggest bigger unmet needs. Smaller PPGs indicate better meeting of patients' needs.



Information Gaps (Table 2): CNMI's highest two information PPGs in 2014 were a) preparing for work/school and b) resources to meet basic needs (76.9 and 61.5, respectively). All PPGs fell from 2014 to 2016. The biggest PPG drop was in preparing for work/school which fell to zero. The top 2 information PPGs in 2016 were: a) resources to meet basic needs and b) aging with a bleeding disorder (both 30.8). Treatment plans was the most reduced CNMI information PPG between 2014 and 2016.

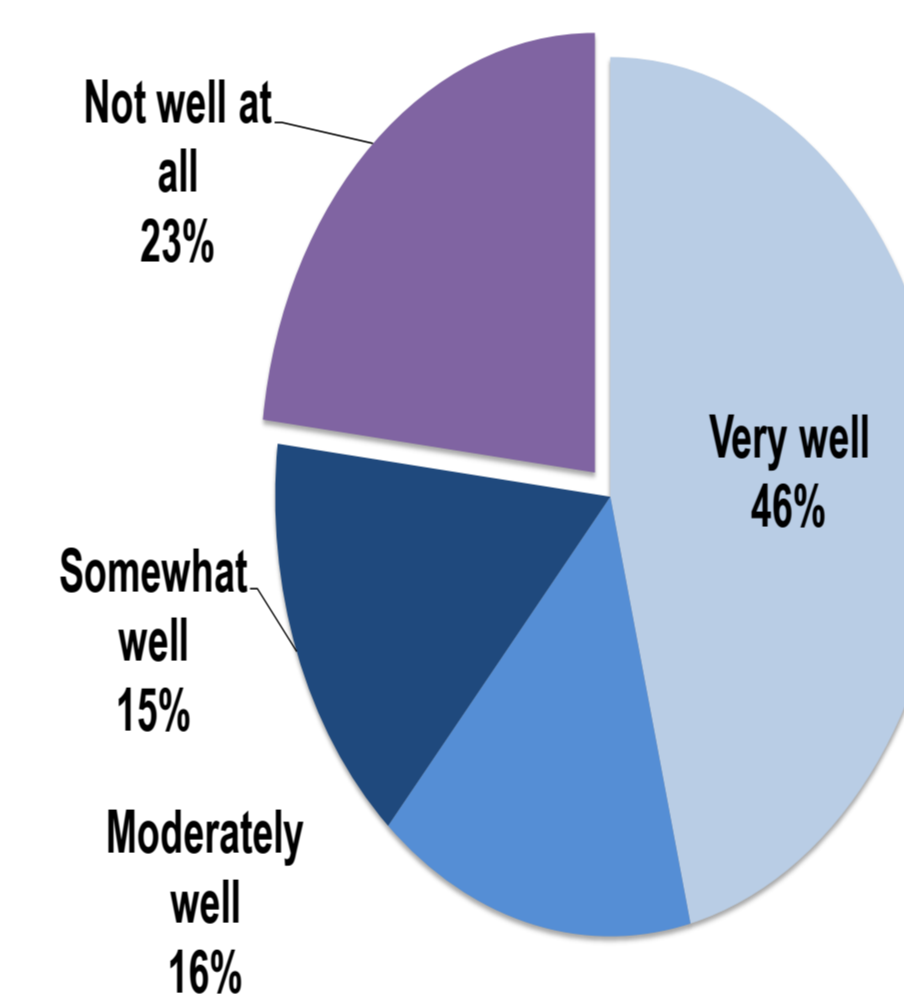
HTC Service Gaps: The top two CNMI PPGs for HTC services in 2014 were for nursing (92.3), and physical therapy, social work, pharmacy, and genetic counselling (all 76.9). All fell by at least half in 2016. The top 2 HTC services PPGs in 2016 were in orthopedics and dietary, with PPG virtually unchanged at over 60. The most reduced between 2014 and 2016 were for a hematologist (92.3).



Table 2: CNMI Bleeding Disorders Patients' Needs Assessment – Gaps in Information Needed & Received: 2014 and 2016

Information on...	2014			2016		
	Need	Rec'd	Gap	Need	Rec'd	Gap
Diagnosis	100.0%	84.6%	15.4	100.0%	92.3%	7.7
Inheritance	84.6%	38.5%	46.2	100.0%	84.6%	15.4
Signs/Symptoms	84.6%	53.8%	30.8	84.6%	76.9%	7.7
Treatment Plan	84.6%	30.8%	53.8	76.9%	76.9%	0.0
Services available	46.2%	15.4%	30.8	46.2%	38.5%	7.7
Preventing bleeds	76.9%	30.8%	46.2	84.6%	76.9%	7.7
Medical emergency	84.6%	38.5%	46.2	76.9%	69.2%	7.7
Coping	38.5%	23.1%	15.4	76.9%	61.5%	15.4

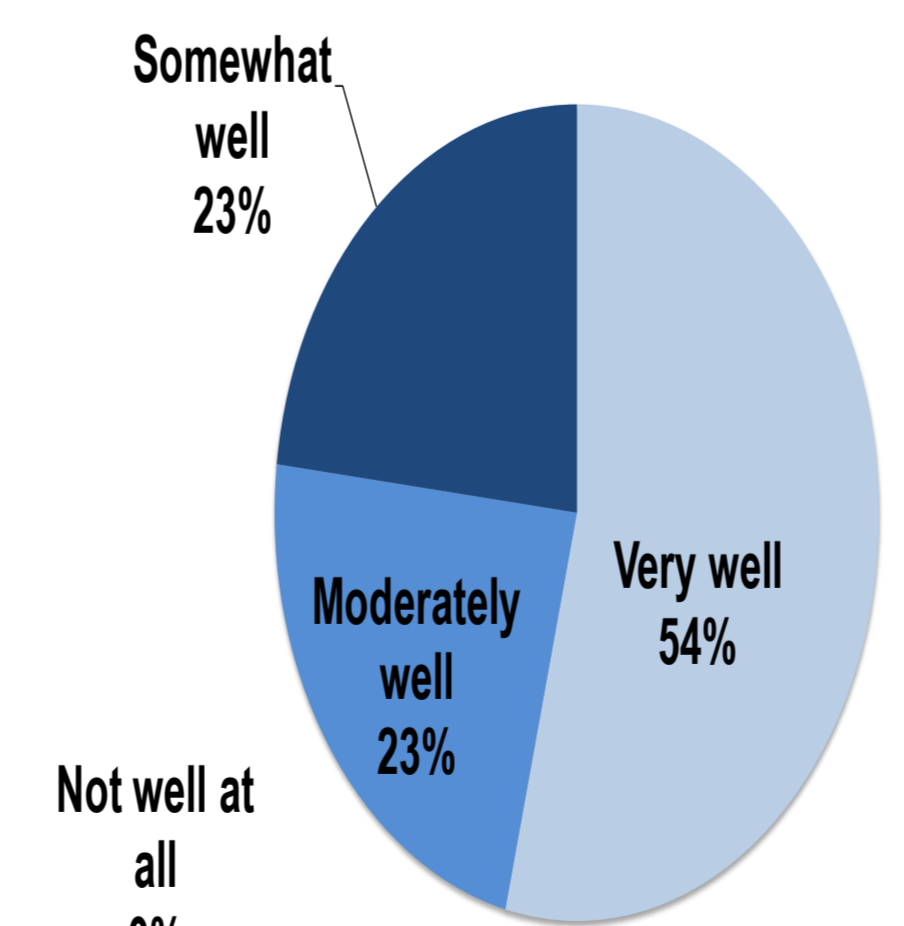
Figure 2: CNMI Patient Perception of HTC Care Management, December 2014



Almost 25% report that historically, their bleeding disorder was poorly managed.

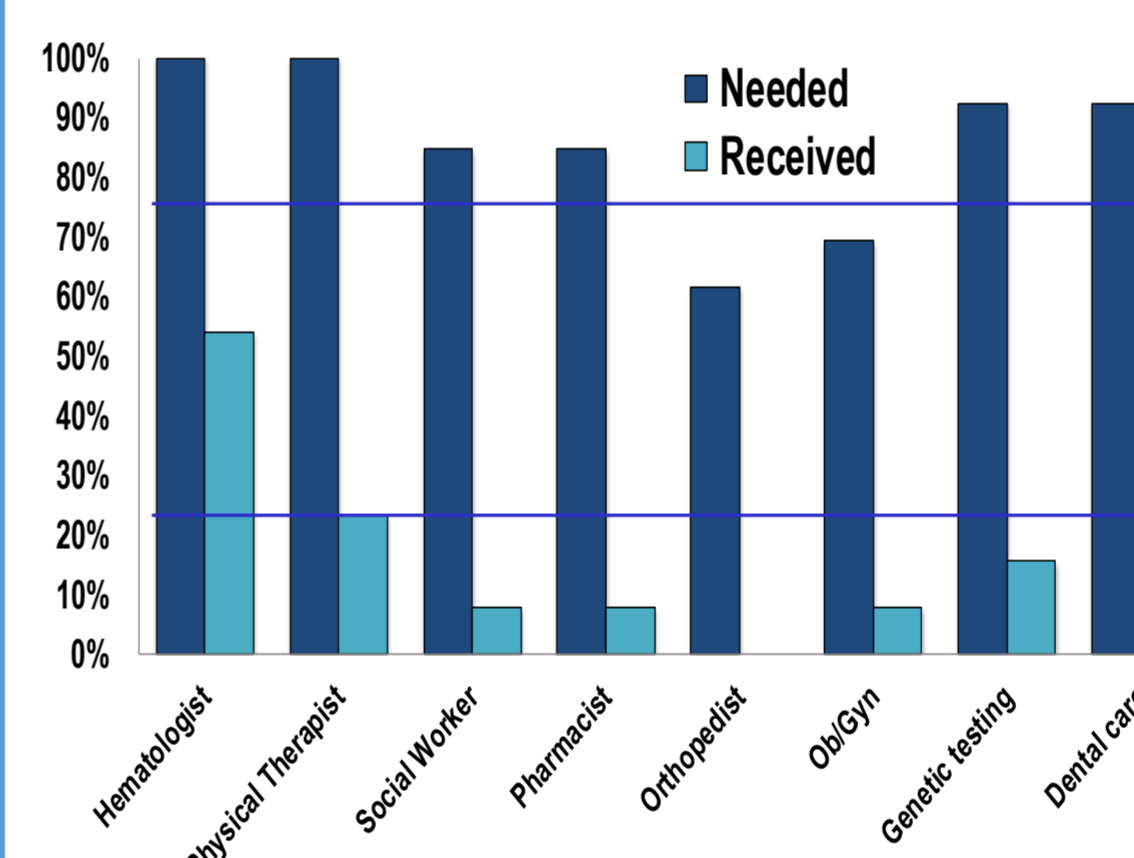
Care Improves, Service Gaps Reduced – 2016

Figure 4: CNMI Patient Perception of Care Management, April 2016



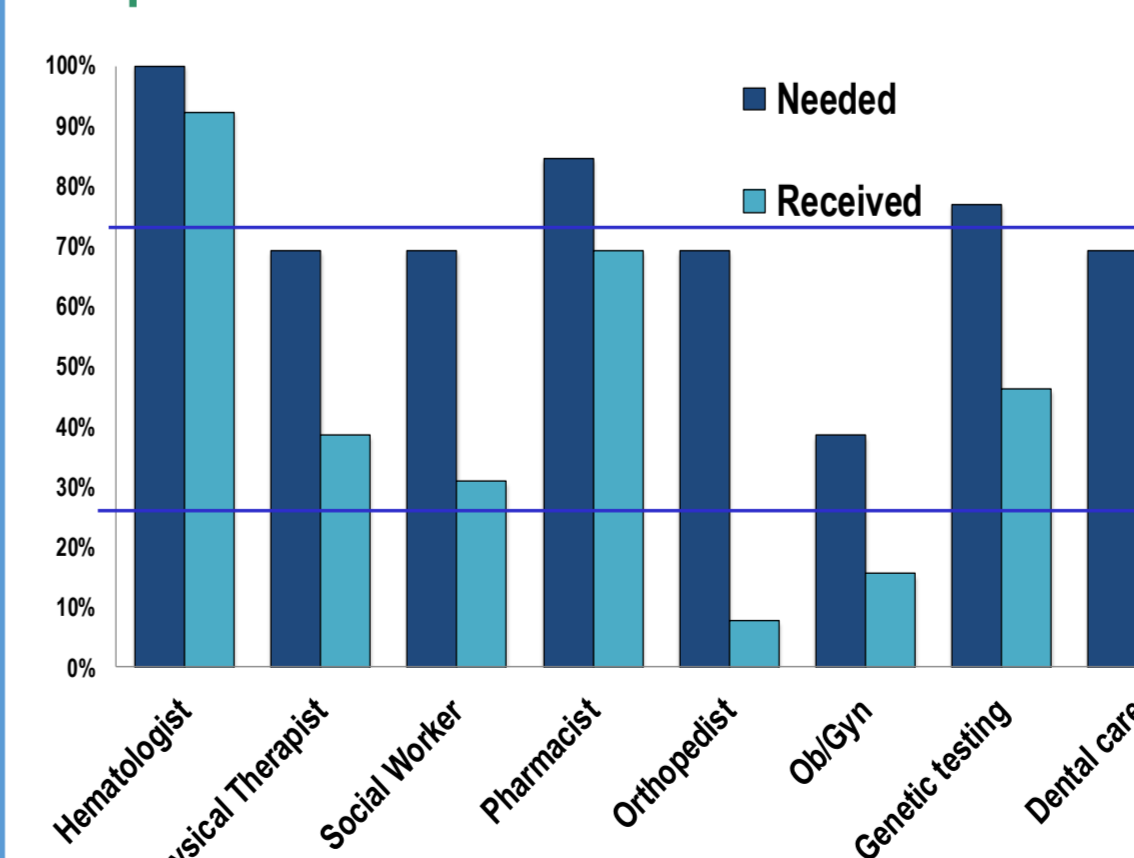
Zero patients reported their disease was poorly managed. Three quarters reported their disease was moderately well or very well managed.

Figure 3: CNMI Patient Perception – HTC Clinician Services Needed & Received December 2014



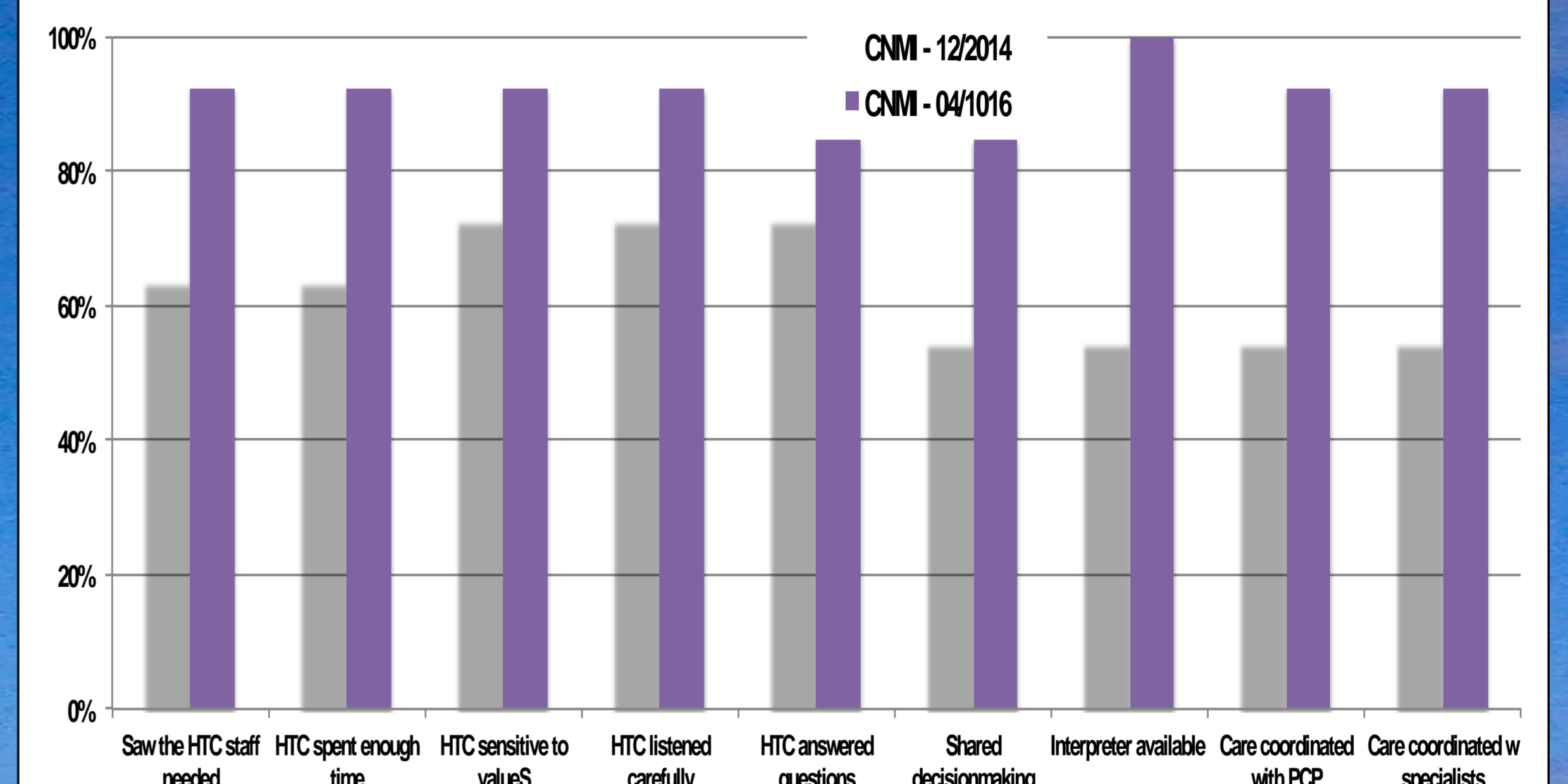
These baseline data reflect bleeding disorder clinician availability before the hemophilia team started in January 2015. Most CNMI residents received bleeding disorder services off-island years ago at their initial diagnosis.

Figure 5: CNMI Patient Perception – HTC Clinician Services Needed & Received April 2016



By April 2016, most patients reported lower needs for clinical HTC services. Services received more closely matched services needed.

Figure 6: Patient Centered Care: % reporting CNMI HTC Performed 'well' or very well' Dec. 2014 & Apr. 2016



CNMI patients reported increases in all aspects of patient centered care 2014-2016.



Conclusions

- Nationally uniform patient assessments of healthcare information and service needs are valuable when starting services in medically underserved areas.
- These assessments are critical to determining baseline priorities for intervention, tracking changes over time, documenting impact of the new HTC services, and comparing to HTCs at regional and national levels.
- The 2014 CNMI baseline gap assessment data helped guide priorities for local capacity building. By 2016, patients reported significant improvements in all bleeding disorders information and services needed and received.
- Percentage Point Gap method is an easy yet scientifically recognized method to quantify gaps, useful to low resource areas.

Acknowledgements

Special thanks to: Region 9/Western States; UCSF Division of Pediatric Hematology/Oncology and James N. Huang, MD; CNMI Maternal Child Health Bureau of the Department of Public Health: Margarita Aldan and Ann Marie Satur; Marianas Health: Pam Carhill, PT, Susan Satur, and Andrea Carr; Biogen for educational conference support 2014; Orthopedic Institute for Children LA and Cindy Bailey; and Let's Move Marianas

Disclosure: Author Tiffany Lin is the recipient of the 2016 HTRS/Novo Nordisk Clinical Fellowship Award in Hemophilia and Rare Bleeding Disorders from the Hemostasis and Thrombosis Research Society (HTRS), which is supported by Novo Nordisk Inc.

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