



# HEARTLAND

## REGIONAL GENETICS NETWORK



Heartland Regional Genetics Network (HRGN)  
Preliminary Annual Data  
2022-2023



What were  
our  
Strategies  
and  
Results?





Family  
Together  
(Kansas)



Munroe-Meyer  
Institute  
(Nebraska)

Oklahoma  
Family Network  
(Oklahoma)

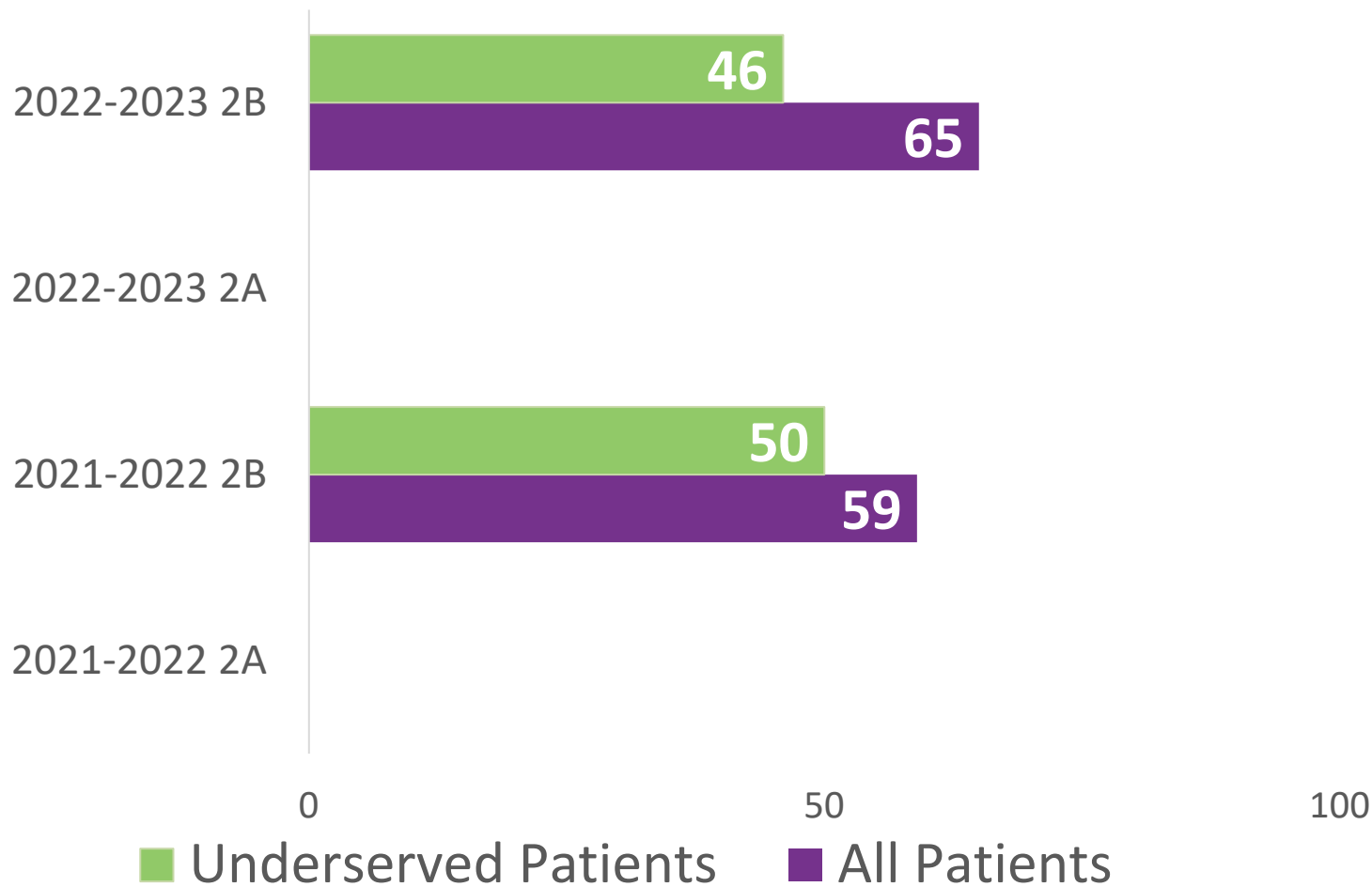
Build  
Partnerships  
to Improve  
Access to  
Genetic  
Services

Family Consultants and Health Care  
Providers Support Access to Genetics  
through Facilitated connections





## **FACILITATED CONNECTIONS:** HEALTH CARE PROVIDER (2A) AND FAMILY NETWORK PROGRAMS (2B) SUPPORT PARENTS' ACCESS TO GENETIC SERVICES DURING THE PAST TWO GRANT YEARS.







Engage  
Members of  
Underserved  
Communities  
to Improve  
Access to  
Genetics  
Services





## Distribution of Materials

- Brochures for parents
- NBS video
- Early Hearing & Detection Video
- Tip sheet for providers

## Training

- 23 adults participated in a training for Marshallese families
- 53 participated in Marshallese Interpreter Training

## Health Screening and Clinic

- 25 adults participated in health screen





# Feedback on Marshallese Clinic and Community Training

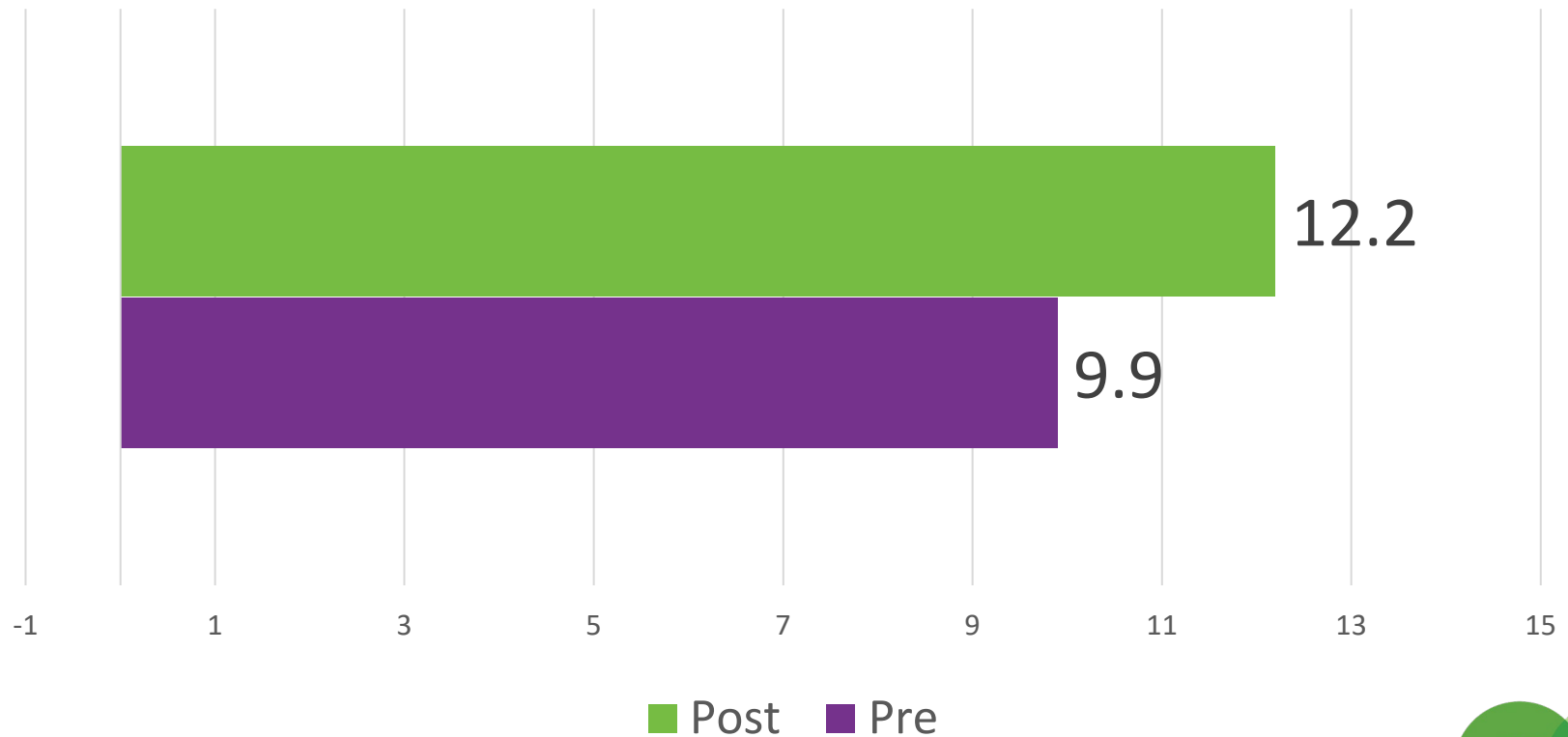
- A culture of trust was apparent at the event.
- Relationships with community partners made a difference.
- Need to expand community partners.
- Families have broad health care needs.
- Need for follow-up and wrap-around services.
- The event was a learning experience for staff attending.





## 24 Participated in Interpreter Trainings

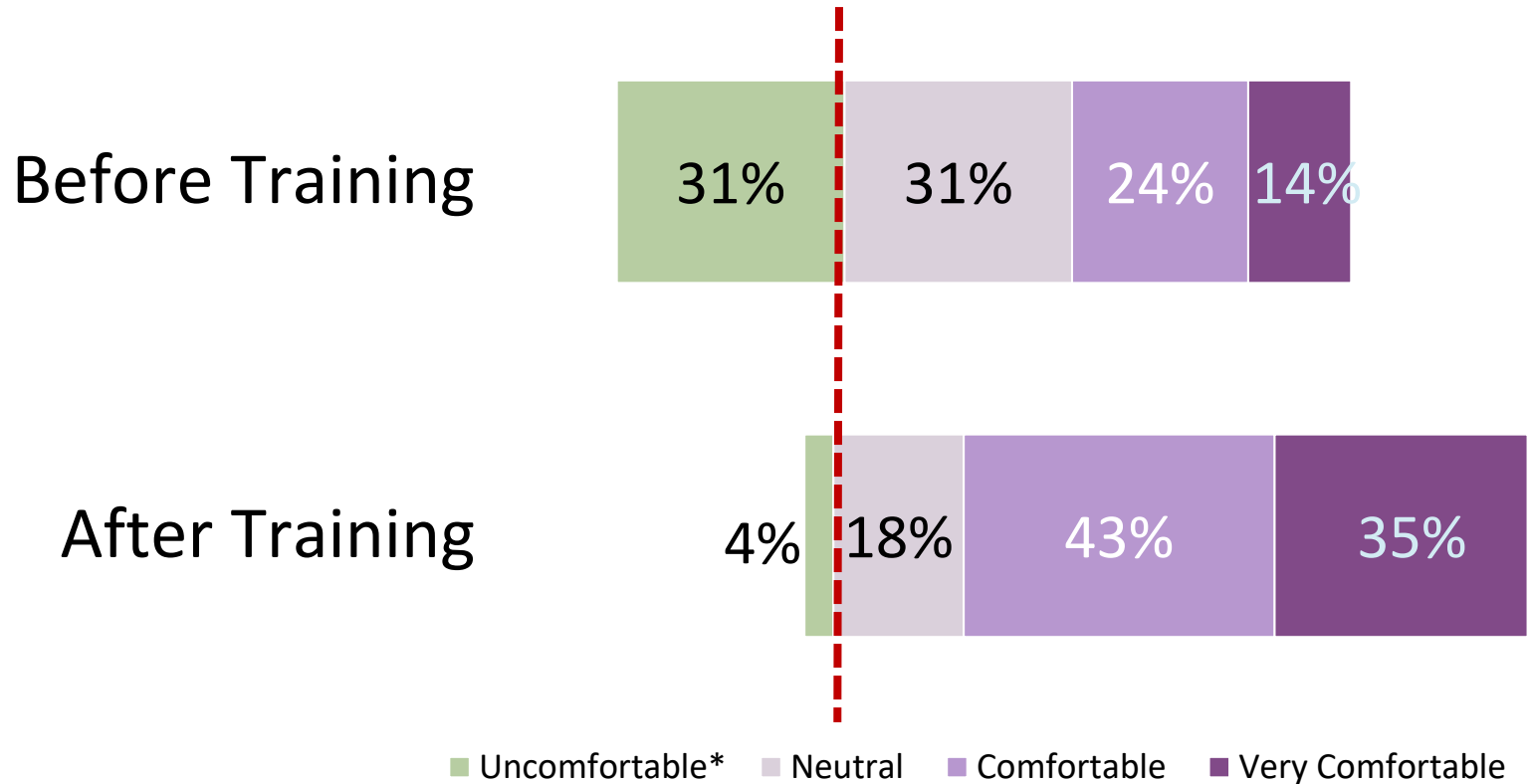
Majority (73%) of participants improved knowledge at the end of the interpreters' training.







# MORE INTERPRETERS RATED THEY WERE COMFORTABLE OR VERY COMFORTABLE IN INTERPRETING GENETIC CONTENT



n=48

\*Represents items as uncomfortable or very uncomfortable



# Videos in Spanish Completed and Distributed on You-Tube

*“Now that they [the videos] are developed, there is a need to figure out the best way to get them in the hands of those that can use them with families.”*

- How to prepare for and understand what will happen at your child’s genetic test
- What are chromosomes and genes?
- What can I expect from an appointment at a genetics clinic?
- How to work with an interpreter for a medical visit
- Newborn Screening





# Need to Disseminate Information about Videos

## STRATEGIES

- Webinars and Presentations could be used to promote the videos
- Additional resources could be included with the videos
- Expanded marketing with promotional materials was recommended





# Need to Disseminate Information about Videos

## TARGET POPULATION

- Students in the health care professions could be a key to building a culturally competent workforce
- Geneticists and genetic counselors should be a primary target for dissemination
- Family support programs' relationship[s] with families is an advantage for dissemination efforts







## Innovative Telehealth Delivery Model

2 Distant Site

9 Originating Sites

Arkansas (5)

Oklahoma (3)

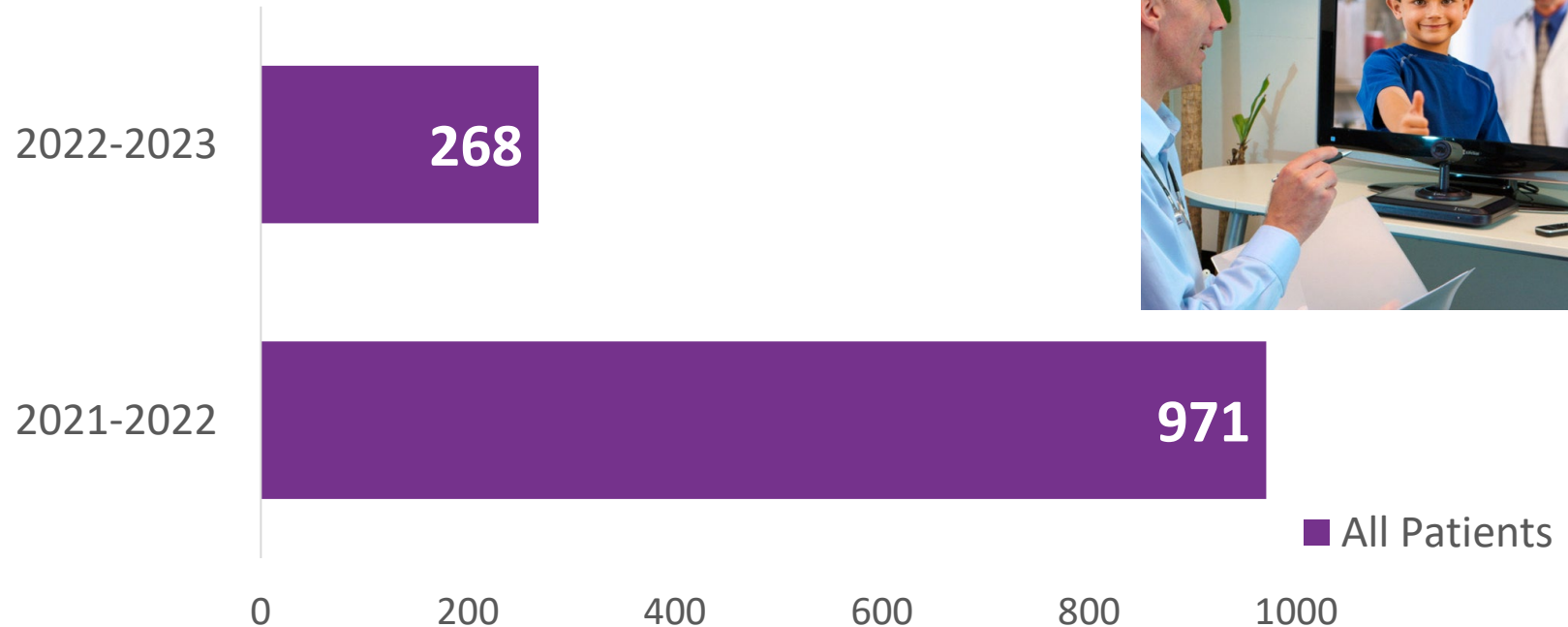
Kansas (2)

Colorado (1)





## TELEHEALTH CLINIC SERVICES: # OF PATIENTS FOR WHOM TELEHEALTH MODALITIES FOR GENETICS WERE USED.



In 2022-2023 91% of the patients were from underserved areas.



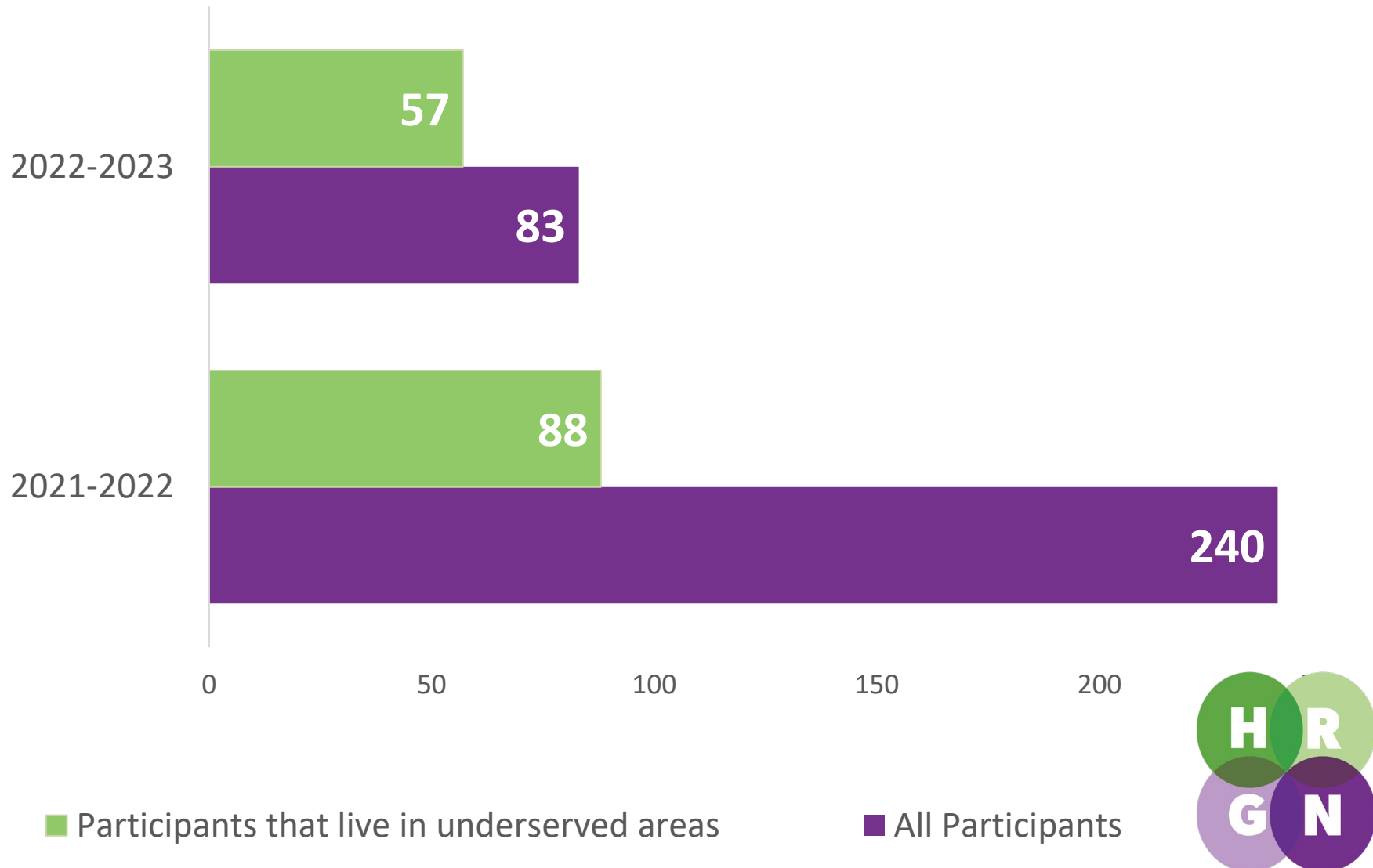


Facilitate  
Learning  
through  
Sharing  
Resources  
and  
Training





## TRAINING: # OF INDIVIDUALS PARTICIPATING IN TRAINING 5 HRGN SPONSORED TRAININGS.





## Videos (7)

## Web-Based Resources

# Pamphlets

# Distance Modules





Questions?

