



# EVALUATION UPDATE: 2014-2015

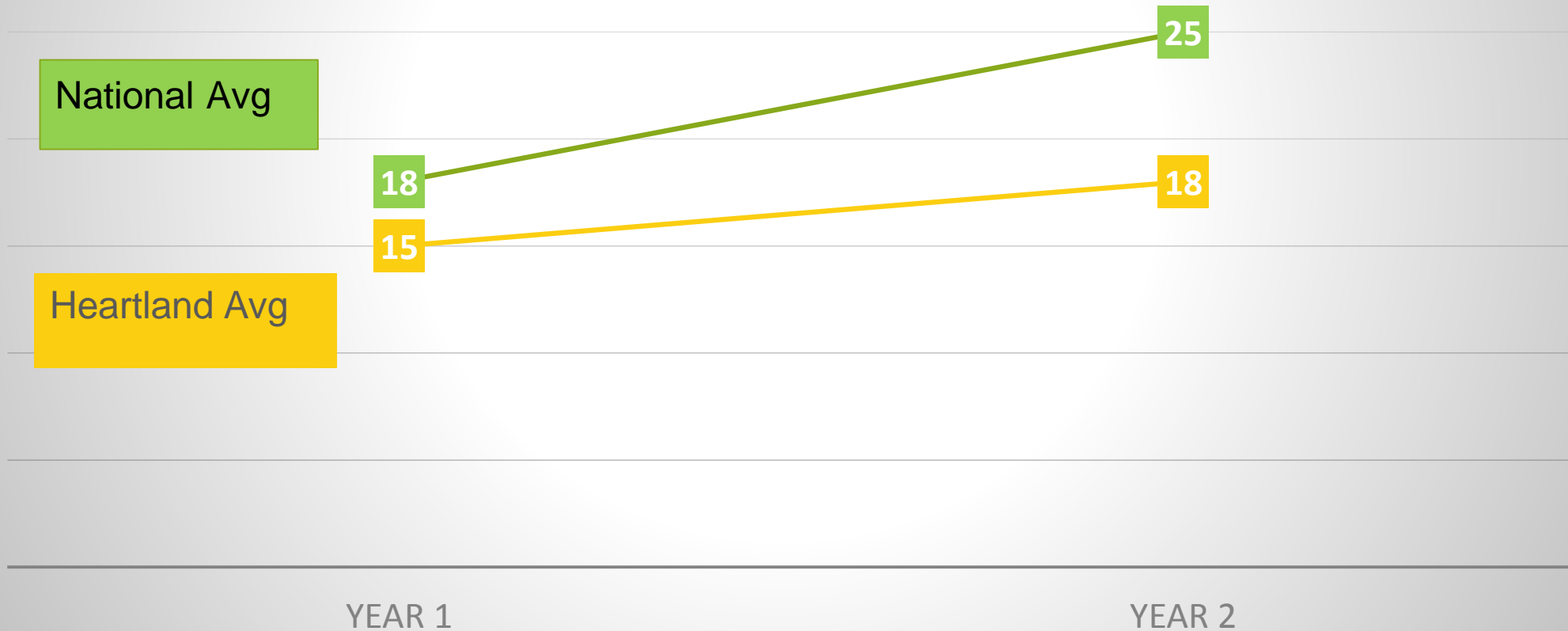


**HRSA PRIORITY 1:** TREAT IN THE CONTEXT OF A MEDICAL HOME THAT PROVIDES ACCESSIBLE, FAMILY-CENTERED CONTINUOUS, COMPREHENSIVE, COORDINATED, COMPASSIONATE, AND CULTURALLY EFFECTIVE CARE.



Heartland Collaborative demonstrated a **20%** increase in Medical Home activities in Year 2.

Heartland has implemented less activity than the national average.



Includes: Medical Home IHP, Transition, and Hispanic Access

# BUILDING ADVOCACY CAPACITY: STUDENT LEADERSHIP MENTORING

- Participated in Conference with follow-up support
- What Worked?
  - Topics were very informative, e.g. strategies for transition
  - Learned to effectively tell your story
  - Incredible connections with staff, presenters and other students
- How she is going to use?
  - Share information with other families and young adults
  - Use the stress release activities
  - Use skills to become a better advocate



**HRSA PRIORITY 3:** EXPAND THE POOL OF THE GENETICS SERVICE WORKFORCE BY DETERMINING NEEDS AND GAPS ACROSS SECTORS TO PROVIDE EDUCATION AND TRAINING, WITH EMPHASIS ON ALLIED HEALTH PROVIDERS, OTHER *SUBSPECIALTIES AND EDUCATORS.*

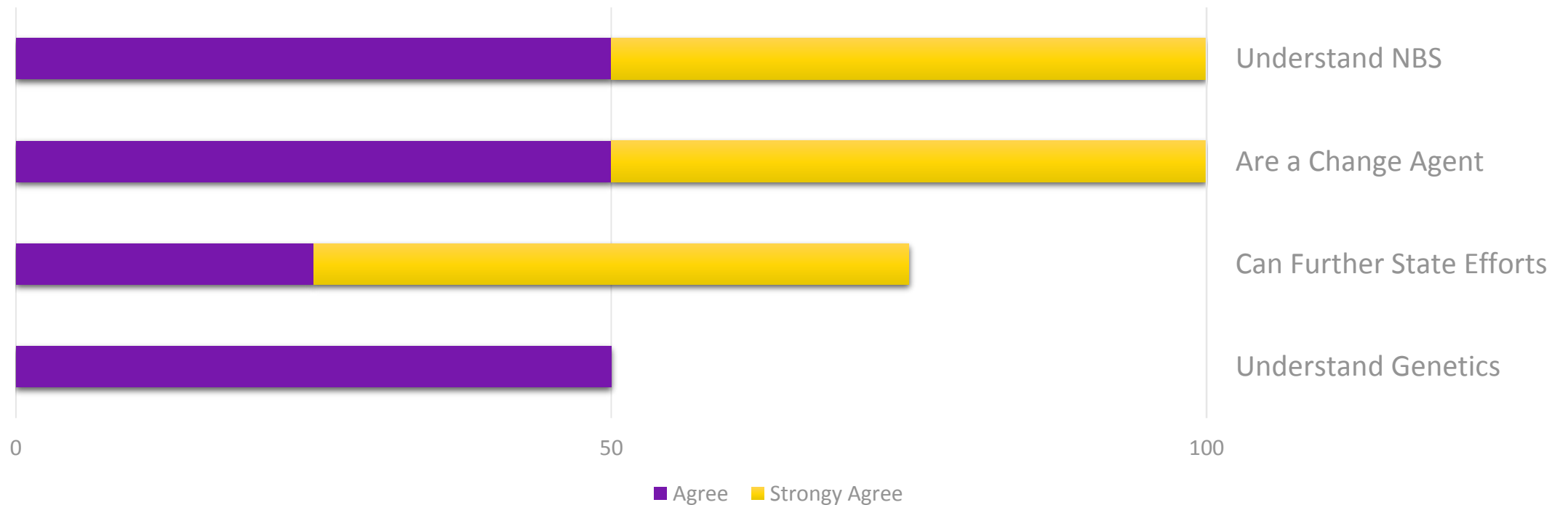


# PARTNERS PROJECT

**Participants demonstrated a good understanding of NBS after participation at APHL.**

Participants viewed themselves as change agents who could make a difference.

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Participants viewed attendance at APHL Conference as an opportunity to expand their knowledge of clinical genetics and NBS.

Information on NBS and Systems  
Approaches to Follow-Up

Awareness of # and Diversity of  
Individuals to Implement Screening

Breadth of Services Available and  
Unique Approaches across States

The majority of the state partners targeted dissemination of information through articles and education activities and their strategy for change.

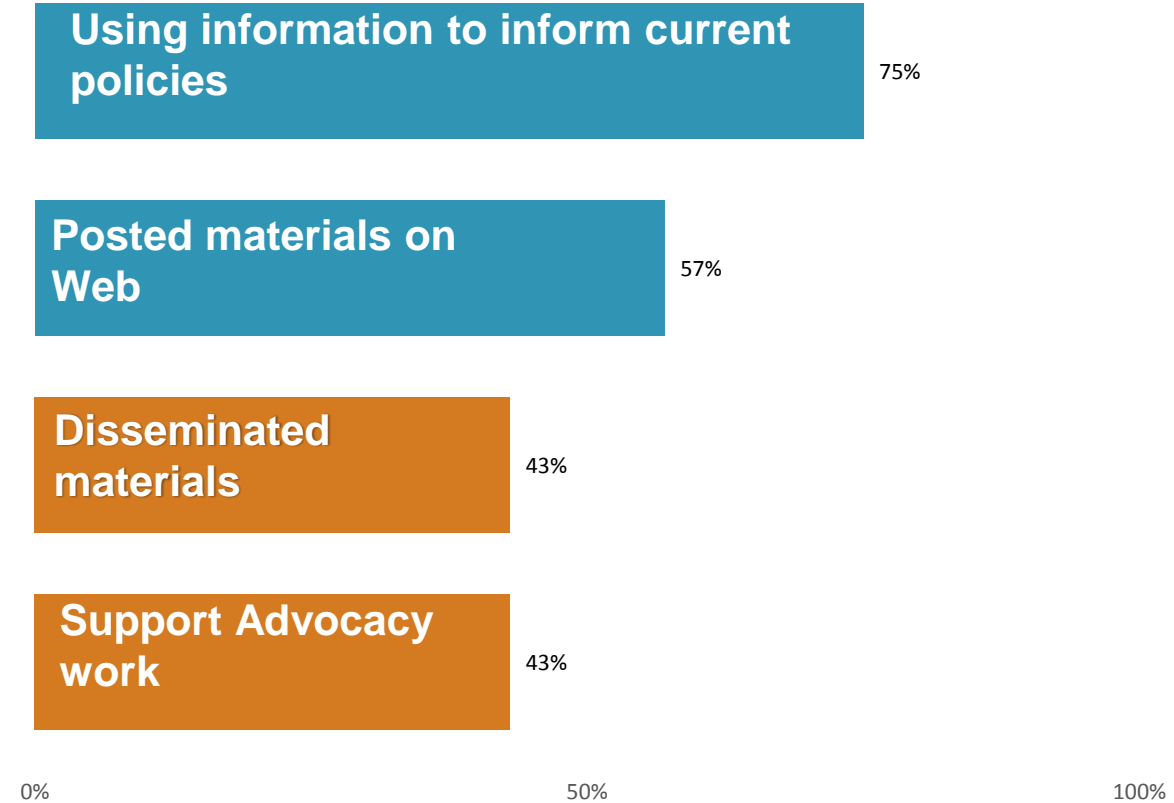
Partners' Next Step to Action	States				
	AK	IO	MO	NE	OK
Dissemination of NBS information through education opportunities and articles.	█	█	█		
Development of Condition-Related Action Plans		█			
Policy Position Paper to Increase Infrastructure Supports and Services				█	
Linkages between state NBS program and Midwives Association			█		
Establishment of quality improvement process to improve NBS process					█



# EHDI EXCHANGE

- Summarize areas targeted for discussion and change

## The ACA Forum resulted in action as state level planning was initiated.



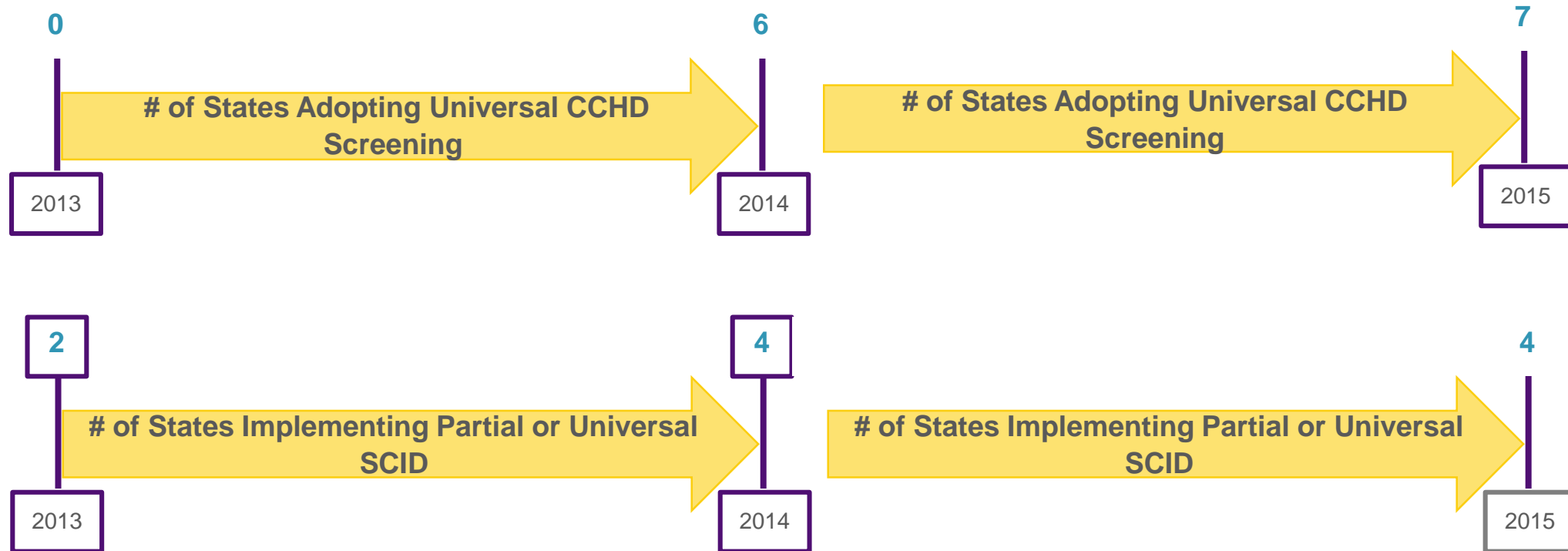
Over 75% of the participants strongly agreed that the ACA Forum resulted in increased knowledge about ACA and its related policies.

**HRSA PRIORITY 4:** BUILD CAPACITY IN STATE PUBLIC HEALTH DEPARTMENTS TO ENHANCE AND SUSTAIN THE DELIVERY OF NEWBORN AND CHILD SCREENING AND GENETIC FOLLOW-UP AND TREATMENT SERVICES.



# MAJORITY OF STATES HAVE ADOPTED UNIVERSAL CCHD SCREENING.

STATES HAVE MADE PROGRESS IN ADOPTING CCHD AND SCID SCREENING OVER THE PAST TWO YEARS.

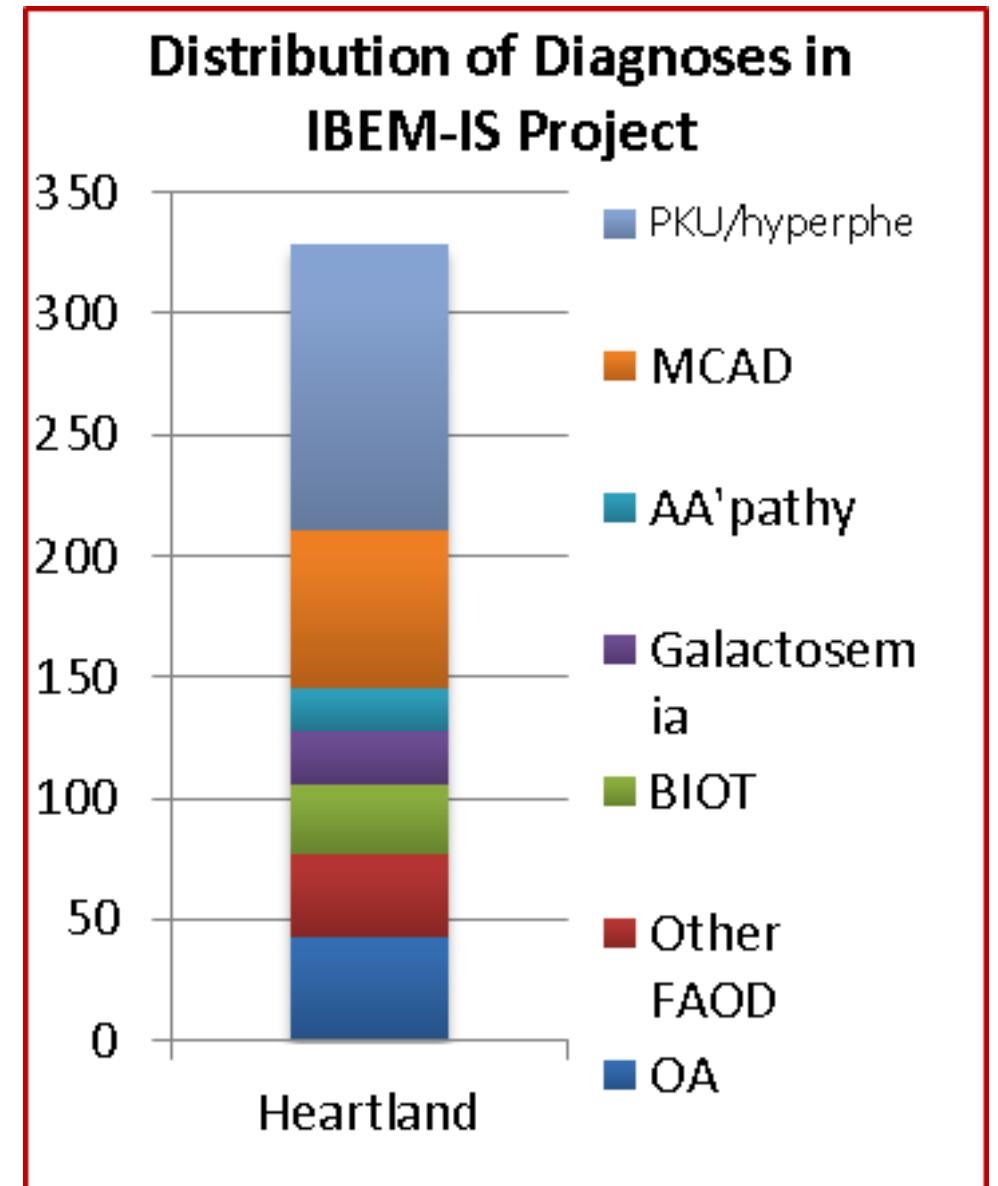


HRSA PRIORITY 8: EXPAND STATE AND REGIONAL COLLABORATIVE SYSTEMS OF COHORTS OF PATIENTS FOR LONG-TERM MONITORING AND ANALYSIS OF FOLLOW-UP AND TREATMENT FOR PROVIDER AND/OR PATIENT ACCESS.



## 4 STATES PARTICIPATE IN LONG TERM FOLLOW-UP PILOTS IN 2013-2014

- Oklahoma
- South Dakota
- Nebraska
- Missouri



**HRSA PRIORITY 10:** BUILD CAPACITY IN STATE PUBLIC HEALTH DEPARTMENTS TO ENHANCE AND SUSTAIN THE DELIVERY OF NEWBORN AND CHILD SCREENING AND GENETIC FOLLOW-UP AND TREATMENT SERVICES.



# Lest We Forget, The Heartland is Hazardous!



Aerial view of the Missouri River flooding on July 30, 1993, at U.S. Highway 54 just north of Jefferson City, Missouri, looking south (photograph from the Missouri Highway and Transportation Department).

## Missouri Flooding July 30<sup>th</sup>, 1993



## Ankeny, Iowa June 18<sup>th</sup>, 1974 @ 10:30 PM Category 4 Tornado, 2 Miles Wide



# AR/MO NBS LABORATORY DRILL, 2014

- First planning conference call in April, 2014
- Face to face planning meeting in Little Rock on May 13<sup>th</sup>
- Reserved August 12<sup>th</sup> for drill date with backup date of August 20<sup>th</sup> (August 20<sup>th</sup> was used)
- AR was disaster state with MO as assisting state
- 200 NBS samples utilized
- EMAC's Mission Ready Package (MRP) process was utilized for the first time for NBS
- The AR Civil Air Patrol was utilized to fly the samples to MO

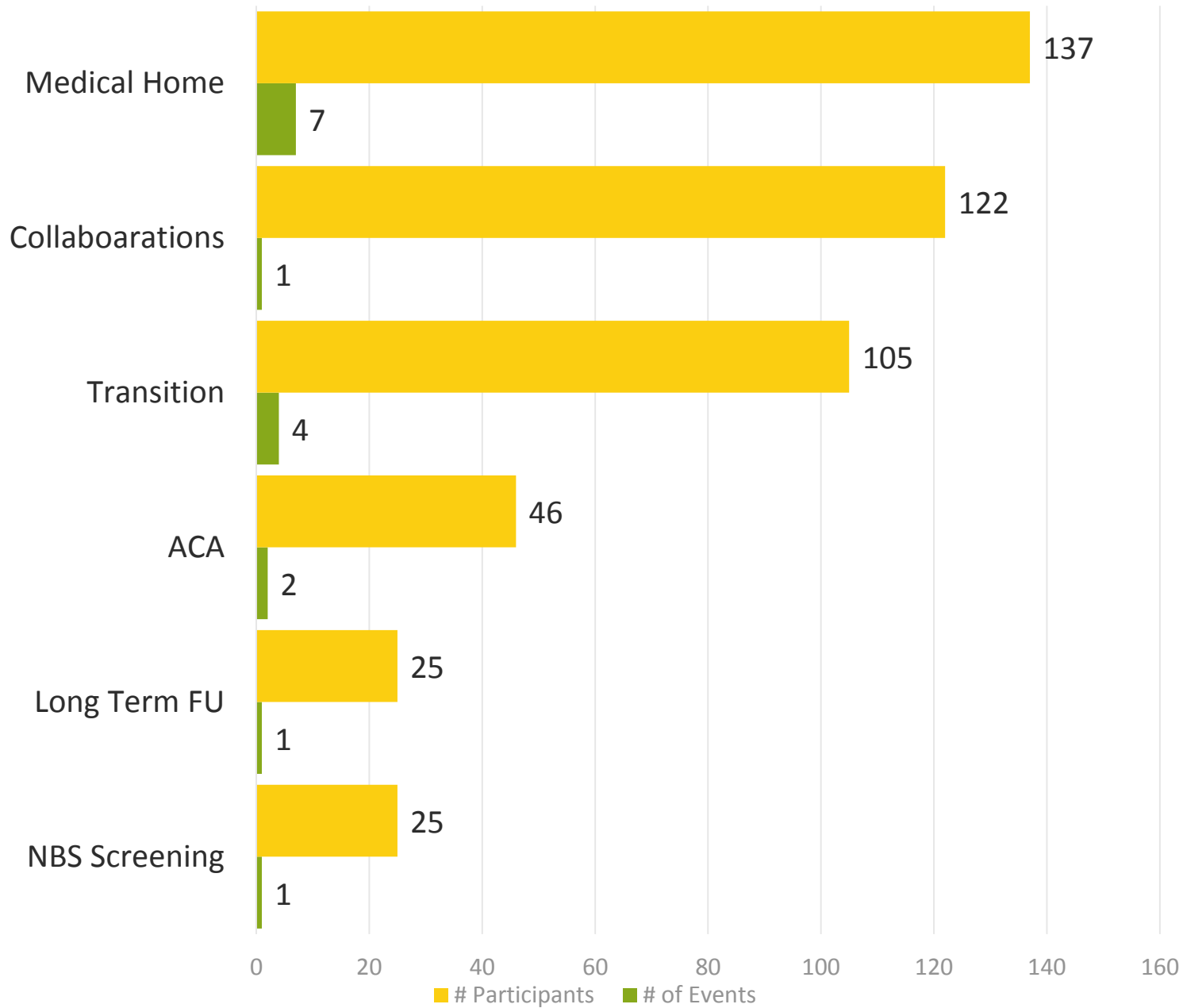
# HIGHLIGHTS FROM THE AR/MO DRILL

- First NBS drill to use EMAC's MRP process
- Drill began at 8:00 am and all EMAC approvals were attained by 11:15 am
- The AR Civil Air Patrol volunteered to transport the NBS samples by plane straight over the Ozarks mountains from Little Rock to Jefferson City (this served as a drill for them too)
- MO State Lab received AR's samples at 12:30 pm that same day
- Sample processing in MO began at 1:00 pm
- The 200 NBS samples' parallel testing showed the same 3 presumptive positive (referred) screens for both states
- This was the best, fastest and smoothest drill we have ever conducted in the Heartland (This was Drill #16)



## NATIONAL DATA

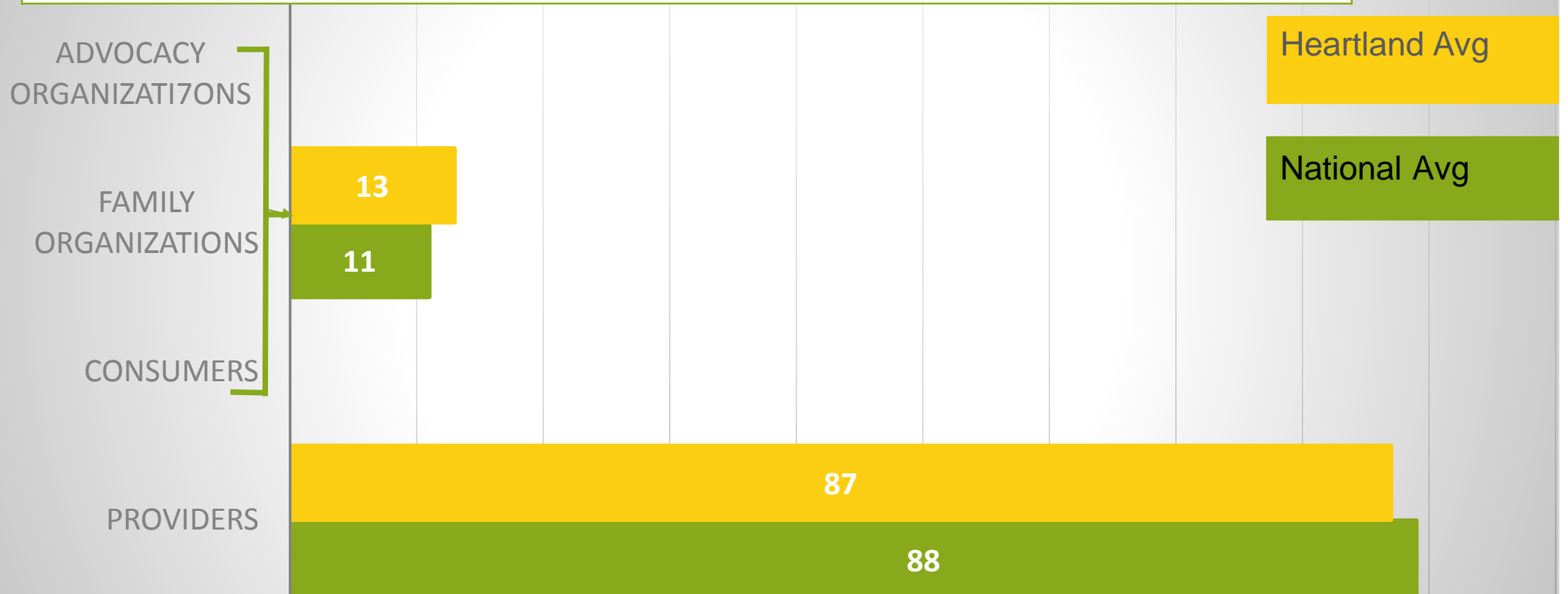
Heartland Regional  
Data



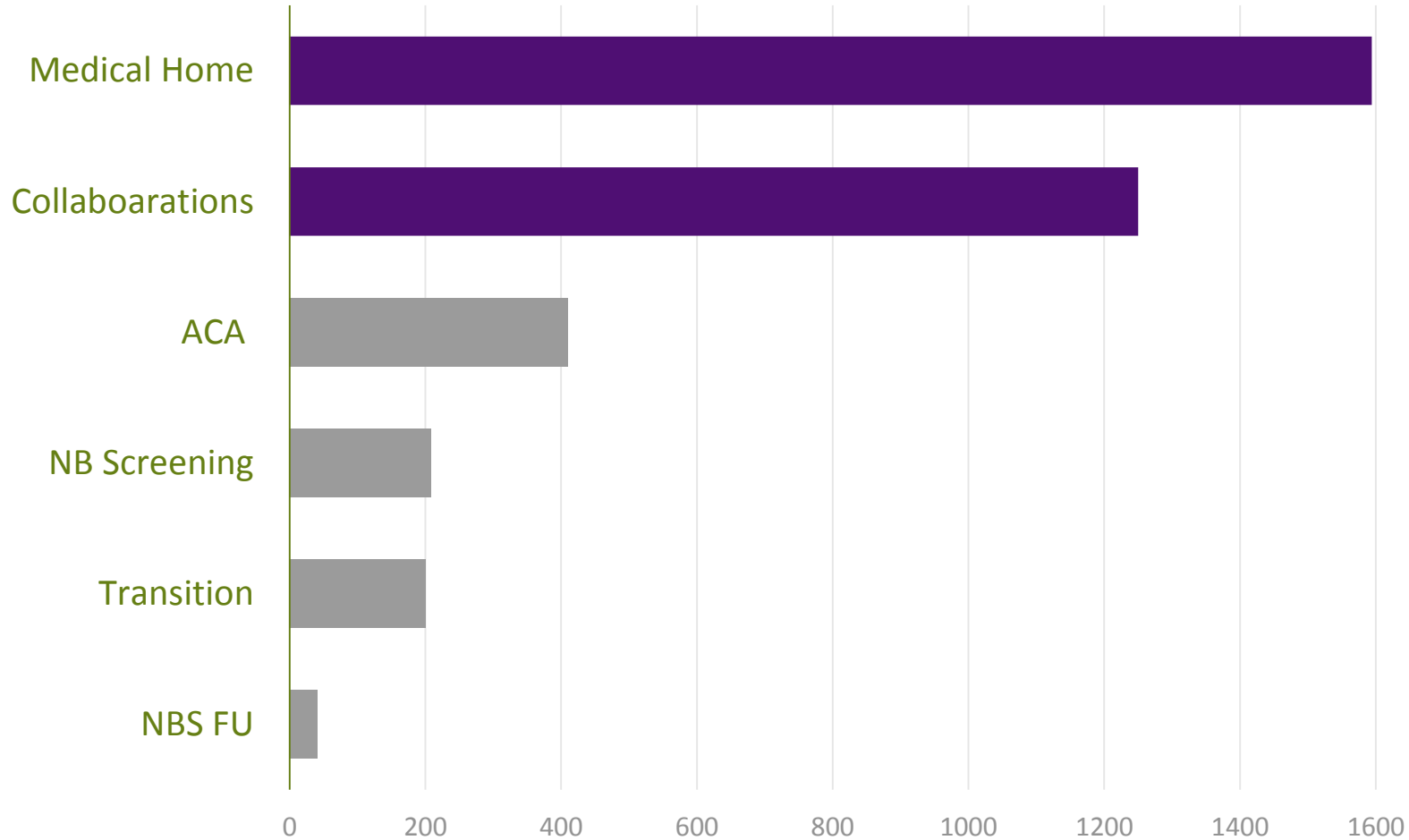
**THE MAJORITY OF HEARTLAND'S TRAINING TARGETED MEDICAL HOME.**



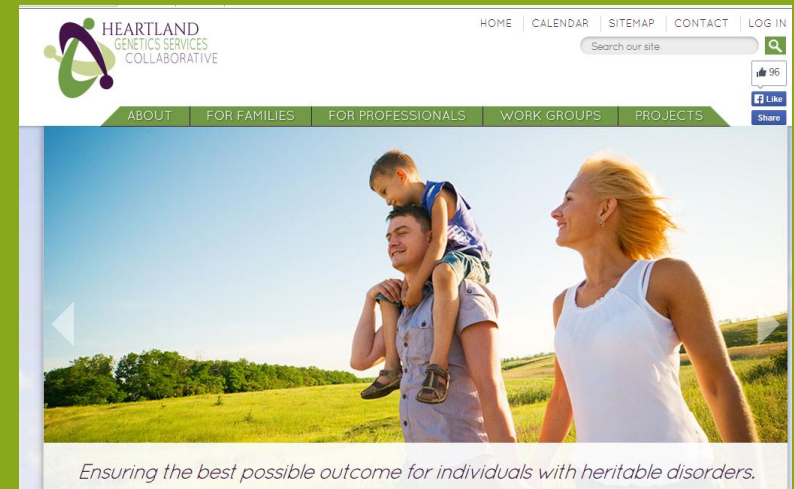
Heartland Collaborative mirrored the national percentages in types of individuals participating in Collaborative activities.



# of Unique Visits on Heartland Website



INDIVIDUALS ACCESS THE HEARTLAND COLLABORATIVE WEBSITE PRIMARILY FOR INFORMATION ON MEDICAL HOME AND COLLABORATION .





WORKING  
TOGETHER  
SURVEY: A  
NATIONAL  
MEASURE OF  
COLLABORATION

Email distribution  
on May 4<sup>th</sup>



If you were not present during this presentation, please use this link <https://www.surveymonkey.com/r/5TTC892> to access the evaluation form. We value your opinion and your suggestions will help us improve future Heartland events. Please respond by Monday, May 18 by COB.





THANKS!!