

Next Steps for ICARE

ICARE meeting April 13, 2015



National Institute of
Neurological Disorders
and Stroke

Purpose of ICARE

- to inform ICARE members and interested public about the funding landscape for epilepsy research
- to assess progress being made against current epilepsy research priorities
- to help guide future funding priorities by highlighting current gaps and opportunities in epilepsy research

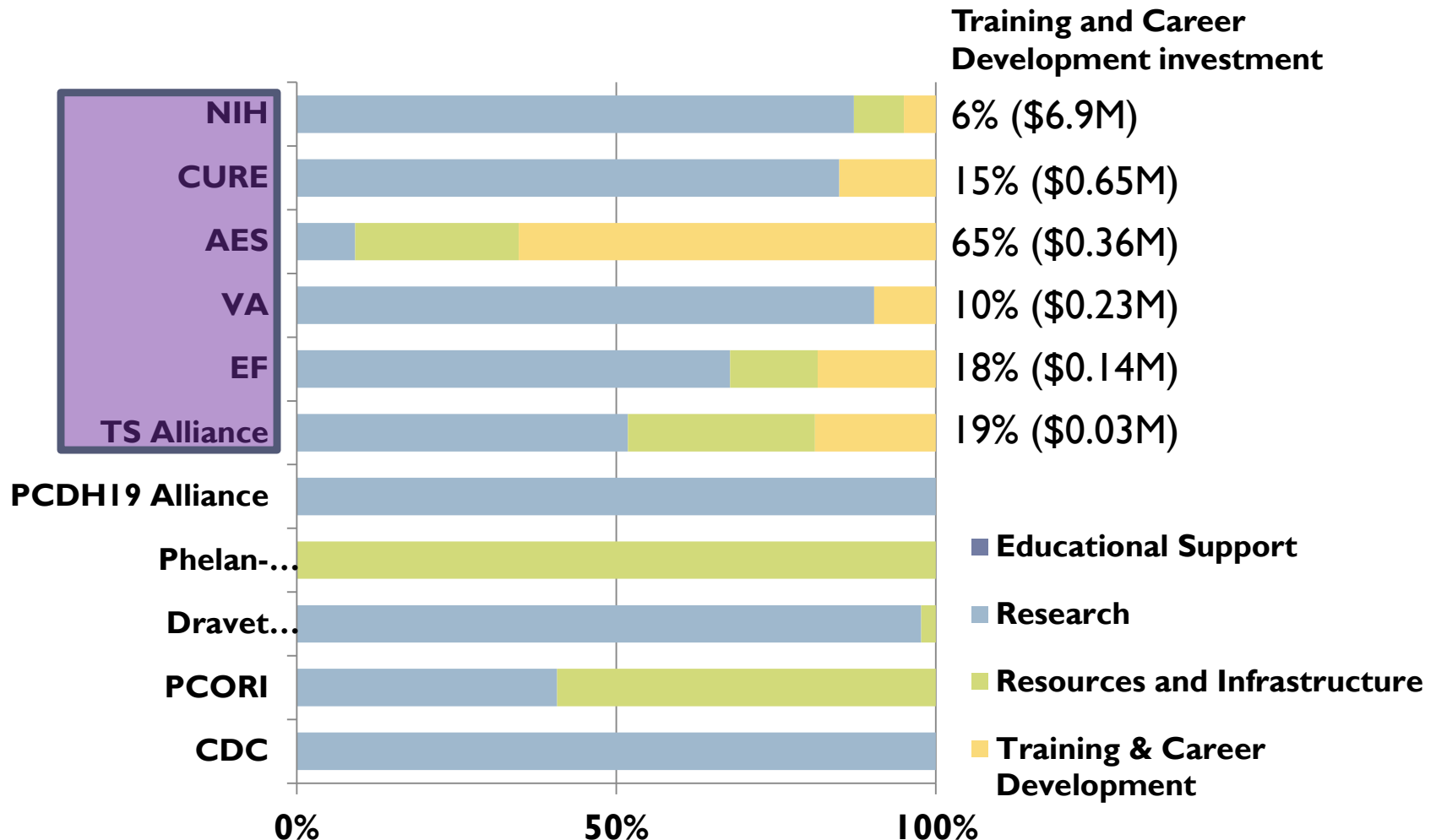
By working together, can we make faster and further progress than any one of our organizations can do alone?

- *Identify shared goals and potential partners*
- *Strategically leverage critical resources*

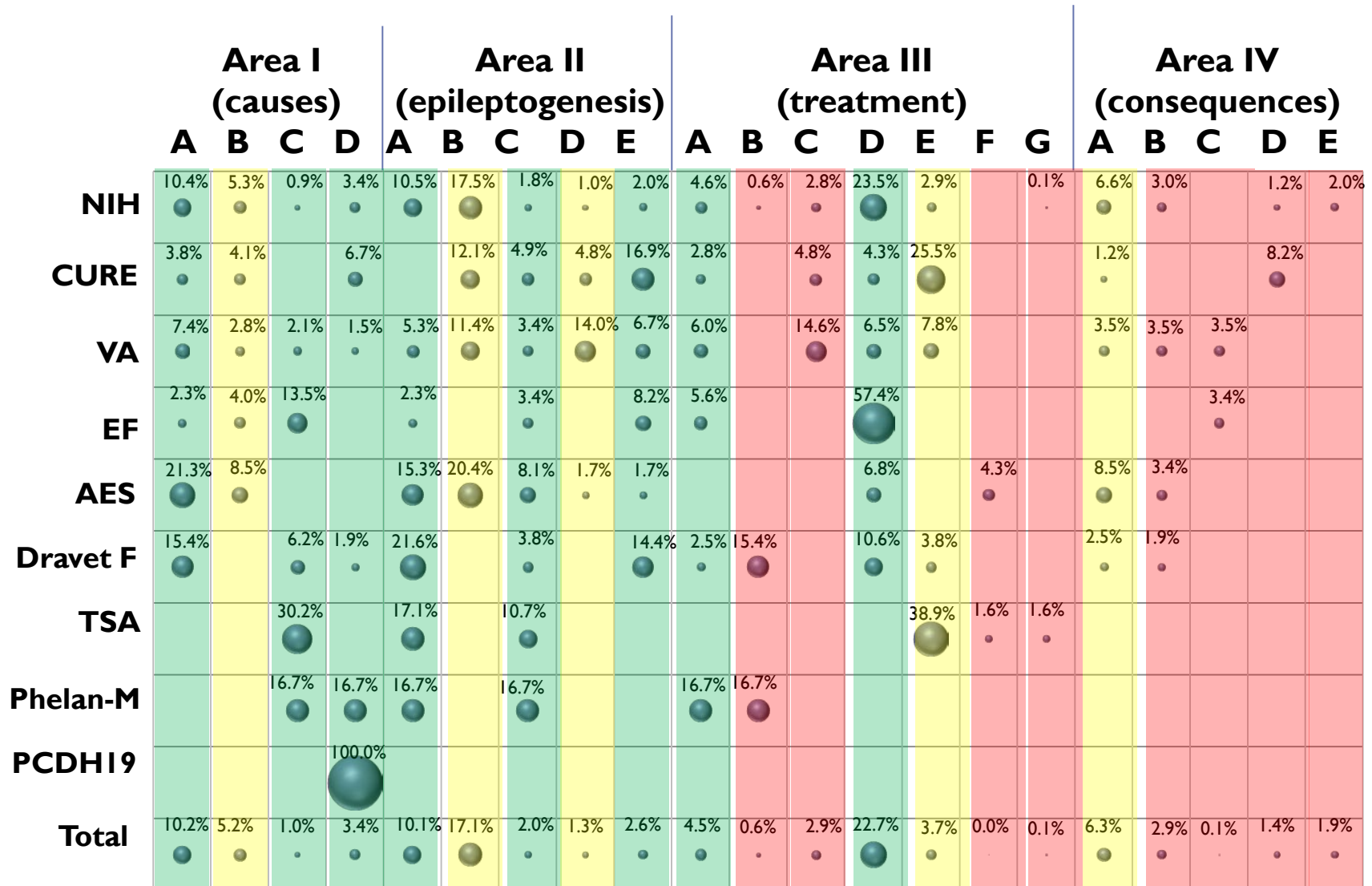
Levels of Collaboration Scale

	Frey et al., 2006	
Networking	<ul style="list-style-type: none"> -Aware of organization -Loosely defined roles -Little communication -All decisions are made independently 	
Cooperation	<ul style="list-style-type: none"> -Provide information to each other -Somewhat defined roles -Formal communication -All decisions are made independently 	
Coordination	<ul style="list-style-type: none"> -Share information and resources -Defined roles -Frequent communication -Some shared decision making 	
Coalition	<ul style="list-style-type: none"> -Share ideas and resources --Frequent and prioritized communication -All members have a vote in decision making 	
Collaboration	<ul style="list-style-type: none"> -Members belong to one system -Frequent communication is characterized by mutual trust -Consensus is reached on all decisions 	

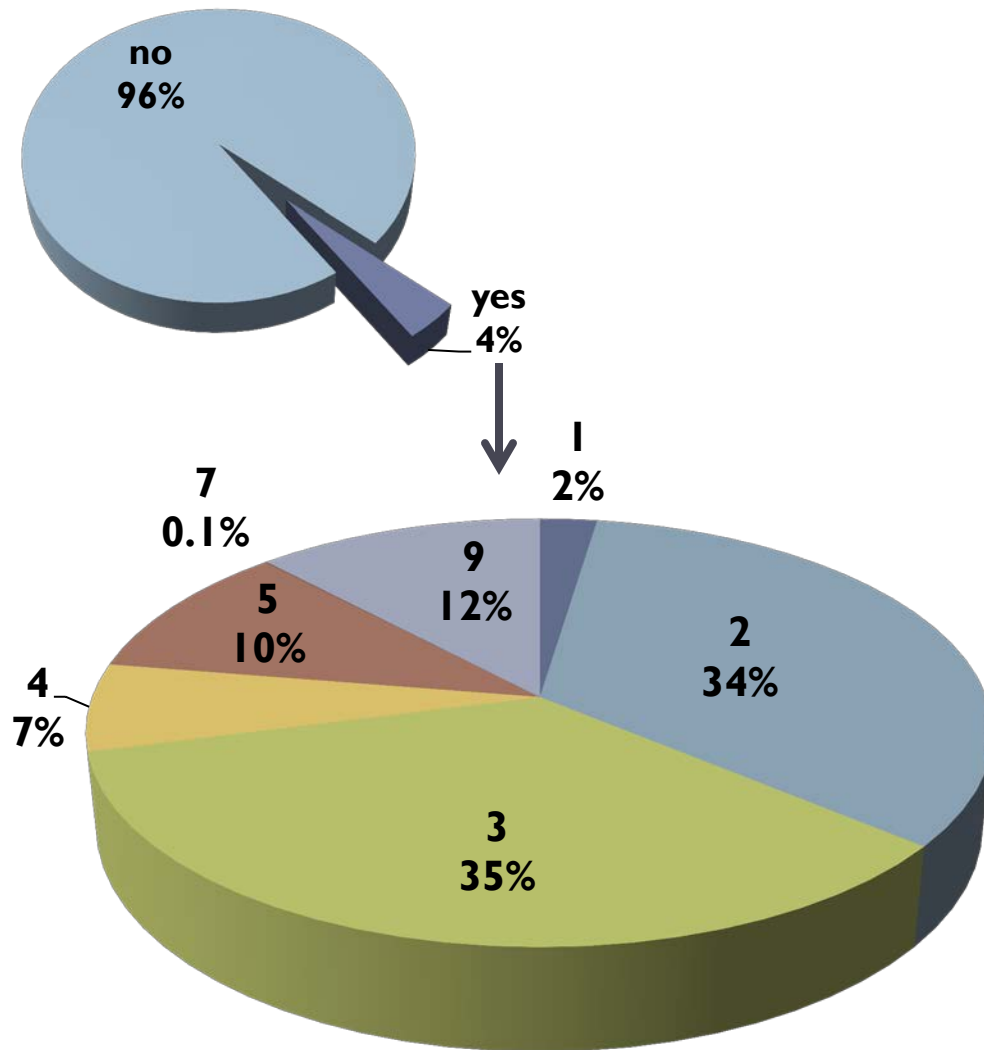
Funding Organization Investments in Training and Career Development



Disparities in Funding across Benchmark Areas



2013 Epilepsy Research Portfolio by 2012 IOM Recommendations



1. Validate and Implement Standard Definitions and Criteria for Epilepsy Case Ascertainment, Health Care and Community Services Use and Costs, and Quality-of-Life Measurement

2. Continue and Expand Collaborative Surveillance and Data Collection Efforts

3. Develop and Evaluate Prevention Efforts for Epilepsy and Its Consequences

4. Improve the Early Identification of Epilepsy and Its Comorbid Health Conditions

5. Develop and Implement a National Quality Measurement and Improvement Strategy for Epilepsy Care

7. Improve Health Professional Education About the Epilepsies

9. Improve and Expand Educational Opportunities for People with Epilepsy and Their Families

Collaborative Opportunities

- Working Groups for Horizontal Collaboration
 - Areas of mutual interest (e.g. SUDEP & early mortality)
 - Training
 - Genetics
 - Surveillance
 - Others?
 - Areas of gaps
 - Psychiatric co-occurring conditions
 - Health professional education - ?
- Strategic Partnerships for Vertical Collaboration
 - Research ➡ Evidence ➡ Guideline ➡ Policy ➡ Education
 - Self management
 - Precision medicine