



Comparative Effectiveness Research on Intellectual and Developmental Disabilities at the Patient-Centered Outcomes Research Institute

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BACKGROUND

- The Patient-Centered Outcomes Research Institute (PCORI) is widely acknowledged as a leader in driving U.S. clinical research to become more patient-centered through funding of comparative clinical effectiveness research (CER).
- CER is a type of clinical research that compares two or more medical treatments, services or health practices to help patients and others make better-informed decisions.
- PCORI considers developmental disabilities (DD) to be chronic disabilities that originate at birth or in the developmental period and result in differing levels of support in physical, learning, language and/or behavioral areas. Intellectual disabilities, which fall under the umbrella term of DD, involve differences in cognitive function (i.e., reasoning, learning, problem solving) and adaptive behavior.

OBJECTIVES

- Provide an overview of PCORI's IDD CER studies and identify opportunities for future research.

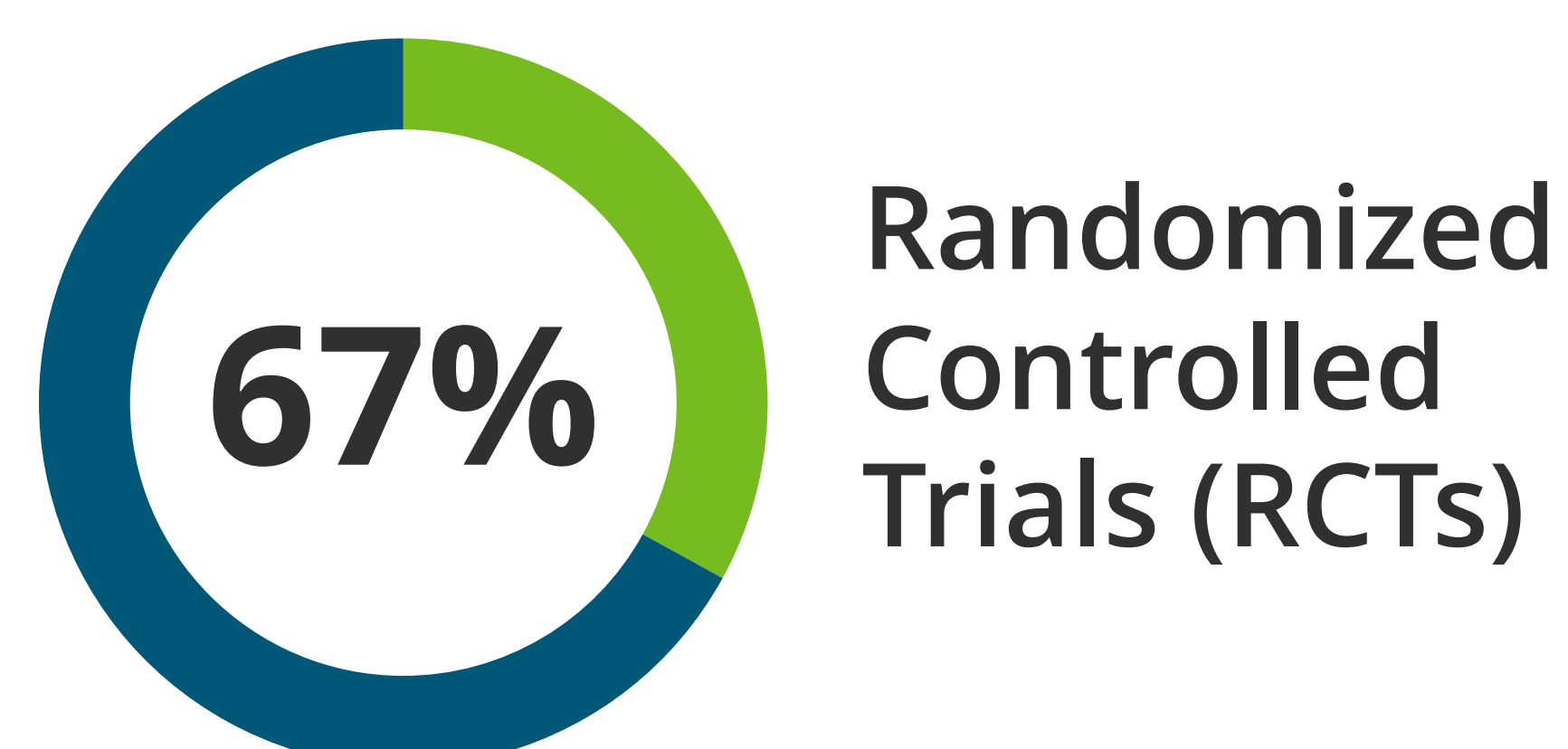
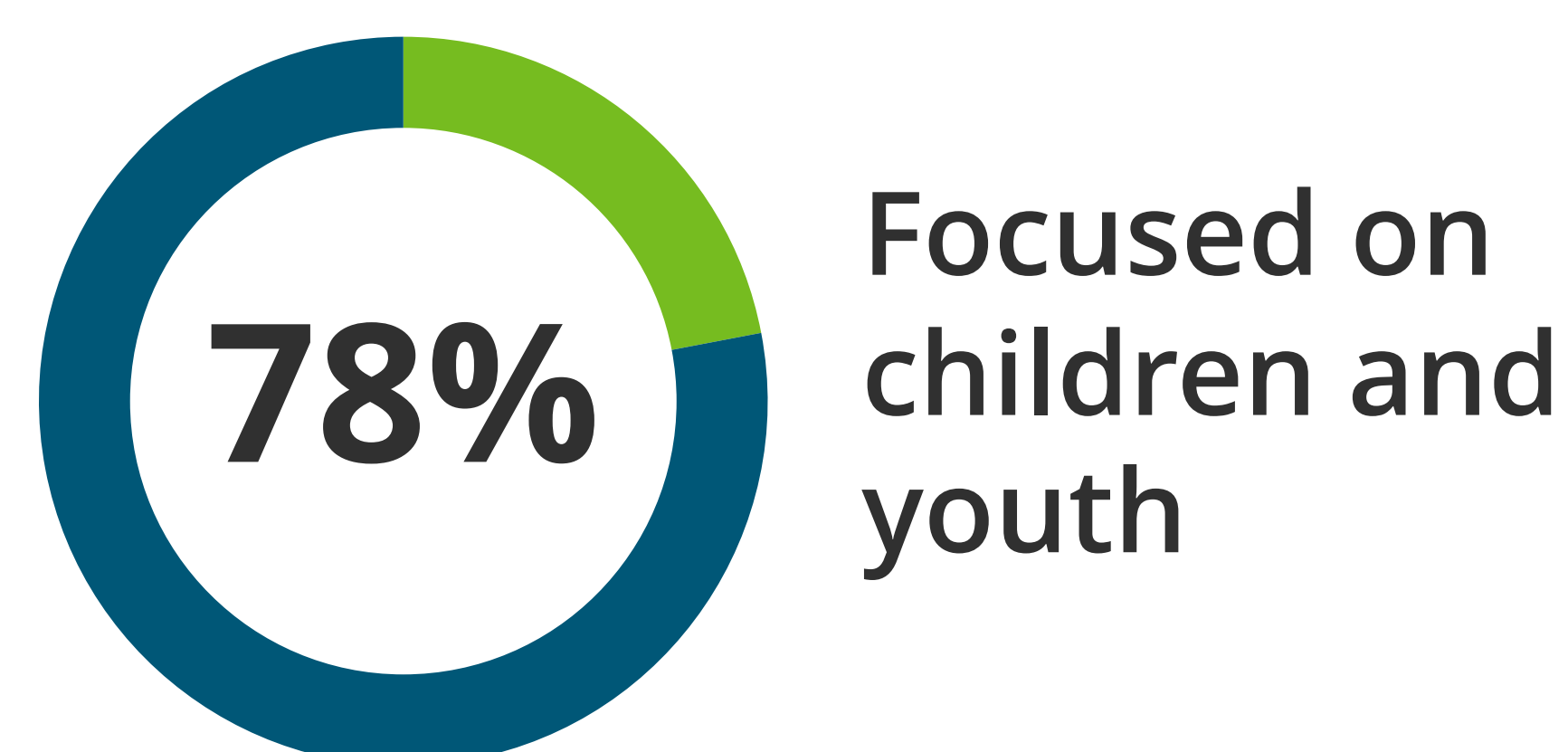
METHODS

- An IDD-specific algorithm was applied to PCORI's CER study database.
- Staff reviewed results and adjudicated discrepancies; several variables were abstracted.

RESULTS

**36 Awarded
IDD CER studies**

Study Characteristics

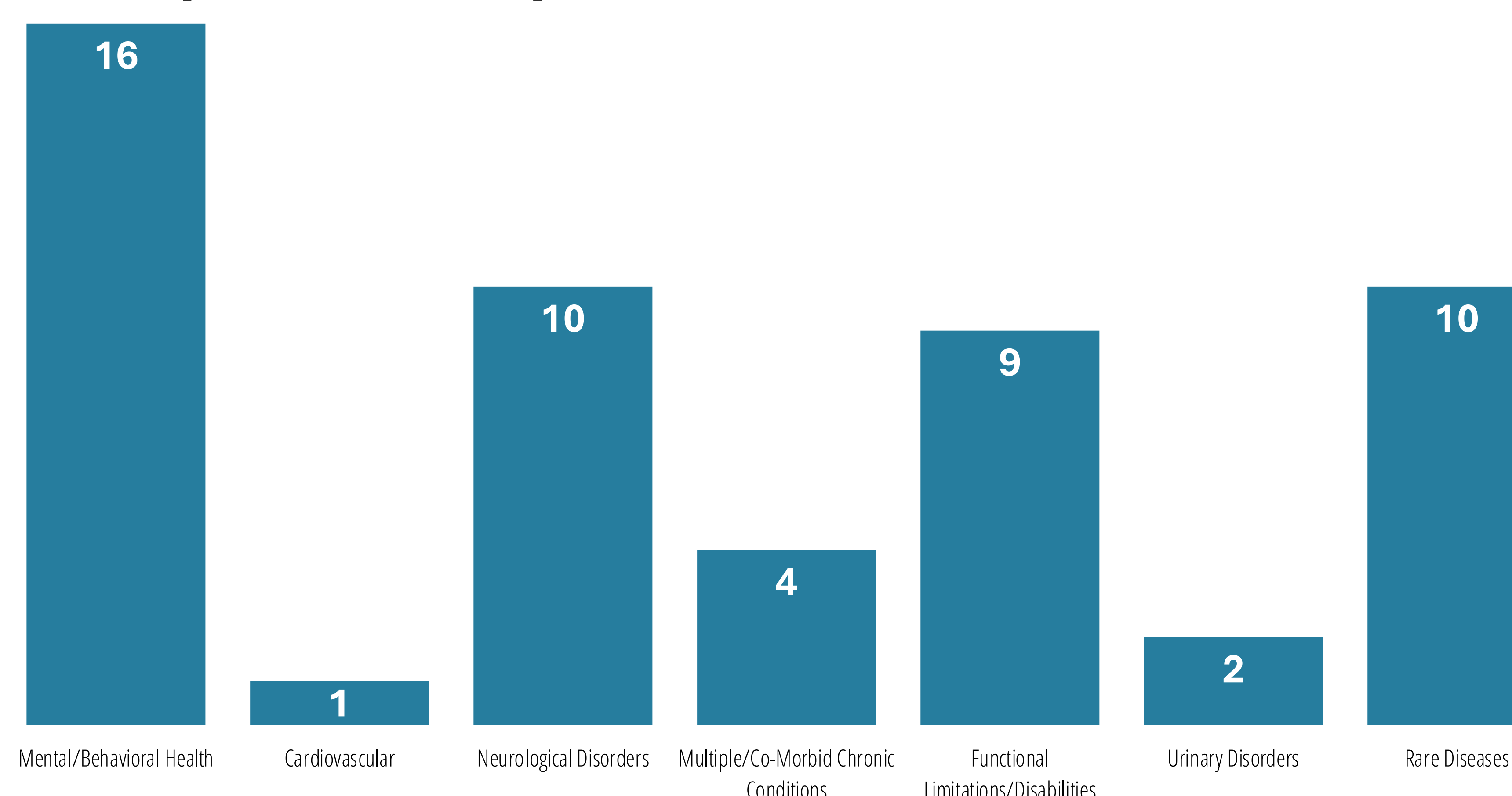


Sample sizes range from 80 to 1,500
Median sample size = 300

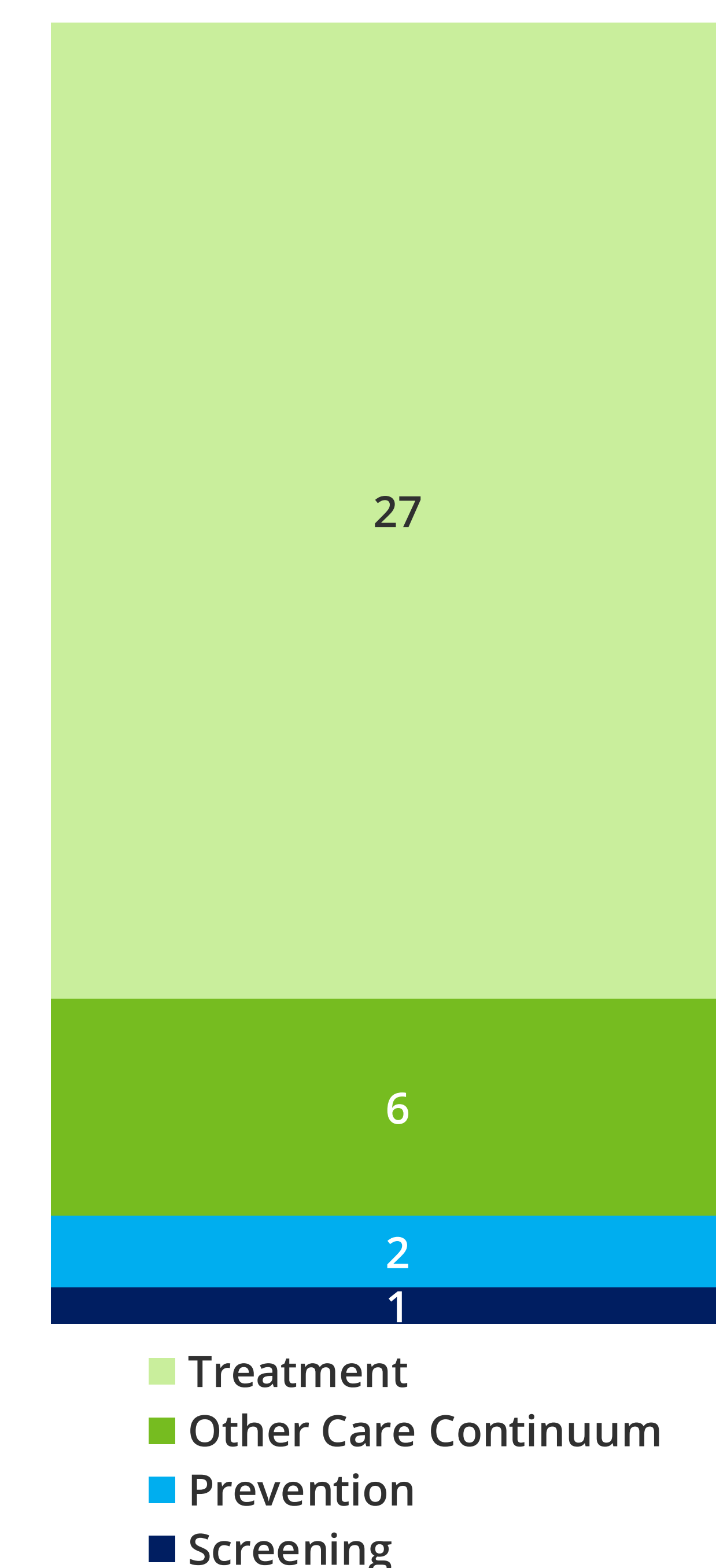
Study Designs in the IDD CER Portfolio



Populations Represented in the IDD CER Portfolio



Number of Studies Along the Care Continuum



Populations captured include Autism, ADHD and general IDD among others

DISCUSSION & NEXT STEPS

- Most studies are RCTs, compare two or more treatments and focus on children; improving mental and behavioral health studies comprise nearly half of awards.
- There are opportunities for IDD CER among populations not currently addressed in our portfolio, as well as in areas beyond treatment, such as screening, prevention, diagnosis and transitions of care.

CONTACT & RESOURCE

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Find us online at:
www.pcori.org