

# ***NDAR Update: The last three months***

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*IACC Mtg – Oct 23, 2009*

***NDAR***

National Database for Autism Research



# Major Milestones Since July 15

## ■ July 2009

- ◆ Presentation to IACC
- ◆ Data submitted by 7 ACE PIs

## ■ August 2009

- ◆ Terms & conditions language for 43/60 ARRA ASD Grants
- ◆ Strategy defined to improve data quality & consistency across different ASD databases (NDAR, AGRE, etc.)
- ◆ 2 ARRA-supported staff hired
- ◆ Ped MRI Data Rep 3.0 public release (children < 4.5 yrs old)

## ■ September 2009

- ◆ Data Dictionary Tool released - community to define data
- ◆ Completed migration of Ped MRI Data Rep to UCSD
- ◆ NDAR Governance Board meeting
- ◆ Award of ARRA ASD & AGRE link to NDAR Grants
- ◆ Award of NIMH supplement to link IAN to NDAR
- ◆ Start tech support of ARRA ASD PIs, AGRE staff, & IAN staff

# The Data Challenge

## The Medium is NOT the Message

- NDAR is a robust medium - but message requires data
- NDAR is not self-populating - data from investigators
- Data submission is not free - incentives are needed
- Incentives depend on data sharing regime, comprising:
  - ◆ Strategy, policy, & practice
- NDAR data sharing regime must extend beyond the 11 ACEs & intramural ASD research projects

***Urgent need to meet the data challenge and change the NDAR data sharing regime to increase data***

# Meeting the Challenge & Changing the Regime

## Address Urgency – General Strategy

- Proactively & persistently pursue data submission from the ACEs & intramural ASD research projects
- Add data from projects beyond ACEs and intramural  
*Provide user-friendly support to all data submitters*
- Link other significant ASD data bases with NDAR  
*Provide solutions for working across linked ASD databases that increase utility & quality of data*

# Addressing Urgency – Specific Efforts

## Data from ACEs & Intramural ASD Projects

- Aggressively communicated with ACE PIs regarding their obligation to submit & share data via NDAR
- Current ACEs & intramural data from:
  - ◆ 2,059 research subjects
  - ◆ 18 clinical assessments
  - ◆ 1853 observations
  - ◆ 8 NDAR Collections
  - ◆ 68 datasets
- First data available for sharing in May 2010

***Compliance with NDAR data sharing agreement has increased greatly over the last three months***

# Addressing Urgency – Specific Efforts

## Adding Data from Beyond ACEs & Intramural

- Migrating data from STAART & CPEA Centers:
  - ◆ Up to 9,400 research subjects
  - ◆ 37 clinical assessments
  - ◆ 33,450 observations
  - ◆ 15 sites
  - ◆ Data available for sharing May 2010
  
- 43 of 60 ARRA ASD Grants to submit data from:
  - ◆ More than 12,000 research subjects (>25,000?)
  - ◆ A wide variety of measures
    - ◆ Will increase the number of data elements
    - ◆ Will increase number of data definitions
  - ◆ First data sharing Dec 2010 (desc) / Feb 2013 (exp)

# Addressing Urgency – Specific Efforts

## Linking ASD Databases with NDAR

- NDAR's federation capability allows direct access to data in linked databases
- Autism Informatics Consortium – harmonizing across:
  - ◆ Simons Foundation, Autism Speaks, Prometheus, & NDAR
- NDAR linkage strategy will
  - ◆ Improve quality, consistency, & usability of data in all DBs
  - ◆ Help development of community-based standards
  - ◆ Have low cost but high benefit to investigators
- Linkage will increase data access to users of any of the linked databases - will add value to all linked DBs

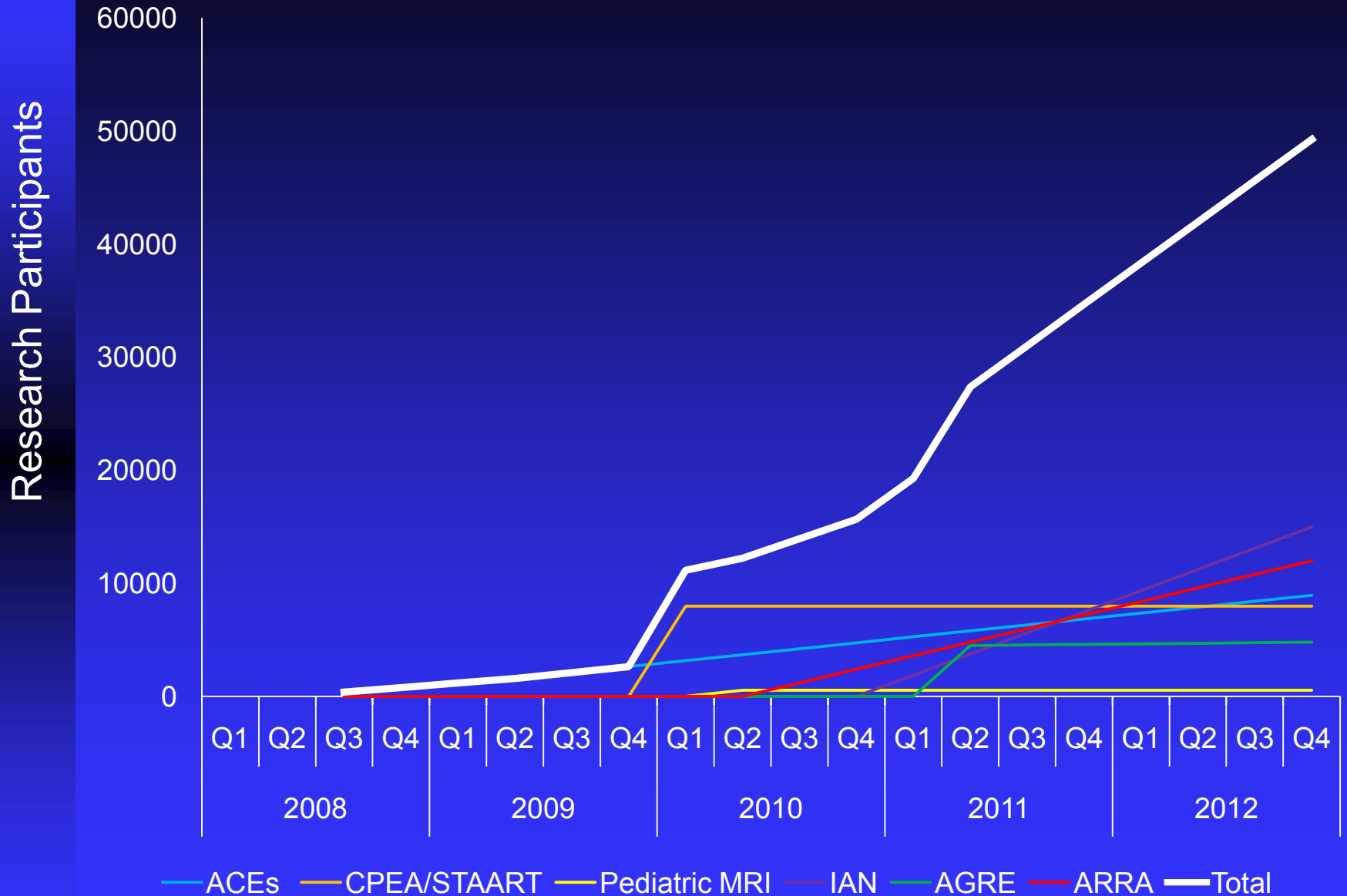
# Addressing Urgency – Specific Efforts

## Current Linking Activities

- NIH Ped MRI Data Rep (600; NDAR funds)
  - ◆ Projected completion: March 2010
- NIMH Genomics Rep (3,000; NIMH funds)
  - ◆ Started: June 2009
- AGRE database (6,000; ARRA funds)
  - ◆ Started: September 2009
- IAN database (30,000, NIMH funds)
  - ◆ Started: September 2009
- NIMH Transcriptome Atlas of Human Development (100, ARRA funds)
  - ◆ Started: September 2009



# Projected Number of Research Participants



# NDAR and Data for NDAR

## The Bottom Line

### ■ Robust

- ◆ Many significant capabilities
- ◆ Community-building platform (collaboration & standards)

### ■ Respected

- ◆ Frequent consultation beyond ASD
- ◆ Much interest in federation by major ASD data resources
- ◆ NDAR active in harmonization across ASD informatics

### ■ Regime

- ◆ More data available due to:
  - ◆ Direct data submission from broader ASD community
  - ◆ Linking to data in other ASD databases
- ◆ Data influx and sharing will not be instantaneous – will accrue over years