



2009 IACC Scientific Workshop:

Updating the Strategic Plan for
Autism Spectrum Disorder (ASD)
Research

September 30 - October 1, 2009

Bethesda, Maryland

Panel 4: “Which treatments and interventions will help?”

- Clinical Experts
 - *Robert Hendren, Eric Samstad*
- Research Experts
 - *Edwin Cook, Bryan King*
- Family/Personal Experts
 - *Joyce Chung, Sharisa Kochmeister*
- Coordinated by IACC Liaisons
 - *Thomas Insel, Stephen Shore*

Panel 4: Noted Research Gaps in the 2009 IACC Strategic Plan

- No mention of emergence of new technologies as interventions in need of study
- Need greater focus on data for “decision makers” (comparative effectiveness, sequence of interventions, Rx algorithm)
- Absence of interventions for adults and for non-verbal individuals
- Need focus on potential novel treatments emerging from mechanistic studies
- Need trials with predictors of outcomes and assessment of functional outcomes (including quality of life)

For Discussion Purposes Only

Panel 4: New Opportunities for Advancing Research and Knowledge about ASD

- New technologies (such as emerging tools and devices for communication, social skills, and cognition)
- Comparative effectiveness research agenda (incl. use of administrative data and registries)
- Integrating predictors (biosignatures, family history, clinical features) in all trials
- Molecular-based novel therapies (e.g. Fragile X, Tuberous sclerosis)
- Registries to integrate data across trials

Panel 4: Suggestions for Prioritizing Short- and Long-Term Research Objectives

- Integrate short-term objective #1 (biosignatures) with #2 - #4 (RCTs) and add quality of life and function to outcome measures
- Add studies in adults to objective #4 (RCTs)
- Emphasize:
 - *Need for new treatments and comparative effectiveness (What do we need?) and*
 - *Urgency of testing widely used interventions (original short term objective #6)*

Panel 4: Summary & Discussion Questions

- Major points: heterogeneity (need personalized interventions, lifespan (need studies for adults), and outcomes (need measures of function)
- How to balance portfolio between novel, targeted interventions and testing of current modestly helpful interventions?
- How to fulfill need for “personalized” information within large scale randomized controlled trials?
- Need for broad portfolio that provides actionable information about range of interventions (medical, behavioral, technological) and policies