Working Group 7 – Conference Call #1 Summary September 20, 2016; 12:30pm EDT

Welcome and Introductions

Working Group Members in Attendance: Alison Singer – Chair Daisy Christensen Samantha Crane Robert Ring Maureen Durkin Paul Lipkin Gretchen Navidi Jessica Rast Catherine Rice Michael Rosanoff Andy Shih

Working Group Members Absent: Adriana DiMartino Michelle Freund Dan Hall Robin Harwood

Summary of 2013 Portfolio Analysis – Group Discussion (Pages 1-4, Data Analysis Slides)

1. Comments/observations on the overall portfolio?

• Working group members took note of projects that were categorized as "not specific to Question 7 objectives." Some of the topics of these projects included electronic medical records, telehealth, multi-faceted core facilities, among others.

Analysis of Question 7 Objectives (Multiyear Funding Table and 2013 Project List)

1. Has there been an adequate number of projects for each objective?

• It was noted that one objective (7.G) was completed despite having no autism-specific projects associated with it. During a previous assessment of the 2011 Strategic Plan objectives by the IACC, it was determined that this objective was fulfilled by a broader CDC environmental tracking tool project.

2. For each objective, do the funded projects cover the scope of the objective? Any noted areas of progress or gaps?

• The goals and progress associated with Objective 7.H, which is related to the National Database for Autism Research (NDAR), should be reconsidered in the next version of the Strategic Plan. The addition of new projects and the linking of new resources since the last update of the

Strategic Plan could mean that the percentage of data contributed may no longer meet the 90% goal stated in the objective.

• The purpose of Objective 7.I was to propose supplementary funding that would be aspirational in trying to accelerate and increase the use of data. The working group recognized that foundational opportunities need to continue to be built upon. During the development of the next Strategic Plan, the members will consider the projects under this objective that have been funded and address how to further advance the intent of this objective.

3. Was the recommended budget for each objective reached? If less was spent, but the number/scope of projects was appropriate, should the objective be considered completed but accomplished with less than the expected budget? In cases where more was spent than the recommended budget, was it because many more projects were funded in that area or because projects were more costly than originally projected? Are there any concerns with regard to funding associated with objectives?

- Working group members discussed whether the color coding scheme used to summarize the status of each objective is an accurate representation of the current state of the science. The color coding indicates the achieved number of projects and budget levels for an objective. However, this is just one layer of analysis; a more qualitative discussion is needed to fully understand the progress that has been made in the field. This is the purpose of the working group's second conference call. Working group members noted that some of the fulfilled objectives need to be taken to the next level, especially considering the need for improved translation from research to policy and practice.
- There was concern regarding the lack of funding in previous years for Objective 7.M. This objective was written narrowly in reference to specific Center for Medicare & Medicaid Services "Promising Practices" papers and does not reflect overall progress on dissemination that may have taken place. The next version of the Strategic Plan may need to be broader in this area and focus on achieving dissemination rather than on specifying the particular method used.

4. Does the working group observe any areas of this question or specific projects that appear to be duplicative? Does the working group have suggestions about how duplication of effort can be avoided in this area?

- Working group members felt that some duplication is appropriate as long as it does not cause excessive redundancy and as long as there is coordination that can prevent wasted efforts. It will be important to take into consideration whether instances of duplication have value.
- Duplication serves a purpose, and the discussion of duplication folds nicely into NIH's recent efforts to improve rigor and reproducibility of studies. NDAR could provide helpful solutions to this issue, perhaps by creating a method for cataloging all ongoing National Institutes of Health-funded autism projects.

5. Are there areas of emerging research that do not appear to be represented strongly in the portfolio that should be considered for mention in the new Strategic Plan?

• Areas identified by the working group that should be considered for inclusion or additional emphasis in the next Strategic Plan included:

- Disparities in access to autism services, screening, and diagnosis. Although this is included in Question 1, there may be cross-cutting aspects that should be considered for Question 7
- Integration of data networks, and approaches for capitalizing on the existing Patient-Centered Outcomes Research Institute networks
- Implementation science, incorporated as part of dissemination, especially as it relates to cross-cutting aspects appropriate for inclusion under Question 7
- Members of the working group would like to also reflect relevant activities by the for-profit sector, if possible, especially considering the increasing movement toward building more precompetitive research collaborations between academia and private industry.

Wrap up and preview of next call

- The next call will include a discussion of research updates since the development of the last Strategic Plan.
- The next call will take place October 6 at 10:30am EDT.