IACC Strategic Plan Question 7 Working Group Conference Call #2

October 6, 2016

Question 7 (Infrastructure, Surveillance, Dissemination/Outreach, Collaboration) Topics:

- Biobanking; brain tissue collection
 - Autism BrainNet, NIH Neurobiobank, ATP, NIMH Repository
- Databases, data sets, data access and sharing
 - o NDAR, AGRE
 - Education and services data sets (e.g., CMS) making them more accessible to researchers
 - Increasing coordination between sequencing projects to prevent duplication and increasing researcher access to data
- Enhancing collaboration; US and international
- Encouraging participation in research
 - New models? Crowd sourcing, virtual cohorts, activity tracking...
 - o Increasing diverse participation in research
- Surveillance and prevalence studies
 - o ADMM
 - o Surveillance in younger age groups
 - o Adult surveillance
 - o International surveillance
- Dissemination of research and outreach
- Research workforce development, training (now to be addressed separately in each chapter, but Q7 group may provide input)
- Global policy?

This document does not reflect decisions of the IACC and is for discussion purposes only.