

NIA – Genetic & Biomarker Disclosure workgroup

An overview and update

Oct 20, 2018

ADC Directors meeting

Neelum T. Aggarwal, MD

Carey E. Gleason, PhD, MS

Work Group Co - Chairs

Progress so far

- Spring 2018 – WG leadership identified
- Leadership meetings
- WG invites sent with request for participant’s “reasons for joining”
- Full WG meeting monthly via phone conferences – 6 calls
 - Established WG Aims
- Established sub-committee organizational structure
- Designated sub-committee leaders



Aims

- 1) Organize and critically evaluate the existing research regarding Genetics and Biomarkers, and their use in dementia risk prediction
- 2) Using findings from Aim 1 to improve messaging and training
 - a) Improve and standardize messaging regarding genetic and biomarker risk and disclosure practices to patients, research and clinical trial participants and the lay public
 - b) Develop innovative educational programming focusing on the role of health literacy, culture, ethnicity, care access to guide disclosure of biomarker and genetic status

Aims (cont.)

- 3) Develop programming and best practices
 - a) Guide the development of *an ongoing* multi modal educational program that includes community partners in the design and execution of the content, programming and dissemination activities
 - b) Integrate best practices for engaging underserved / under represented communities in Genetic and Biomarker research

NIA Genetic and Biomarker Disclosure Working Group
Co-Chairs – Neelum T. Aggarwal
Carey E. Gleason

Research, Data/Analytic Committee
Chair – Ellen Wijsman

**SubComA
Symptomatic Persons**
Co-Chairs- Judy Heidebrink,
Jennifer Lingler

**SubComB
Asymptomatic**
Co-Chairs: Deborah Blacker, Malia
Rumbaugh

Members/Partners

Alzheimer's Assn	U of C – Irvine ADRC
AFTD	U of C – San Diego ADRC
Arizona ADC	U of C – San Francisco
BABES	U of Kentucky
Banner Alzheimer's Institute	U of M – ADC
Boston U ADC	U of Minnesota
Brigham & Women's/ Harvard Medical	U of Pennsylvania ADC
Columbia	U of Pitt – ADRC
Indiana U	U of Utah
LBDA	U of Wash ADRC
Mass ADRC	Wake Forest
Mayo Clinic ADRC	Washington U – ADRC
NCRAD	Wisconsin – ADRC
Rush ADC	Amer. Health Lawyers Assn
	NIA/JBS International
	NIA/PCORI

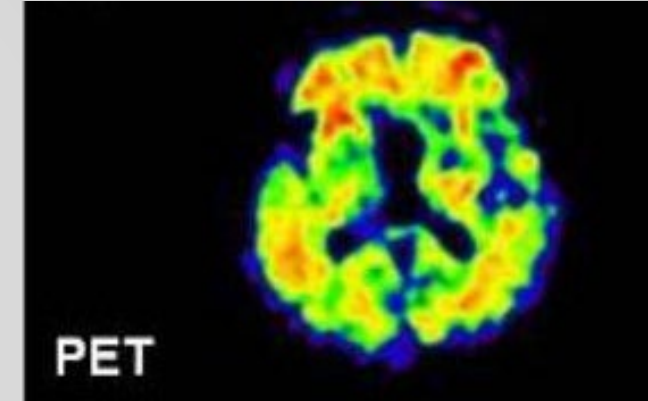
Patient/Community Engagement Committee
Chair: Jamie Tyrone

Ethics/Health Care Law Committee
Chair: Robyn Shapiro

Training Committee
Chair: Li San Wang

Development of Subcommittees

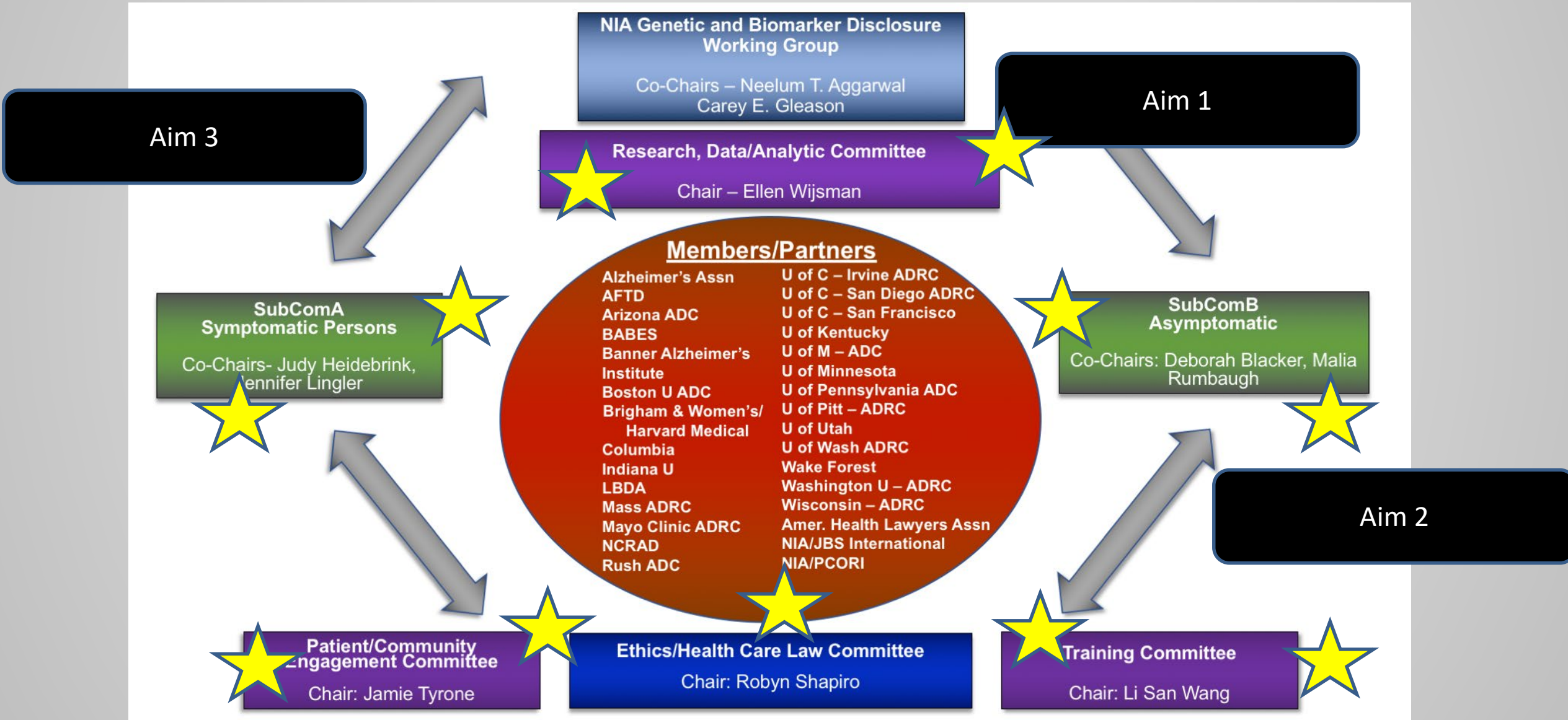
- A. Disclosure with Symptomatic individuals
- B. Disclosure with Asymptomatic individuals



Realized needed additional subcommittees to

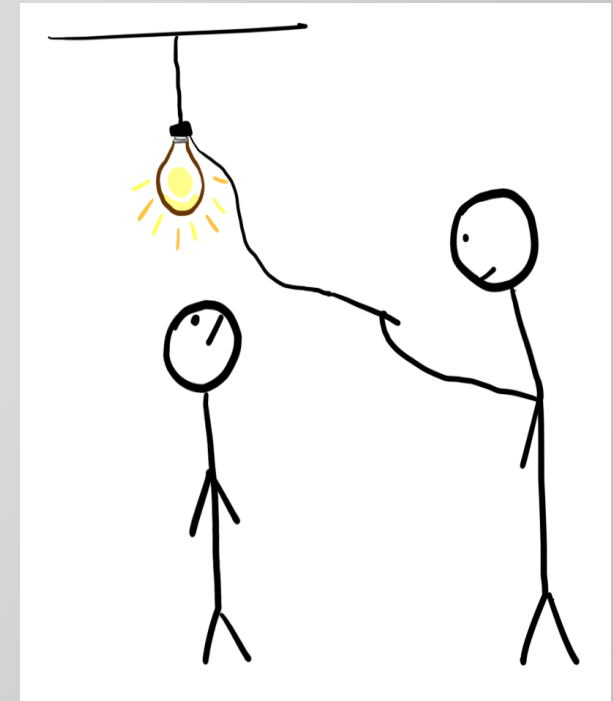
- 1) Interpret/translate existing data – “Research, Data/Analytic Subcommittee”
- 2) Provide patient/participant perspective “Patient Community Engagement Subcommittee”
- 3) Provide legal counsel – “Ethics/Healthcare law Subcommittee”
- 4) Engage trainees – “Training Subcommittee”

Working Group STRUCTURE



Next steps

- 1) Stakeholder feedback (today)
- 2) Finalizing the meeting schedules of the Subcommittees
- 3) Continuing monthly calls with full WG members for updates
- 4) Monthly Leadership calls for assessing progress of all Committees with their deliverables



Thank you for your attention

Questions? Comments?

Neelum T. Aggrawal:

Neelum_T_Aggarwal@rush.edu

Carey E. Gleason

ceg@medicine.wisc.edu

