NIA – ADC Planning Panel

Report to Center Directors

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# Planning Panel Members

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Committee Structure, May-Dec 2016

**ADC Planning Panel**
B. Greenberg, Chair
N. Silverberg, C. Elliott, NIA

**Sub-committees**

**Interactions**
S. Manson, A. Newman, Co-chairs
P. DeJager, N. Foster, B. Gelman, J. Larkin, S. Lovestone,
C. Patel, T. Sherer, D. Shineman, A. Tomkinson

**Clinical**
N. Foster, M. Schmitter-Edgecombe, Co-chairs
J. Galvin, B. Jagust, J. Larkin,
L. Launer, S. Manson, W. Nilsen

**Disease Mechanisms & Risk**
J. Galvin, B. Jagust, Co-chairs
K. Bales, M. Carillo, L. Launer, S. Lovestone,
I. Mackenzie, A. Newman, T. Sherer

**Translational**
K. Bales, D. Shineman, Co-chairs
M. Carillo, P. DeJager,
C. Patel, A. Tomkinson

**Task force: Data Analytics**
M. Carillo, P. DeJager, J. Galvin,
J. Larkin S. Lovestone, C. Patel,
M. Schmitter-Edgecombe, A. Tomkinson
Overview

- Building on existing strengths across the ADC program, improve capacity to contribute to NAPA 2025 goals.

- Develop strategic recommendations to NIA for prioritization and staged implementation. “Blue sky”. No un-funded mandates.

- No changes proposed to ADC Core structure

- Recommendations should be viewed as ADC-wide rather than specific to each individual Center to enable meta-analyses, allowing flexibility for each Center to focus on its own unique cohorts and research priorities.

- While topics need to be discussed sequentially, they should be viewed as an interwoven “whole” – none stands alone.
The panel’s goal was to identify how the ADC network is uniquely poised to address gaps that were identified in the most recent AD/ADRD research summits, rather than identify the gaps themselves.

Utilize ADC’s as sources of leading expertise to identify specific areas of research to which groups of Centers can contribute and to establish collaborative studies.

Importance of considering that clinical disease is not merely a vectorial pathogenesis, but a balance between simultaneous neurodegeneration and resistive compensatory mechanisms, with a net balance of degenerative progression in clinical disease.
Clinical research capacities

- Combine clinical research assets, diversity of participants, and leveraged capabilities and resources in epidemiology, with contributions of strengths, idiosyncrasies and demographics from individual Centers to achieve a broader cross-center capacity.

- Centralized facilitation of recruitment/retention through all stages of disease spectrum.

- Utilize cross-Center capacities to investigate “movement” of standard and novel diagnostic biomarkers through disease progression in natural history studies and at intervals during interventional trials.
Research Theme
Topic C – Autopsy Capabilities

Maximize value of neuropathology expertise across ADCs

- Build neuropathology expertise more broadly across ADC network.

- Through NACC and ADC network, survey scope of collected autopsy material with respect to disease stage and clinical characterization. Work towards filling any existing gaps through concerted efforts.

- Discussions focused on importance to neuropathological studies of:
  - Overall prioritization in light of limited resources
  - Clinical characterization
  - Alignment and development of standard protocols/assessments with advances in technology and clinical/biomarker research
  - Training of neuropathologists in the sub-field of neurodegenerative diseases
  - Economic challenges
Accelerate translational research across the spectrum of AD, ADRDs and mixed dementias using healthy cognitive aging and cognitive resilience as comparators, with a strong focus on understanding disease heterogeneity.

- ADCs are key resources for:
  - Clinical research and biomaterials to support translational studies
  - Providing opportunities for cross-validation between pre-clinical studies and clinical outcomes
  - Expertise that can help to drive translational research

- Recognizing that drug-discovery research has not been a core focus of most ADCs, create opportunities for ADCs to contribute substantially more to translational research through interactions with NIA/NIH translational programs, academic collaborations and industry.
Collaboration Theme
Topic E – Cross-ADC Interactions

Cross-ADC interactions/networking: Transform existing Centers into more coherent network that facilitates interactions and optimizes utilization of unique resources and capabilities contributed by individual ADCs that will enable a more rapid development of knowledge related to disease progression, patient outcomes & biomarker development.

- Thematic cross-collaborations and sub-networks provide potential for leveraging expertise to expand the overall capabilities and impact of the Centers network. “The whole is greater than the sum of its parts.”

- Diminish barriers using “central navigator” and optional “collaboration cores” to streamline processes, facilitate interactions, integrate assets.
  - Will facilitate interactions not only among ADCs, but with academic and industrial research more broadly.

- Note: this is not necessarily an ADC-wide “mandate,” but can be implemented stepwise with those Centers who wish to engage, and expanded/contracted as appropriate based on outcomes.
Collaboration Theme
Topic F – Interactions beyond ADC network

- The next “layer of the onion.” Expand interactions and collaborations with other relevant programs focused on neurodegenerative disease and aging.

- Will require efforts to align evaluations and assessments.

Develop strategic interactions across relevant NIH, VA, other federally supported Center programs, non-governmental organizations and large epidemiological studies.
Enablement Theme
Topic G – Infrastructure & Analytics

Infrastructural supports to enable prior recommendations: Modernize and expand the computer and data analytics systems required to facilitate interactions among the ADCs and broader research community.

- “Start with NACC. Build from NACC.” Repeat.
- Leverage/modernize existing data and computer systems to support all interactions, providing unified data hub for broad access to data and locations of samples for research to enhance opportunities for sharing.
- Build incentives with appropriate protections for providers and consumers of data and samples across ADCs and research sectors. Contractual and ethics issues to be taken under proactive consideration.
Enablement Theme
Topic H – Expanded Training

Further development of training programs: Enhance multi-faceted training programs focused on improving research and clinical care workforce capacity across the Center network.

- Training considerations developed at personnel level across disciplines, and at programmatic levels to expand knowledge in neurodegenerative diseases and aging.

- Includes cross-training through personnel exchanges/rotations with industrial sector.
Future Considerations

- Additional cross-ADC interactions will be considered that were not yet part of the panel’s discussions, e.g.:
  - Creation of an ADC network with expertise in mHealth and telemedicine that could design and launch home-based studies focused on preserving physical and functional independence of patients with dementia, preventing or delaying admission to hospitals or care facilities.
  - Research on palliative care
  - Surveys of Advanced Care Planning in persons across the spectrum of disease.
  - Etc.
With huge appreciation to the panel members, NIA staff, ADC Directors, NACC, NCRAD, and a cast of .... dozens.