

# 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

### Disease Mechanisms & Risk

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

### Clinical

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

### Translational

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

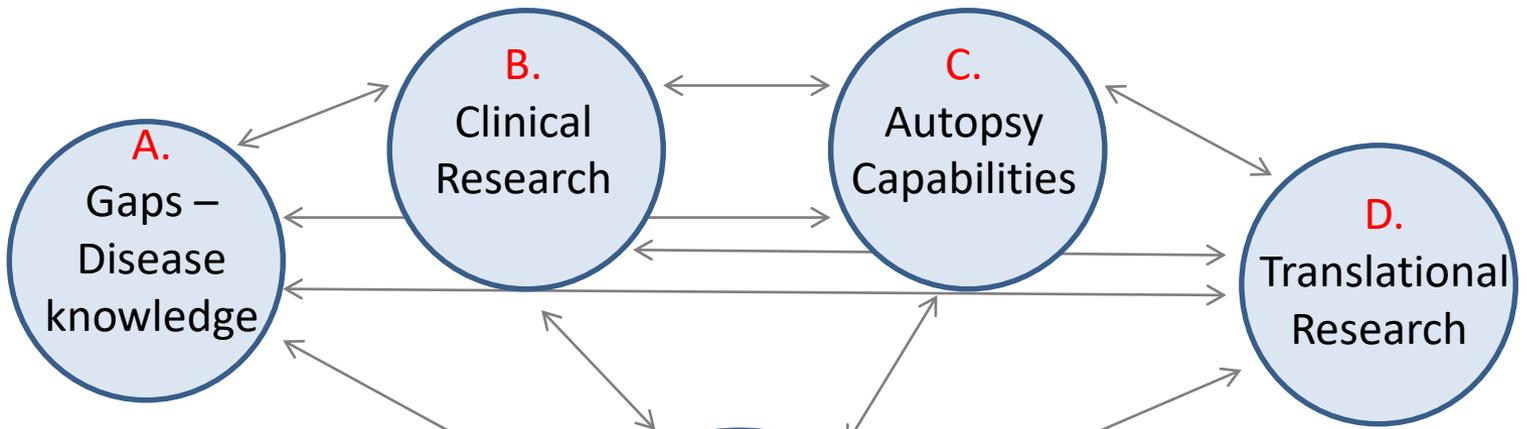
### Task force: Data Analytics

M. Carillo, P. DeJager, J. Galvin,  
J. Larkin, S. Lovestone, C. Patel,  
M. Schmitter-Edgecombe, A. Tomkinson

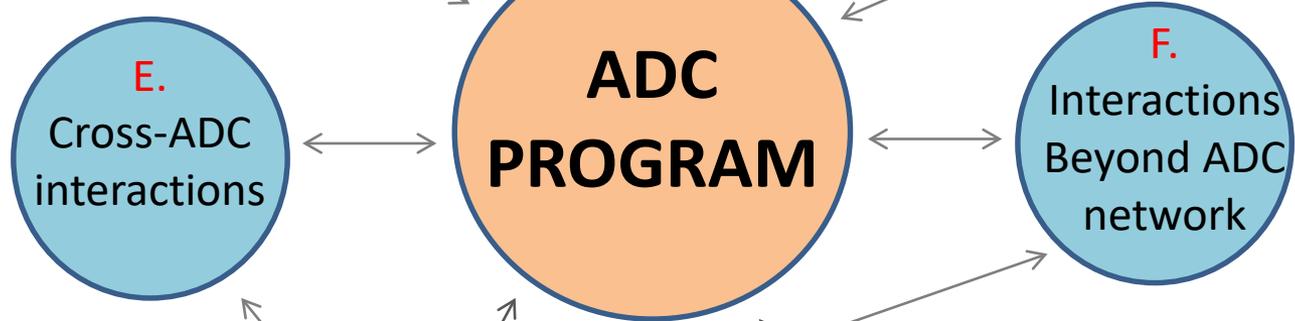
# Overview

- 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.

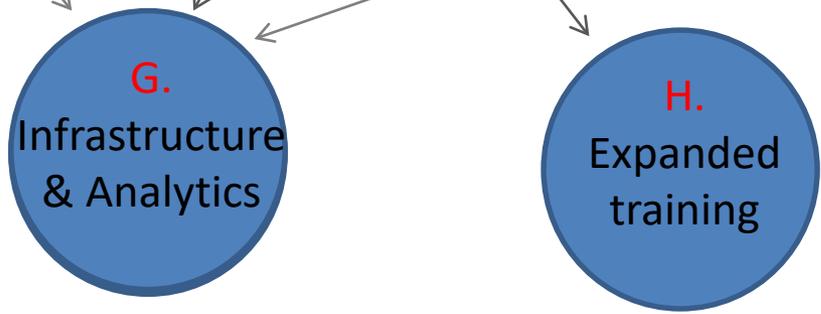
**Research**  
A-D



**Collaboration**  
E, F



**Enablement**  
G, H



Arrows  
To all  
A - G

# Research Theme

## Topic A – Gaps in Disease Knowledge

*Gaps in disease mechanisms and risks: Expand the set of tools to identify knowledge gaps in disease mechanisms/risks, clinical outcomes and prevention strategies.*

- 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.

# Research Theme

## Topic B – Clinical Research

### *Clinical research capacities*

- Combine clinical research assets, diversity of participants, and leveraged capabilities and resources in epidemiology, with contributions of strengths, idiosyncracies 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

# Research Theme

## Topic D – Translational Research

*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

*Develop strategic interactions across relevant NIH, VA, other federally supported Center programs, non-governmental organizations and large epidemiological studies.*

- 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.

# 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

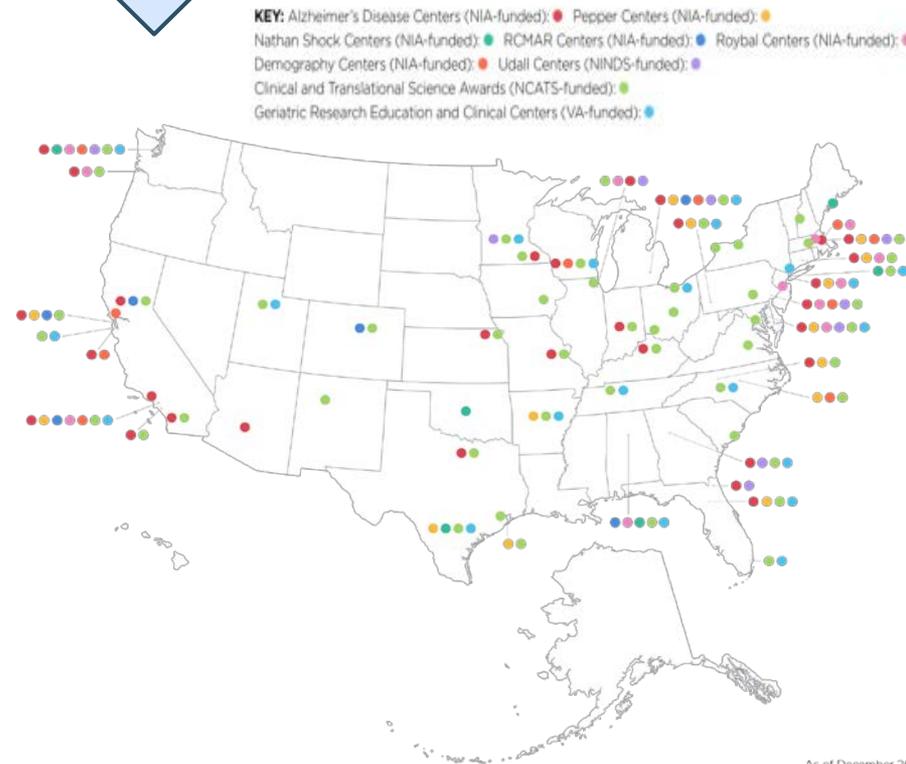
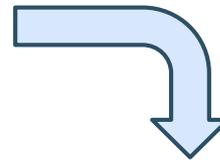
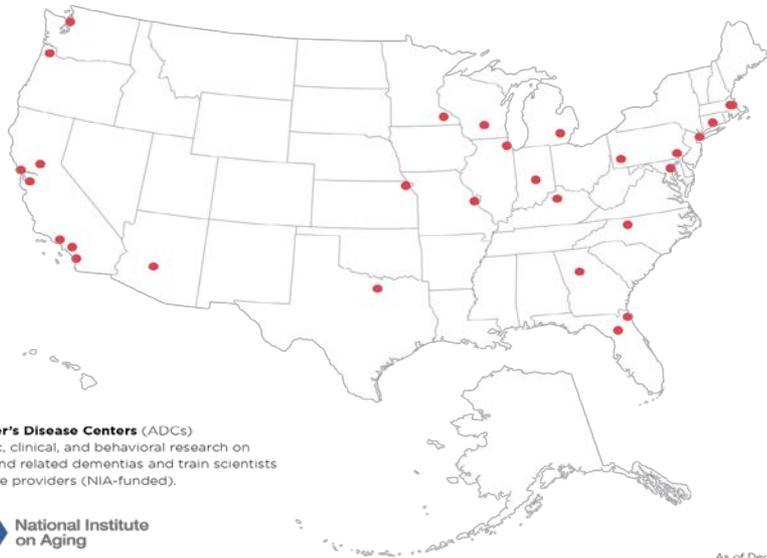
*Further development of training programs: Enhance multi-faceted training programs focused on improving research and clinical care workforce capacity across the Center network.*

- 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.

# Discussion



With huge appreciation to the panel members, NIA staff, ADC Directors, NACC, NCRAD, and a cast of .... dozens.