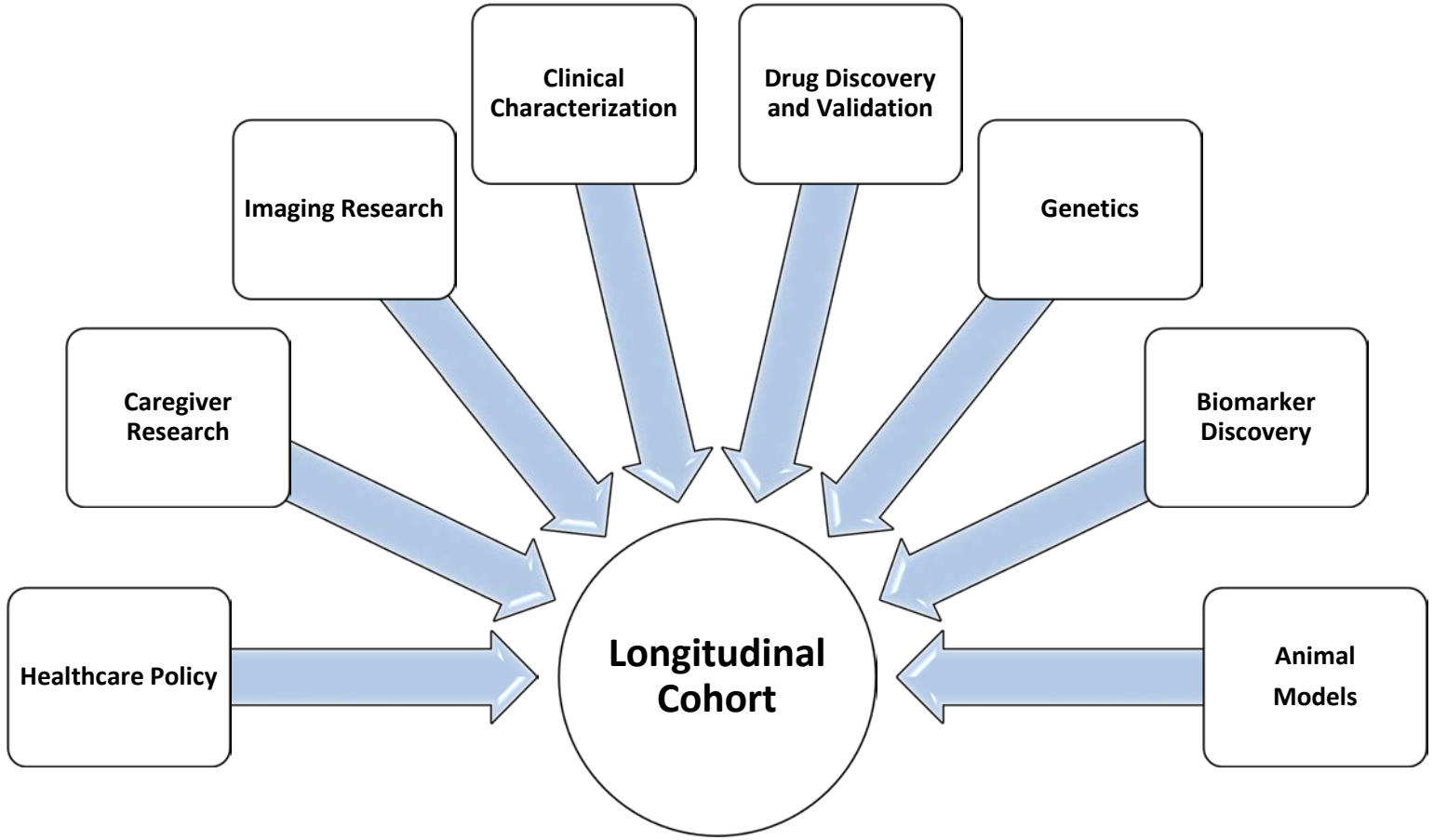
Unique Role of ADCs

- Studying AD and related dementias (ADRDs), including use of real world clinical data, to test hypotheses about disease pathogenesis and heterogeneity, risk and protective factors, with the aim of improving diagnosis, prevention and treatment
- Accelerating translational research advances from the bench to clinical practice
- Developing strategies to address prevention of AD including identification of earliest markers, informing development of candidate trial designs and defining risk/protective factors
- The lifeblood of these activities is the longitudinal cohort



Outreach and Recruitment Goals

- Ensure recruitment of novel cohorts at high risk (age, genetics, co-morbidities, cognitively normal individuals with amyloid- and/or tau-PET positivity) with careful biomarker characterization
- Ensure inclusion of research participants across the Center network that represent the full range of disease, including those eligible for primary and secondary prevention up to those in the moderate to late stages of the disease
- Enable ADCs to recruit individuals from specific populations (e.g., ethnic, racial, social groups, high cardiovascular risk load, etc.) with the goal of strengthening the diversity of the overall cohort
    - Include sufficient numbers of underserved populations and populations with unique risk/protective factors to embrace the heterogeneity inherent to AD, ADRDs and co-morbidities.
- Expand research in the areas of recruitment and retention in AD and ADRD, including autopsy consent
- Develop tailored recruitment strategies and related materials, including brochures, videos, online content, pre-post event assessments, etc., that can be adapted individually at each center
- Seek opportunities to extend outreach by incorporating caregivers into research, where appropriate.
- Encourage recruitment of staff, scientists and trainees that represent a range of racial and ethnic diversity that aligns with the local research participant demography.

Sample OR Core Activities

- Establish a “meta-registry” across ADCs of people willing to participate in future research studies
  - sizeable group of well characterized potential research participants
  - minimally evaluated “trial ready” individuals who could participate in therapeutic trials aimed at specific disease stages
- Develop approaches to recruit and maintain these registries across centers, as well as to assure that registry research participants are not overburdened.
- Explore opportunities to facilitate community based trials, in addition to highly selected and potentially biased clinical populations.
- Utilize the registry to facilitate rapid enrollment in clinical studies.
- Identify and recruit high-risk populations in pre-symptomatic stages of potentially incipient disease for prevention initiatives.
- Capitalize on technology-based options to provide wide-spread educational and recruitment opportunities (e.g., telemedicine networking, social media, apps).
- Improve and share evaluation methods (e.g., pre-post event assessments) to determine return on investment for recruitment efforts.