INTEGRATING RESEARCH ON ALZHEIMER’S AND OTHER DEMENTIAS INTO POPULATION HEALTH MODELS: OVERCOMING BARRIERS AND EMBRACING NEW OPPORTUNITIES

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Population Health

“Population Health” is a relatively new attempt to integrate the growing wealth of data on both the community and the individual into a seamless model that describes:

- Health Risks
- Health Treatments
- Health Outcomes
Population Health

- Health Risks: Personal Behaviors, as well as Social, Economic and Environmental Factors
- Health Treatments: How health problems are treated from ER care to Personalized Medicine to Non Traditional Medicines
- Health Outcomes: Survival, Quality of Life, Long Term Results

Collectively these provide a metric for the success of the Health Care Provision System
Defining Population Health ...

“conceptual framework for thinking about why some populations are healthier than others.”
Population Health

From our perspective:
Population Health then is about DATA and how to organize and integrate multiple levels of information on the community, its health infrastructure and social resources to better understand individual health outcomes.

NACDA is one resource for Data Driven answers
The NACDA data archive as spent the past 35 years identifying, gathering and organizing data on aging and the aging life course so we can share these resources with the research community.

NACDA currently supports approximately 1,600 individual studies on ageing and health and adds 30 to 50 new studies to our collections each year.
This is a conceptual model of how to organize data on Population Health from the perspective of a data repository.
Electronic Health Records (EHR)

An electronic health record (EHR) is a digital version of a patient’s paper chart. EHRs are real-time, patient-centered records that make information available instantly and securely to authorized users. While an EHR does contain the medical and treatment histories of patients, an EHR system is built to go beyond standard clinical data collected in a provider’s office and can be inclusive of a broader view of a patient’s care. EHRs can:

- Contain a patient’s medical history, diagnoses, medications, treatment plans, immunization dates, allergies, radiology images, and laboratory and test results
- Allow access to evidence-based tools that providers can use to make decisions about a patient’s care
- Automate and streamline provider workflow
# Electronic Health Record (EHR)

**CBC WITH DIFFERENTIAL - Details**

## Component Results

<table>
<thead>
<tr>
<th>Component</th>
<th>Your Value</th>
<th>Standard Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>WBC</td>
<td></td>
<td>4.0 - 10.0 K/uL</td>
</tr>
<tr>
<td>HGB</td>
<td></td>
<td>13.5 - 17.0 g/dL</td>
</tr>
<tr>
<td>HCT</td>
<td>Results go here</td>
<td>40.0 - 50.0 %</td>
</tr>
<tr>
<td>PLT</td>
<td></td>
<td>150 - 400 K/uL</td>
</tr>
</tbody>
</table>
Genomic Data

Genomic data refers to the genome and DNA data of an organism. They are used in bioinformatics for collecting, storing and processing the genomes of living things. Genomic data generally require a large amount of storage and purpose-built software to analyze.

The aim of genomic data analysis is to determine the functions of specific genes.

It is expensive to collect, manage and use.

The relationship between genetics and environment also remain unclear.
The National Institute on Aging Genetics of Alzheimer's Disease Data Storage Site

NIAGADS is the National Institute on Aging Genetics of Alzheimer's Disease Data Storage Site. NIAGADS is a national genetics repository created by NIA to facilitate access by qualified investigators to genotypic data for the study of genetics of late-onset Alzheimer's disease. NIAGADS collaborates with other NIA resources such as NCRAD, NACC, and ADGC.
Biomarker and Biospecimen Data

Samples of material, such as urine, blood, tissue, cells, DNA, RNA, and protein from humans, animals, or plants.

Biospecimens are stored in a biorepository and are used for laboratory research. If the samples are from people, medical information may also be stored along with a written consent to use the samples in laboratory studies.

Recorded physical measures such as BMI, hip-waist ratios, height, body fat calipers results.

These consist of two types of information: preserved specimens and recorded information on results.
The goal of the National Centralized Repository for Alzheimer’s Disease and Related Dementias (NCRAD) is to support research focused on the etiology, early detection and therapeutic development for Alzheimer disease and related dementias. To accomplish this goal, in 1990, NCRAD was funded by the National Institutes on Aging (NIA). NCRAD is a national resource where clinical information and biological materials, such as DNA, plasma, serum, RNA, CSF, cell lines and brain tissue can be stored and requested. NCRAD currently maintains samples from individuals with Alzheimer’s disease and/or related dementias as well as healthy controls.
Behavioral and Social Health Survey Data

Health Surveys are nationally-representative household surveys that provide data for a wide range of monitoring and impact evaluation indicators in the areas of population, health, and nutrition.

- They provide high level population measures on a wide variety of health measures but typically lack data on small area geography and smaller population groups.
- They are among the most common type of health data available to the public.
The Aging, Demographics, and Memory Study (ADAMS) Wave A

The Aging, Demographics, and Memory Study (ADAMS), a supplement to the Health and Retirement Study, was funded by the National Institute on Aging with the specific aim of conducting a population-based study of dementia. HRS formed a partnership with a research team led by Brenda L. Plassman, Ph.D., director of the Epidemiology of Dementia Program at the Duke University Medical Center. The purpose of this collaboration was to conduct in-person clinical assessments for dementia on selected HRS respondents in order to gather information on their cognitive status. A diagnosis of dementia, cognitive impairment but not demented (CIND), or non-case was assigned on the basis of this assessment. Prior community-based studies of dementia have focused on a particular geographical area or have been based on nationally distributed samples that are not representative of the population. This study is the first of its kind to conduct in-home assessments of dementia in a national sample that is representative of the U. S. elderly population. ADAMS was funded by The National Institute on Aging as a supplement to the Health and Retirement Study (U01 AG09740).
Family caregiving affects millions of Americans every day, in all walks of life. At least 17.7 million individuals in the United States are caregivers of an older adult with a health or functional limitation. The nation’s family caregivers provide the lion’s share of long-term care for our older adult population. They are also central to older adults’ access to and receipt of health care and community-based social services. Yet the need to recognize and support caregivers is among the least appreciated challenges facing the aging U.S. population.
Social Determinants of Health Data

The social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels.

Income and income distribution. Early childhood development.
Education. Food insecurity.
Unemployment and job security. Housing.
Employment and working conditions. Social exclusion/inclusion.
Social Determinants of Health: Know What Affects Health

Social Determinants of Health (SDOH)

Sources for Data on SDOH

Tools for Putting SDOH into Action

CDC Programs Addressing SDOH

Policy Resources to Support SDOH

CDC Research on SDOH

Frequently Asked Questions

Archived Spotlight Resources

Sources for Data on Social Determinants of Health

Sources for Data on Social Determinants of Health

Data can be a catalyst for improving community health and well-being. Understanding data on social determinants of health, such as income, education, and access to healthcare, can help identify and address health disparities.

For more information, visit the CDC's website on Social Determinants of Health.
Population Health is a Tool Kit, NOT a Linear Model.
What to do? Pattern Matching

- We can get overall population health risks and prevalence for Alzheimer’s and other cognitive conditions.
- What are the factors that explain heightened risk?
  - Poverty, pollution, lack of health care access, crime, stress, socioeconomic challenges?
- How do overall factors track national health concerns?
- Are the risk factors concentrated in communities where these populations emerge from?
- What are known health risks in these communities?
- You can make a Population Health Model if you have data.
Connecting Scientists Worldwide

GAAIN is advancing research into the causes, prevention and treatment of Alzheimer’s and other neurodegenerative diseases through a global cooperative of sharing, investigation and discovery.
471,821 Subjects Online from 38 GAAIN Data Partners

Become a GAAIN partner!
Conclusions

- Population Health models are flexible and can be adapted to the needs and infrastructure of almost any organization interested in health outcomes.

- Much of the SDoH information can be obtained as part of public use collections or organized from reports or other data collection methods.

- Much of the individual level information is already available to Public Health Services, health care providers, and NGO or CBO advocacy groups.

- You need data across the spectrum to fully understand population health and why some groups do better than others.
Using NACDA Data

• NACDA data is freely available to all.
• If you have internet access you can obtain and use NACDA data for your research interests.
• NACDA is an international resource open to all members of the research community…EVERYWHERE!!
NACDA Program on Aging

NACDA operates on the internet 24 hours a day, 365 days a year.
• We welcome you as researchers to use our data.
• Visit us at:
  www.icpsr.umich.edu/icpsrweb/NACDA
• Or Google “NACDA aging”
• Twitter @NACDA_Aging