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

NACDA Program on Aging
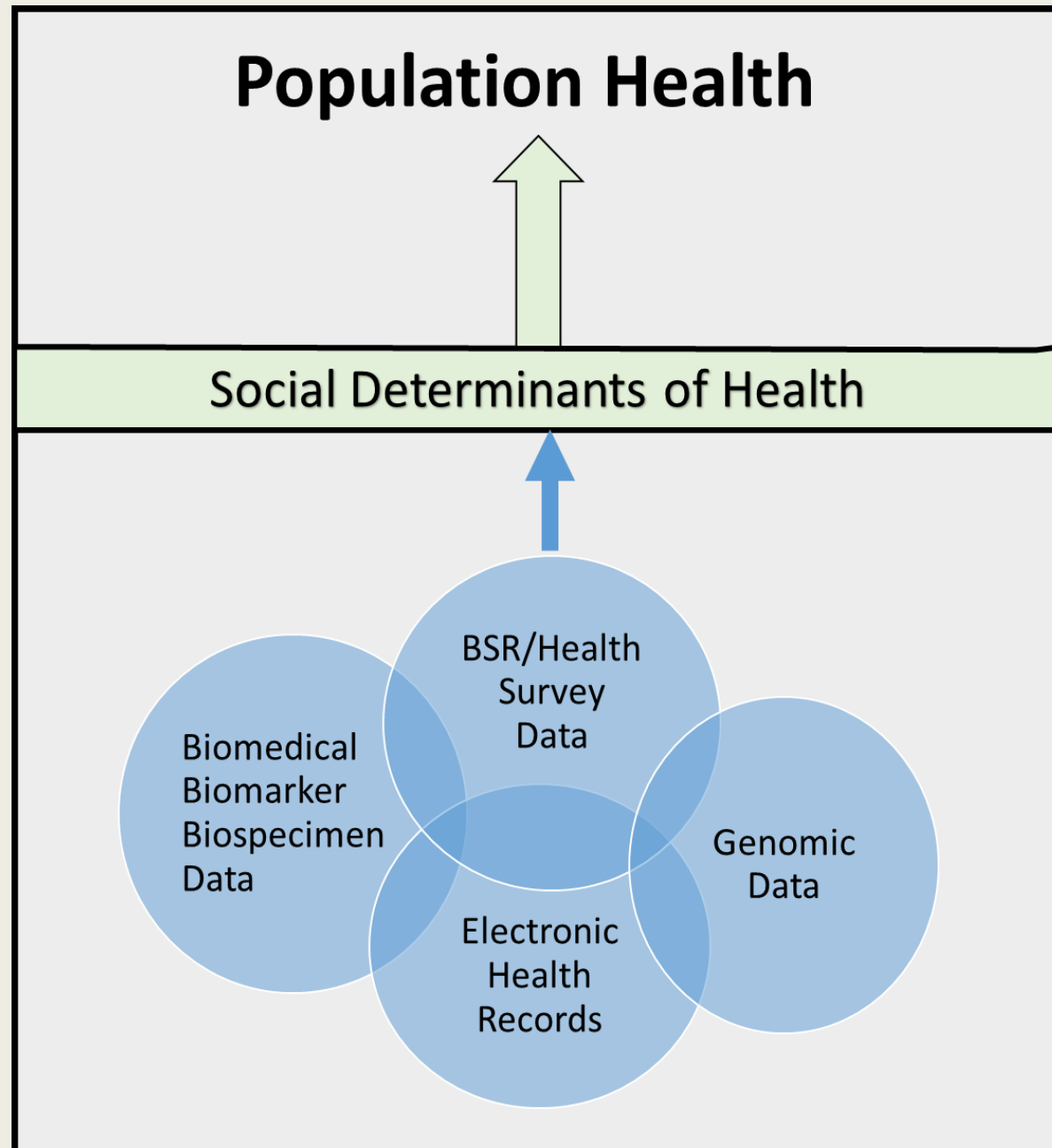

NACDA is part of ICPSR

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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

Population Health

Social Determinants of Health

BSR/Health Survey Data

Biomedical Biomarker Biospecimen Data

Genomic Data

Electronic Health Records

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

ⓘ About This Test

Details | Past Results | Graph of Past Results

Component Results

Component	Your Value	Standard Range
WBC		4.0 - 10.0 K/uL
HGB	Results go here	13.5 - 17.0 g/dL
HCT		40.0 - 50.0 %
PLT		150 - 400 K/uL

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.

www.niagads.org

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 <u>NCRAD</u>, <u>NACC</u>, and <u>ADGC</u>.

BROWSE DATASETS

DISEASE ⌄

DATA TYPE ⌄

SEARCH

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.

National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD)

NCRAD

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Home   About NCRAD   Information For Families   Biospecimens & Data   Banking with NCRAD   Tools for Active Studies

NCRAD History and Mission

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.
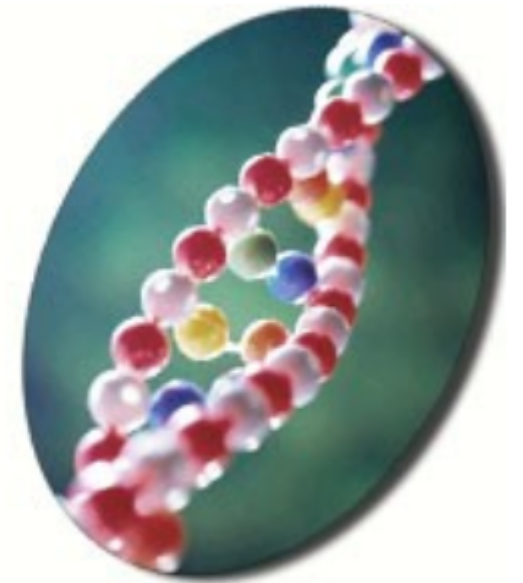
Behavioral and Social Health Survey Data

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.

HRS | HEALTH AND RETIREMENT STUDY

Data Products / What's Available (Public) / Details

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).

Families
Caring
for an AGING
AMERICA

Richard Schulz and Jill Eden, Editors (2016)

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.

Education.

Unemployment and job security.

Employment and working conditions.

Early childhood development.

Food insecurity.

Housing.

Social exclusion/inclusion.

![CDC] **Centers for Disease Control and Prevention**
CDC 24/7: Saving Lives, Protecting People™

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

Social Determinants of Health (SDOH)

Sources for Data on Social Determinants of Health
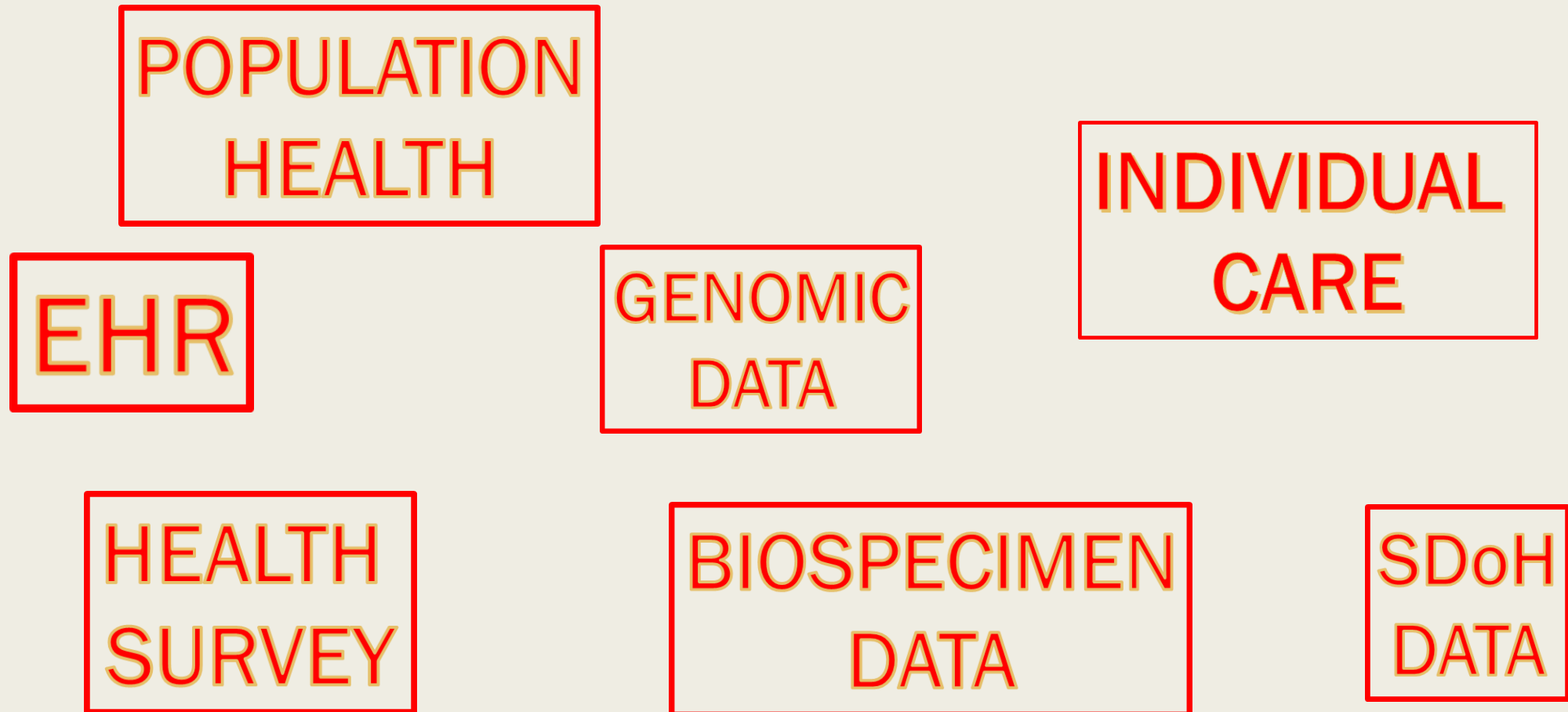
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SOURCES FOR DATA ON SOCIAL DETERMINANTS OF HEALTH

Data can be a catalyst for improving community health and well-being. Understanding data on social determinants of health, such as income, educational

Population Health is a Tool Kit, NOT a Linear Model.

POPULATION HEALTH

INDIVIDUAL CARE

EHR

GENOMIC DATA

HEALTH SURVEY

BIOSPECIMEN DATA

SDoH DATA

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.

gaain.org

471,821 Subjects Online from 38 GAAIN Data Partners

606	565	646	90	1,026	1,943	474	2,394	262	2,619	151
VITA	OASIS	HUG	WMH in AD	BRAIN INSTITUTE LAADC OHSU	HELIAD	EDSD	cherry	I-ADNI	ARWIBO	E-ADNI PharmaCog
APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY
Attributes: 1,017	Attributes: 1,026	Attributes: 1,027	Attributes: 1,023	Attributes: 486	Attributes: 1,024	Attributes: 1,109	Attributes: 4,505	Attributes: 1,055	Attributes: 2,663	Attributes: 1,089

35,768	3,208	242	24,076	1,744	6,818	309	537	938	12,126	15,117
NACC	ADNI	ALZHEIMER'S PREVENTION INITIATIVE COLOMBIA	NCRAD	aibl	KLOSCAD	DCL PARLA	J-ADNI	DART National Taiwan University	Fundació ACE	
APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY
Attributes: 187	Attributes: 1,285									

1,037	6,500	24,975	318	4,424	51,264	202,375	723	51,117	318	881
CHeBA	CPAD CRITICAL PATH FOR ALZHEIMER'S DISEASE	NIAGADS		Penn	clsa élcv	BNA	The AddNeuroMed Study		LMRR	EU
APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY	APPLY

240	1,541	342	38,183	OFFLINE	
DIAN TU	WRAP UNIVERSITY OF WISCONSIN MADISON	DIAN	HRS	WISCONSIN LONGITUDINAL STUDY	Become a GAAIN partner!
APPLY	APPLY	APPLY	APPLY		

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*