Biomedical Informatics and eHealth Core

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1Florida ADRC

UFHealth
NORMAN FIXEL INSTITUTE FOR NEUROLOGICAL DISEASES

OneFlorida
Clinical Research Consortium

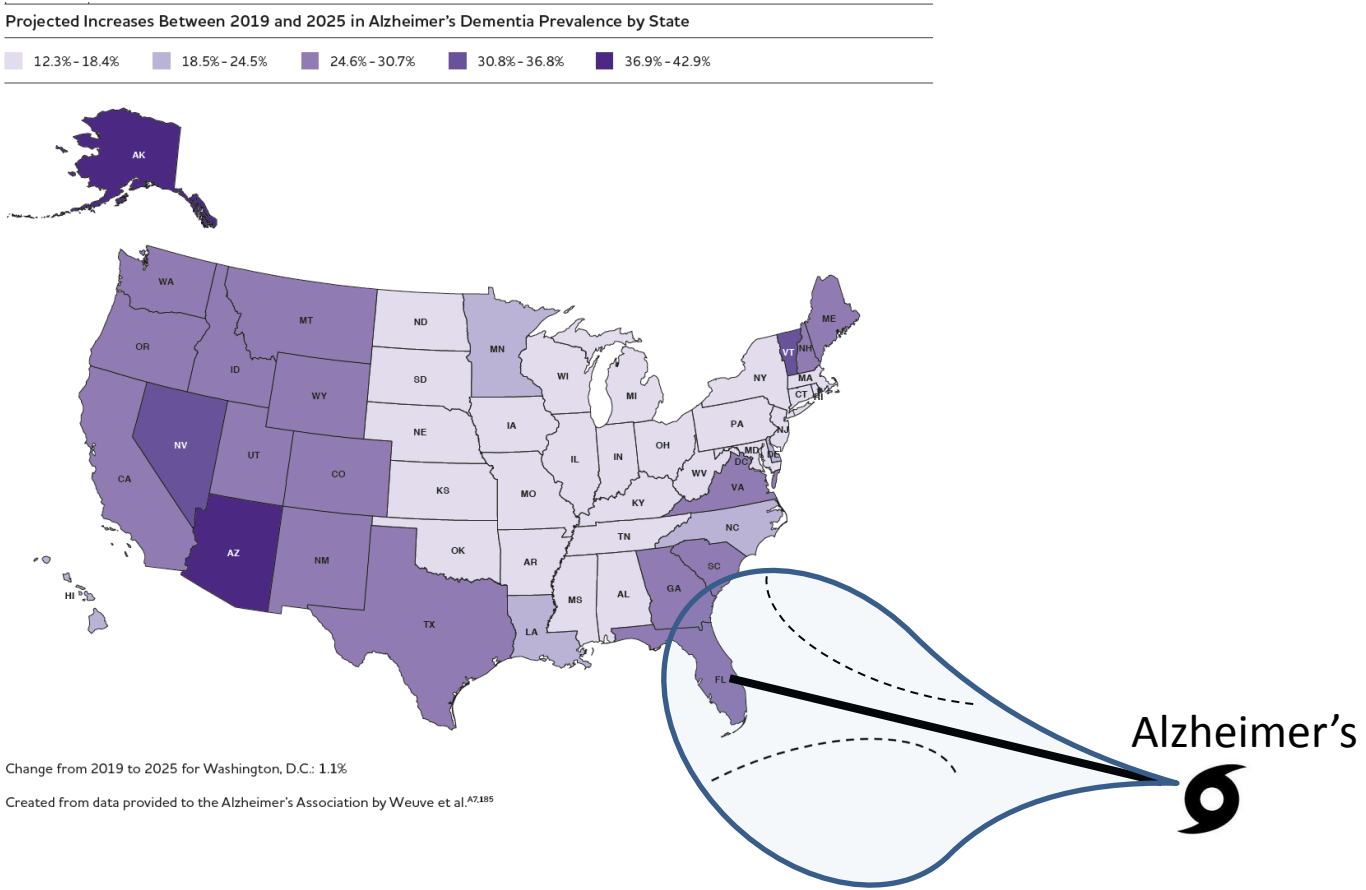
Disclosures

- I came to Florida to find the Fountain of Youth
  - *To preserve and improve brain health*
  - *By preventing cognitive decline and dementia*
  - *Using biomedical informatic & eHealth approaches*

Why Florida?

- Third most populous and oldest state per capita
- Most cases of Alzheimer's disease and related disorders (ADRD) per capita
- The only state that includes ADRD as a priority area in it's State Health Improvement Plan
  - Identify a statewide system of resources and support to formalize the ADRD network
  - Strengthen the capacity of care organizations to assess, diagnose, and treat individuals with ADRD and expand support for caregivers
  - Protect individuals with ADRD from further vulnerability

In the Cone of Uncertainty

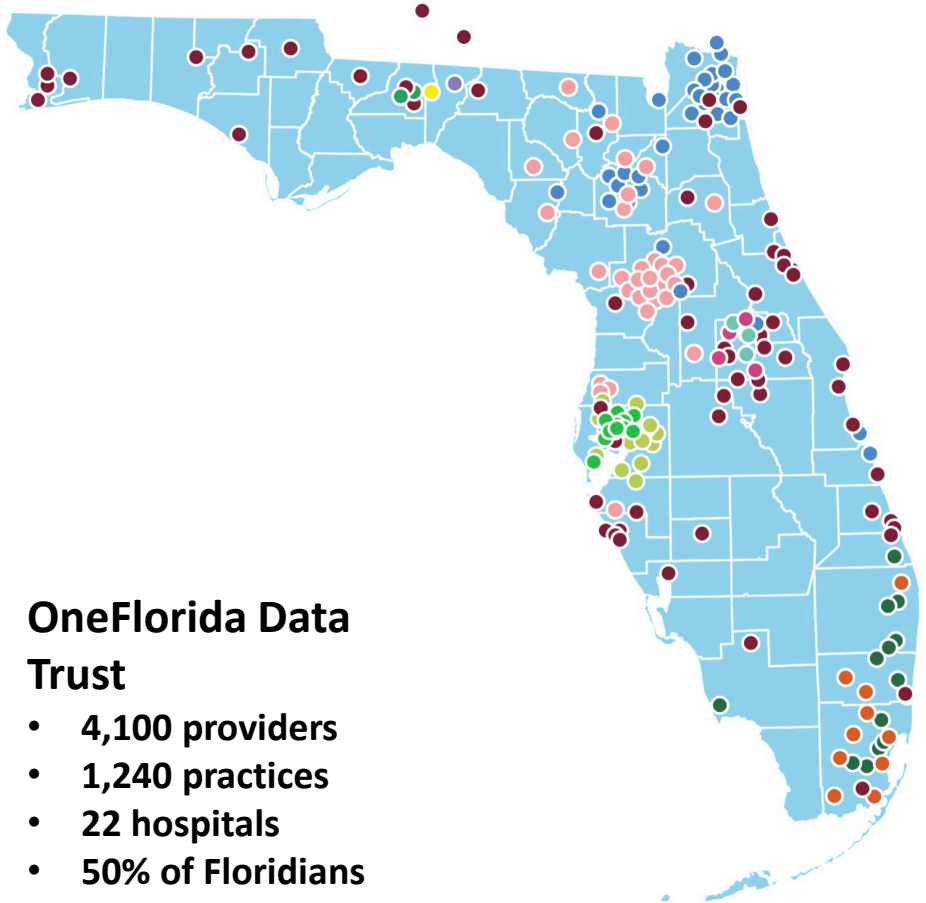


Why Biomedical Informatics & eHealth?

- The electronic medical record (EMR) is the federally mandated “agora” (marketplace) for all healthcare transactions
- EMRs have the capacity to capture hundreds of discrete data elements per encounter, and millions of discrete data elements per person
- EMRs have the capacity to provide clinical decision support (CDS) at the point-of-care
- Common data elements exist across commercial EMRs, in support of platform agnostic registries

1Florida ADRC Bioinformatics and eHealth Core

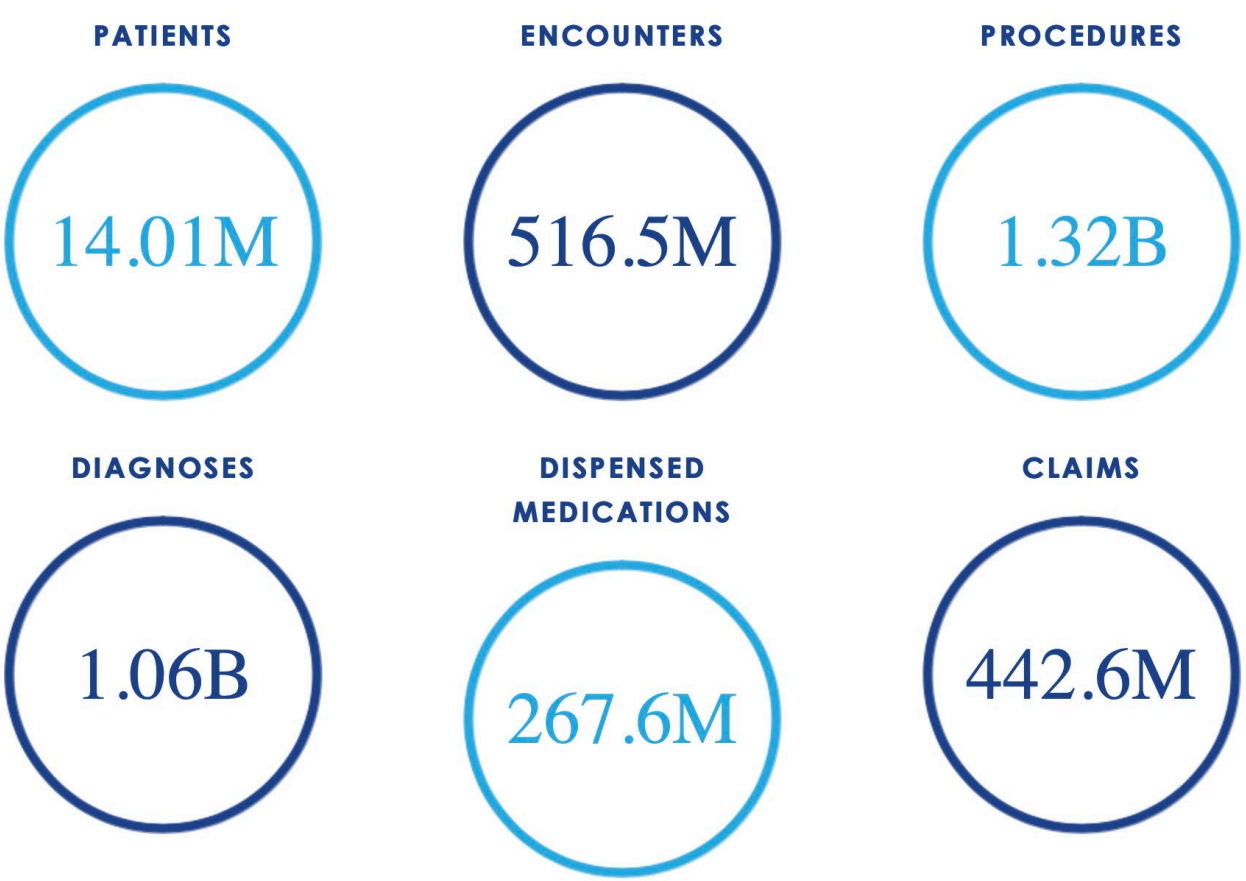
- UNIVERSITY OF FLORIDA AND UF HEALTH
- FLORIDA STATE UNIVERSITY AND THE REGIONAL CAMPUS PRACTICE PARTNERS
- UNIVERSITY OF MIAMI AND UHEALTH
- ORLANDO HEALTH SYSTEM
- ADVENTHEALTH
- TALLAHASSEE MEMORIAL HEALTHCARE
- TAMPA GENERAL HOSPITAL
- BOND COMMUNITY HEALTH CENTER INC.
- NICKLAUS CHILDREN'S HOSPITAL
- COMMUNITYHEALTH IT
- CAPITAL HEALTH PLAN
- UNIVERSITY OF SOUTH FLORIDA AND USF HEALTH



OneFlorida Data Trust

- 4,100 providers
- 1,240 practices
- 22 hospitals
- 50% of Floridians

https://onefloridaconsortium.org


PATIENTS
14.01M
ENCOUNTERS
516.5M
PROCEDURES
1.32B
DIAGNOSES
1.06B
DISPENSED MEDICATIONS
267.6M
CLAIMS
442.6M

1Florida ADRC Bioinformatics and eHealth Core

Aim 1. Data Access

- Provide 1Florida ADRC and other ADRC investigators access to a large statewide repository of linked EMR, claims and social determinants of health (SDoH) data to generate and test hypotheses for ADRD.

Aim 2. Informatic Tools

- Provide 1Florida ADRC and other ADRC investigators with informatics tools that support study feasibility determination, cohort discovery, clinical trials, and population health initiatives in ADRD.

Aim 3. Special Populations

- Facilitate use of the OneFlorida Data Trust as a registry to access existing data and/or collect new data from special populations and their matched controls.

Aim 4. Linkage

- Create linkages with other 1Florida ADRC cores, other ADRCs, and other stakeholder organizations such as the NIA and the Alzheimer's Association.

ADRD Diagnoses Registered in the OneFlorida Data Trust

	MCI	AD	VaD	LBD	FTD	PPA	All*
ICD-10 codes	G31.84 F09	G30.0 G30.1 G30.8 G30.9	F01.50 F01.51	G31.83	G31.09	G31.01	
ICD-9 codes	331.83 249.9	331.0	290.40 290.41	331.82	331.19	331.11	
N	44,068	99,555	31,332	8,968	2,138	512	161,852
Sex							
Male	19,160 (43.5%)	31,227 (31.4%)	12,314 (39.3%)	4,485 (50.0%)	990 (46.3%)	223 (43.6%)	59,096 (36.5%)
Female	24,895 (56.5%)	68,055 (68.4%)	18,999 (60.6%)	4,467 (49.8%)	1,147 (53.6%)	288 (56.3%)	102,441 (63.3%)
Unknown	13 (0.0%)	273 (0.3%)	19 (0.1%)	16 (0.2%)	1 (0.0%)	1 (0.2%)	315 (0.2%)
Race							
White	23,735 (53.9%)	55,458 (55.7%)	16,874 (53.9%)	5,704 (63.6%)	1,392 (65.1%)	347 (67.8%)	89,855 (55.5%)
Black	6,366 (14.4%)	12,367 (12.4%)	6,561 (20.9%)	973 (10.8%)	217 (10.1%)	47 (9.2%)	22,845 (14.1%)
Asian	372 (0.8%)	876 (0.9%)	297 (0.9%)	90 (1.0%)	23 (1.1%)	6 (1.2%)	1,464 (0.9%)
Unknown	6,822 (15.5%)	7,096 (7.1%)	2,007 (6.4%)	439 (4.9%)	183 (8.6%)	41 (8.0%)	14,624 (9.0%)
Ethnicity							
Hispanic	9,492 (21.5%)	25,540 (25.7%)	5,711 (18.2%)	1,974 (22.0%)	371 (17.4%)	77 (15.0%)	36,956 (22.8%)

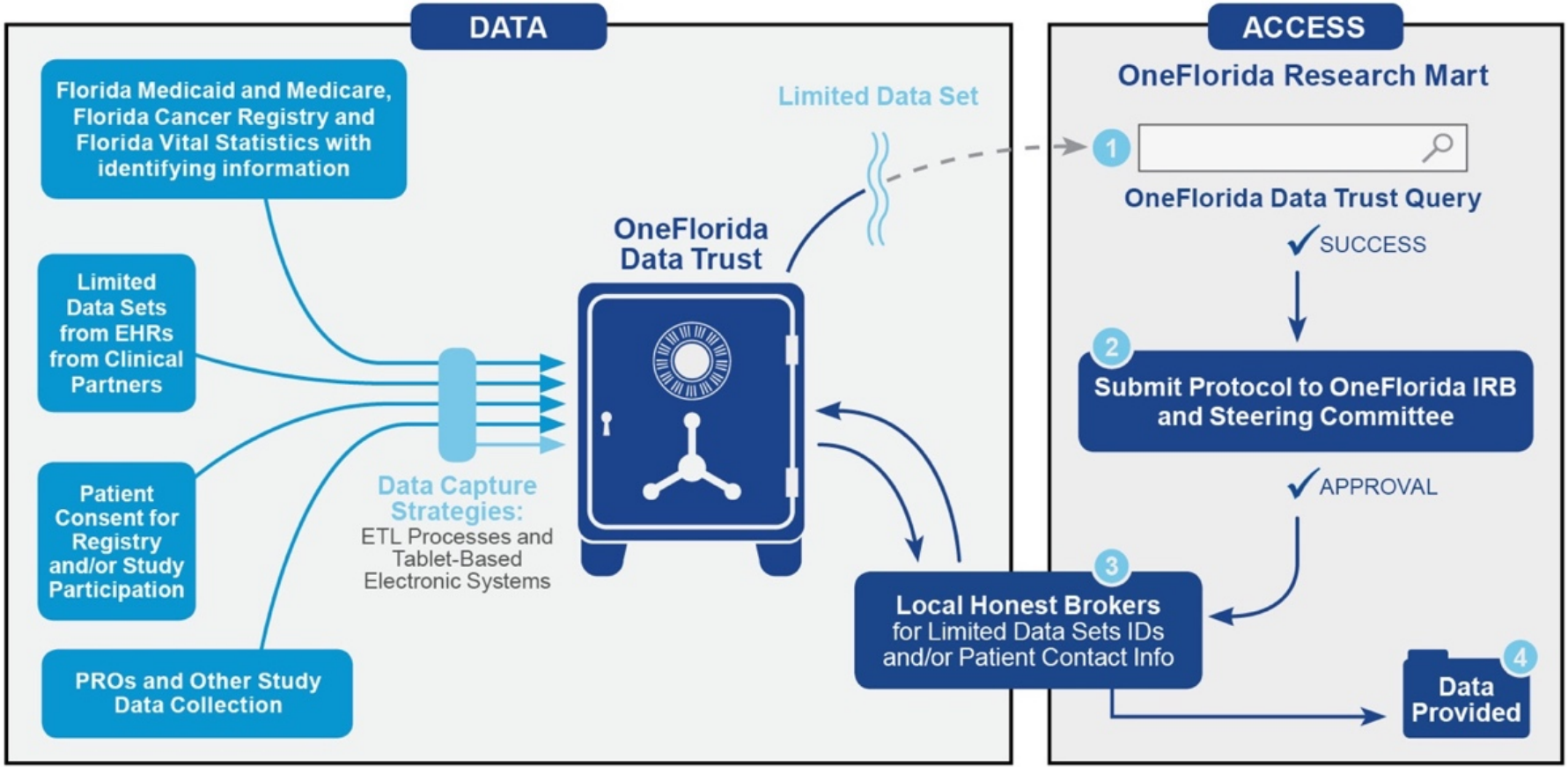
* MCI = Mild Cognitive Impairment, AD = Alzheimer's Disease, VaD = Vascular Dementia, LBD = Lewy Body Dementia, FTD = Frontotemporal Dementia, PPA = Primary Progressive Aphasia, All = All of the Diagnoses Combined

Prevalence rates of AD in communities

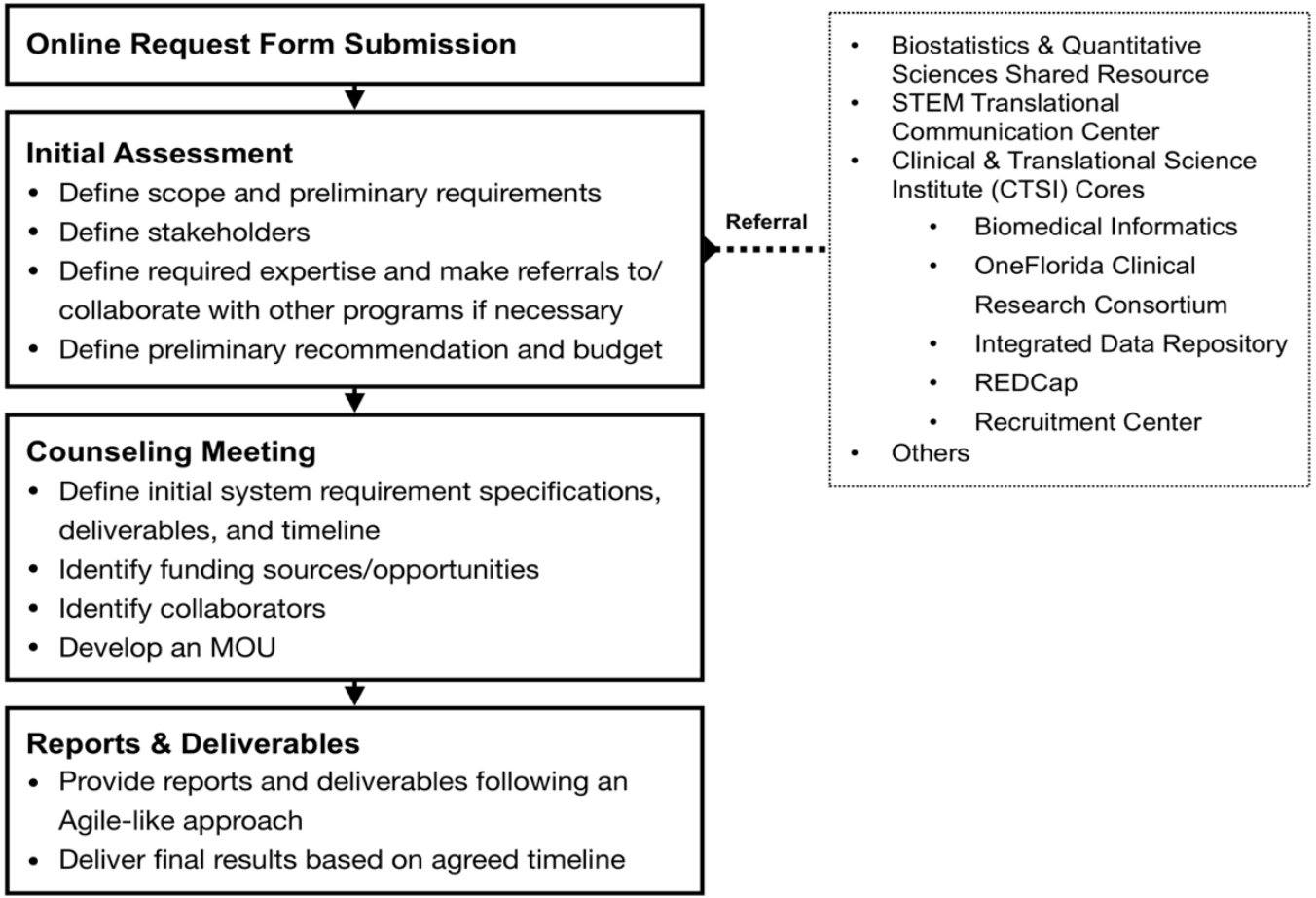
Communities (Ages 65+)	AD Prevalence Rate
Arabs (Israel) [1]	9.8%
Koreans (Republic of Korea) [2]	5.7%
Tuscans (Italy) [3]	4.2%
Floridians (OneFlorida Data Trust)	5.4%

1. Afgin AE, Massarwa M, Schechtman E, Israeli-Korn SD, Strugatsky R, Abuful A, Farrer LA, Friedland RP, Inzelberg R. High prevalence of mild cognitive impairment and Alzheimer's disease in arabic villages in northern Israel: impact of gender and education. J Alzheimers Dis. 2012;29(2):431-9.
2. Kim KW, Park JH, Kim MH, Kim MD, Kim BJ, Kim SK, Kim JL, Moon SW, Bae JN, Woo JI, Ryu SH, Yoon JC, Lee NJ, Lee DY, Lee DW, Lee SB, Lee JJ, Lee JY, Lee CU, Chang SM, Jhoo JH, Cho MJ. A nationwide survey on the prevalence of dementia and mild cognitive impairment in South Korea. J Alzheimers Dis. 2011;23(2):281-91.
3. Tognoni G, Ceravolo R, Nucciarone B, Bianchi F, Dell'Agnello G, Ghicopulos I, Siciliano G, Murri L. From mild cognitive impairment to dementia: a prevalence study in a district of Tuscany, Italy. Acta Neurol Scand. 2005 Aug;112(2):65-71.

OneFlorida Data Trust Infrastructure



Linkages with 1Florida ADRC Cores, Other ADRCs and Stakeholders

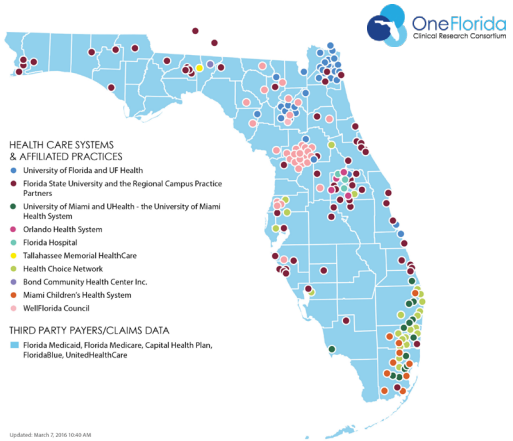


Examples of ADRD Related Applications of Biomedical Informatics & eHealth Core

- Utilizing Data from the EMR to Predict Alzheimer's and Dementia Risk

- Understanding Resistance, Resilience, and Repair in the Health Span (the Over 90 Moonshot)

Utilizing Data from the EMR to Predict Alzheimer's and Dementia Risk



Utilizing Data from the EMR to Predict Alzheimer's and Dementia Risk

Aim 1: Model Building

- Use data captured by the UF EMR to develop an ADRD Prediction Model

Aim 2: Replication

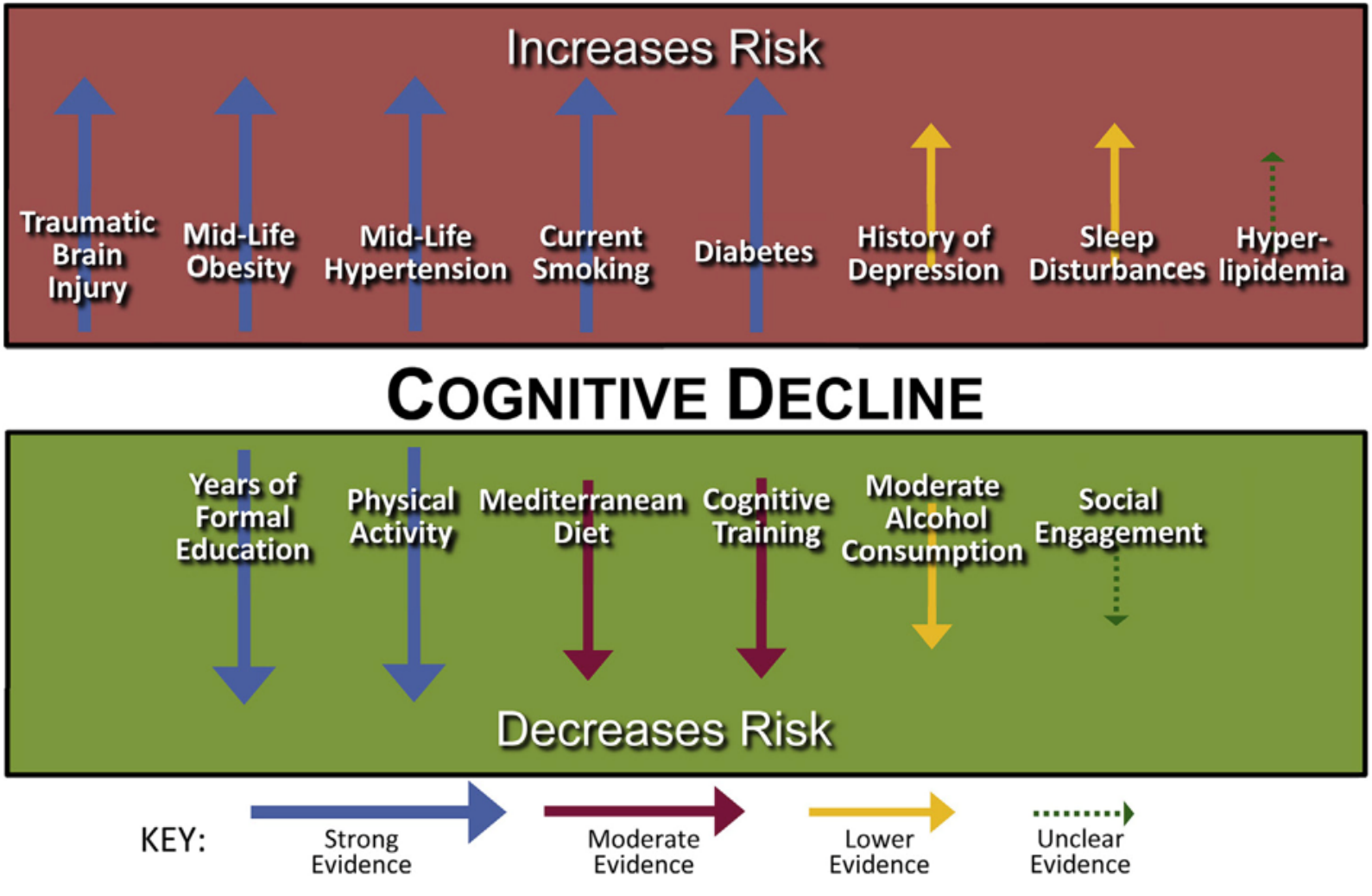
- Replicate the model using the OneFlorida Data Trust registry (http://onefloridaconsortium.org)

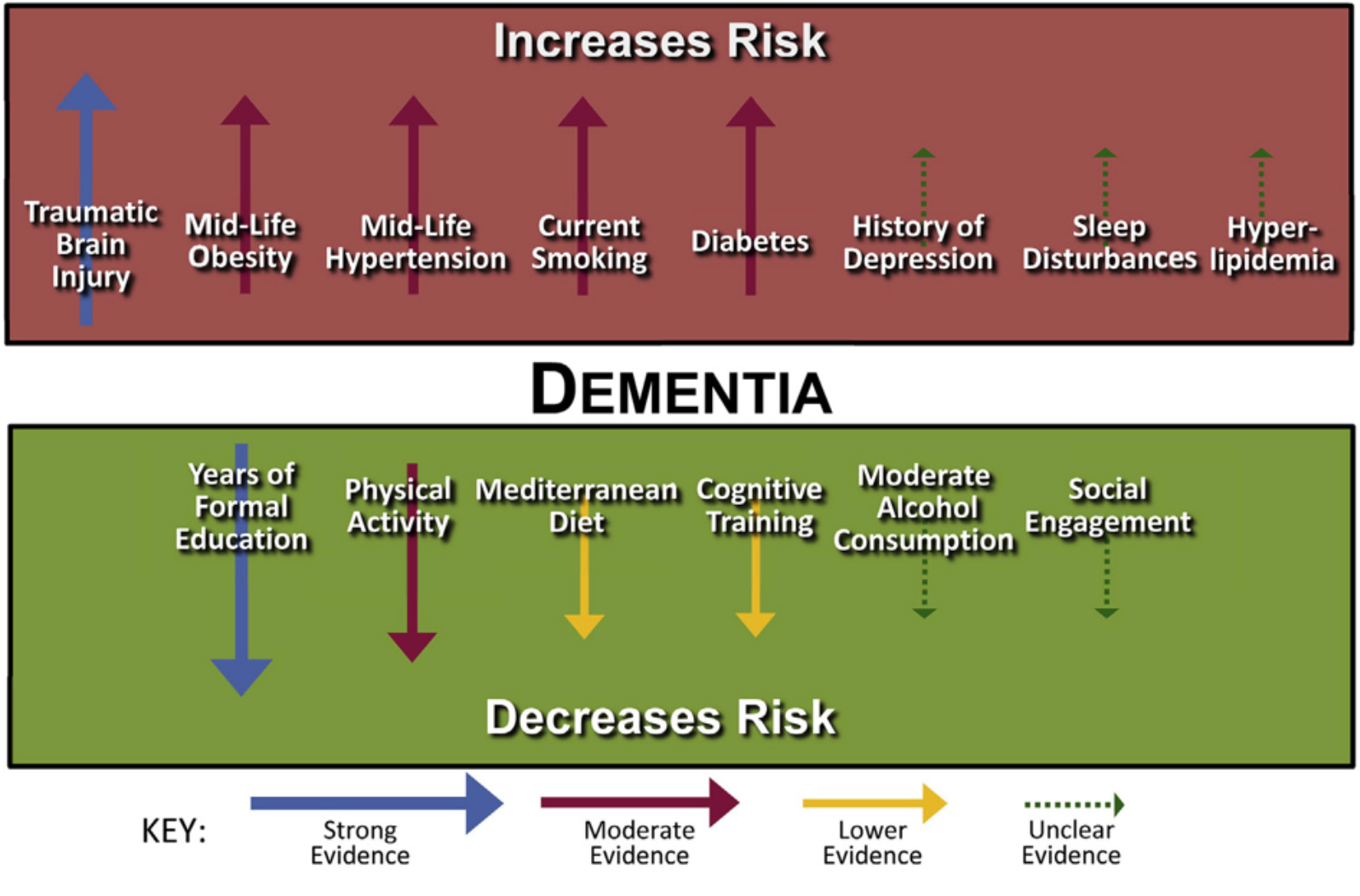
Aim 3: Implementation

- Integrate the replicated model into the UF EMR using clinical decision support tools that identify and refer high risk patient to brain health clinics

Aim 4: Dissemination

- Share the replicated model and tools with other OneFlorida sites


Increases Risk
Traumatic Brain Injury
Mid-Life Obesity
Mid-Life Hypertension
Current Smoking
Diabetes
History of Depression
Sleep Disturbances
Hyper-lipidemia
COGNITIVE DECLINE
Years of Formal Education
Physical Activity
Mediterranean Diet
Cognitive Training
Moderate Alcohol Consumption
Social Engagement
Decreases Risk
KEY:
Strong Evidence
Moderate Evidence
Lower Evidence
Unclear Evidence


Increases Risk
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Mid-Life Obesity
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Hyper-lipidemia
DEMENTIA
Years of Formal Education
Physical Activity
Mediterranean Diet
Cognitive Training
Moderate Alcohol Consumption
Social Engagement
Decreases Risk
KEY:
Strong Evidence
Moderate Evidence
Lower Evidence
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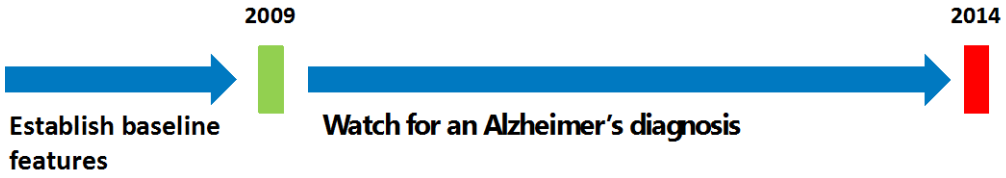
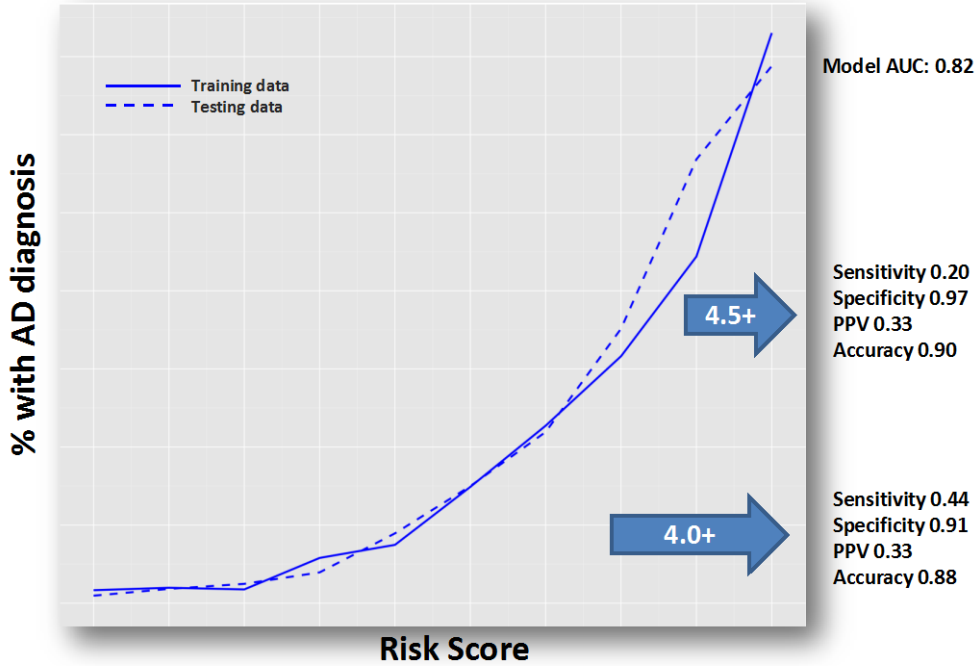
Kitty Hawk Experiment

- NorthShore University HealthSystem (Evanston, IL)
- Can we use the EMR to predict cognitive impairment and dementia (including Alzheimer's)?



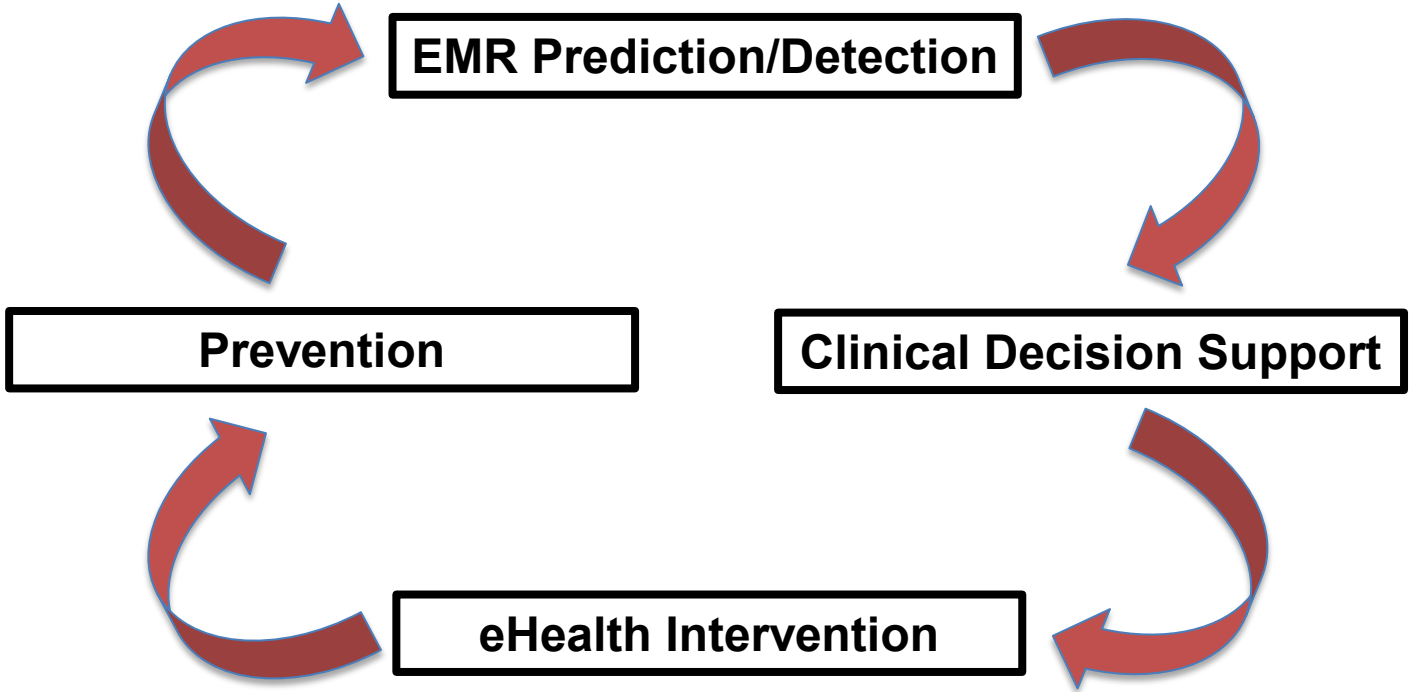
- 29,246 people aged 60+ with a primary visit in 2009
- 62% women
- 82% Caucasian
- 2,193 (7.5%) diagnosed with AD over 5 years



The AD model: under the hood

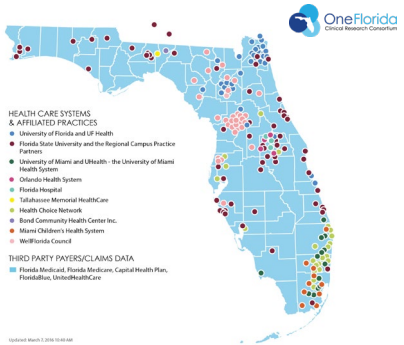
	Parameter Esf mate			Odds Ra*o Es* mate		
Variables	**Coeffic ent**	**95% CI**		**OR**	**95% CI**	
Gender						
Female	Ref	-	-	-	-	-
Male	0.38	0.26	0.50	1.46	1.29	1.64
Family History Alzheimer's	0.51	0.12	0.91	1.67	1.12	2.49
Concussion	0.58	0.36	0.81	1.79	1.43	2.24
Stroke	0.24	0.09	0.39	1.27	1.09	1.48
Diabetes	0.20	0.06	0.34	1.22	1.06	1.41
Sleep Behavior Disorder	2.40	1.21	3.59	11.06	3.37	36.31
Not Alcohol User	0.15	0.03	0.27	1.16	1.04	1.31
Depression	0.78	0.63	0.93	2.18	1.88	2.54
Age						
Agegroups(59,64]	Ref	-	-	-	-	-
Agegroups(64,69]	0.86	0.49	1.24	2.37	1.63	3.46
Agegroups(69,74]	1.84	1.48	2.20	6.27	4.38	8.99
Agegroups(74,79]	2.54	2.19	2.89	12.67	8.93	17.99
Agegroups(79,84]	3.21	2.87	3.56	24.87	17.62	35.10
Agegroups(84,89]	3.60	3.24	3.96	36.64	25.56	52.52
Agegroups(89,109]	4.07	3.68	4.47	58.79	39.59	87.29
BMI						
BMI[30,200)	Ref	-	-	-	-	-
BMI[25,30)	0.13	-0.02	0.28	1.14	0.98	1.32
BMI[18.5,25)	0.43	0.28	0.58	1.54	1.33	1.79
BMI[0,18.5)	0.86	0.43	1.29	2.36	1.53	3.63

eHealth: Prediction and Prevention *in silico*



Closed Loop System

Understanding Resistance, Resilience, and Repair in the Health Span (the Over 90 Moonshot)



Understanding Resistance, Resilience, and Repair in the Health Span (Over 90 Study)

Aim 1: Computable Phenotype

- Identify an informatics-based computable phenotypes that enable identification of individuals over 90 who successfully aged by mining medical & social determinants of health information available within the OneFlorida Data Trust

Aim 2: Recontact

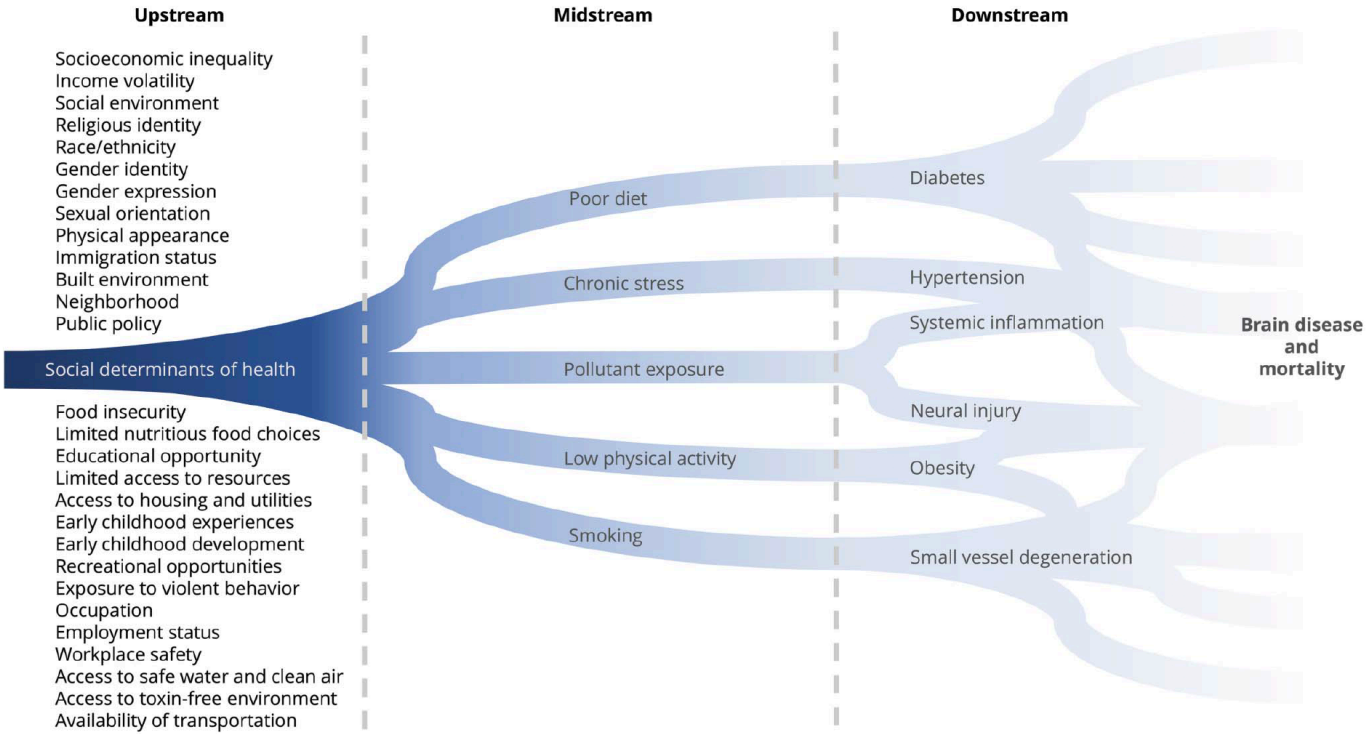
- Directly assess both the resources needed to re-contact individuals over 90 and the participation rate of those contacted

Aim 3: Interventions

- Conduct a pilot study to inform on the feasibility of using computable phenotypes from the OneFlorida Data Trust to identify an over 90 cohort for an intervention aimed at maintaining resilience and independence

Figure Conceptual framework for a population brain health approach that targets fundamental determinants of disease with fundamental interventions

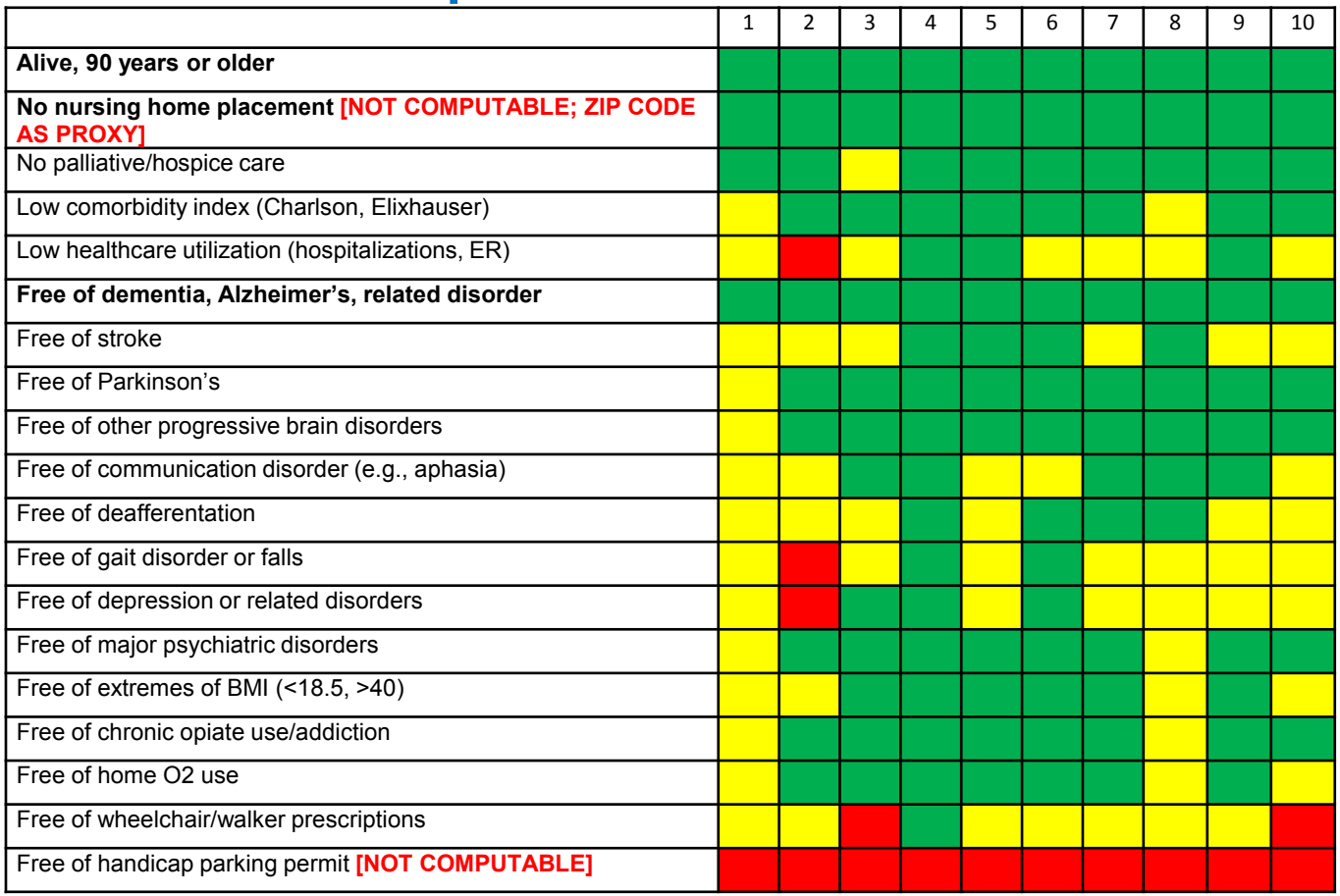
a.k.a. Social Determinants



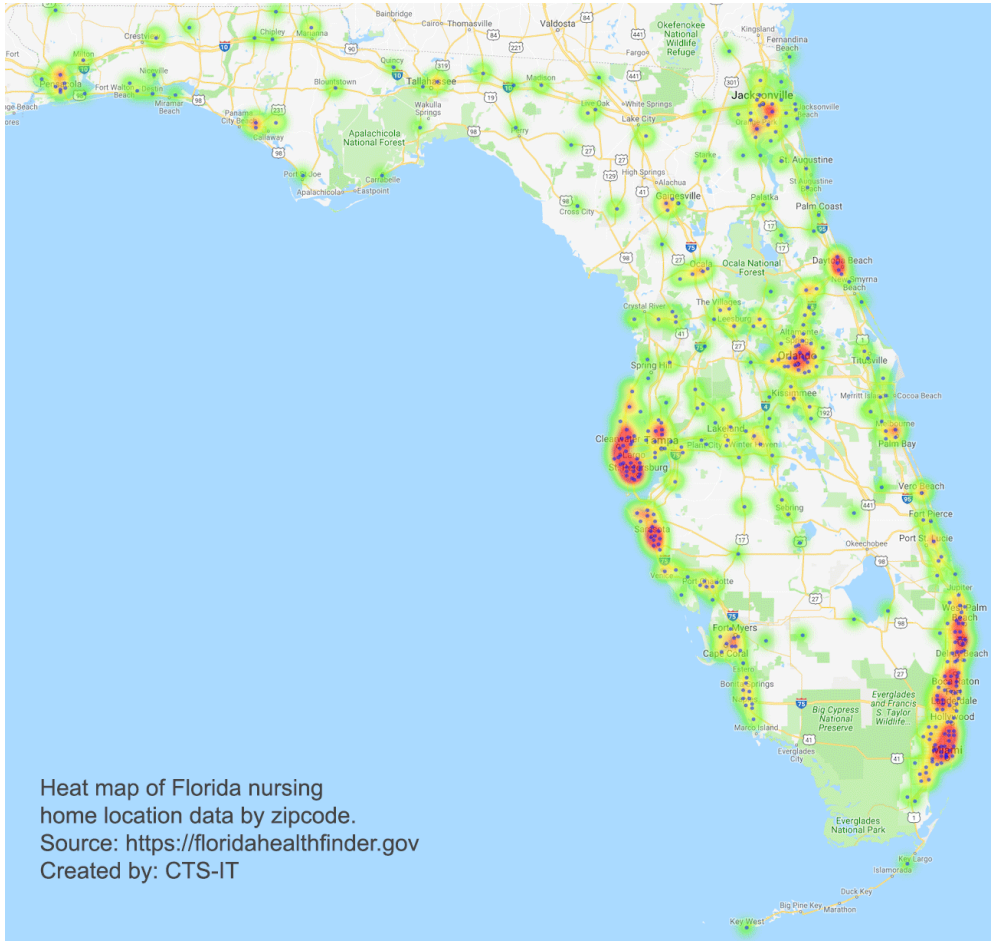
Risk factors for neurologic illness can be grouped by how early they enter the chain of events leading to clinical presentation and determining life expectancy. Downstream factors are immediate to disease and mortality. Midstream factors are intermediate. Upstream factors are fundamental determinants of health and disease—the risks of risks—such as the changing socioeconomic environment that distributes wealth, power, and opportunities. Interventions strategically targeting upstream factors are more likely to be effective at reducing neurologic disease risk compared to downstream or midstream interventions. Adapted from National Collaborating Centre for Determinants of Health (2014). Let's talk: Moving upstream. Antigonish, NS: National Collaborating Centre for Determinants of Health; St. Francis Xavier University. Available at: nccdh.ca/images/uploads/Moving_Upstream_Final_En.pdf. Accessed June 25, 2019.

What is Successful Aging?

And what is computable?



Florida Zip Codes with Nursing Homes



Successful Aging in Florida

Characteristics	Over 90		Over 90 Non-Demented		Over 90 Non-Demented No Nursing Home*		Over 90 Successful Aging (all parameters)	
	N	%	N	%	N	%	N	%
Total	281,927		187,514	66.5%	65,008	23.1%	45,710	16.2%
Demographic								
Sex								
Female	187,092	66.4%	116,405	62.1%	41,097	63.2%	28,276	61.9%
Male	91,511	32.5%	67,831	36.2%	23,618	36.3%	17,158	37.5%
Unknown	3,324	1.2%	3,278	1.7%	293	0.5%	276	0.6%
Race								
White	155,689	55.2%	97,549	52.0%	32,845	50.5%	20,687	45.3%
African American	26,356	9.3%	15,728	8.4%	5,528	8.5%	3,816	8.3%
American Indian	311	0.1%	206	0.1%	64	0.1%	34	0.1%
Asian	2,847	1.0%	1,936	1.0%	775	1.2%	484	1.1%
Pacific Islander	112	0.0%	89	0.0%	44	0.1%	33	0.1%
Multi-race	2,330	0.8%	1,787	1.0%	637	1.0%	433	0.9%
Other	53,420	18.9%	33,676	18.0%	13,747	21.1%	10,515	23.0%
Unknown	40,862	14.5%	36,543	19.5%	11,368	17.5%	9,708	21.2%
Ethnicity								
Hispanic	51,115	18.1%	32,401	17.3%	14,074	21.6%	10,009	21.9%
Non-Hispanic	172,279	61.1%	106,301	56.7%	35,529	54.7%	22,712	49.7%
Unknown	58,533	20.8%	48,812	26.0%	15,405	23.7%	12,989	28.4%

*Zip code as proxy

Long Term Goal: The Fountain of Youth

PONCE DE LEON DISCOVERS THE FOUNTAIN OF FLATTERY

- Whole genome study of Over 90 Floridians who are successfully aged
- Stratify by *APOE* genotype
  - e4/e4 or e4/* versus */*
- What genomic or other factors allow you to age to 90+ free of dementia, despite carrying an Alzheimer risk allele?
- Leverage that knowledge to develop Rx's promoting successful aging

- 12 networks
- 857,000+ providers
- 348 health systems

pcornet®

alzheimer's association®

Genotyping?

NIH National Institute on Aging Designated Alzheimer's Disease Research Center