



**NIA IMPACT**  
**COLLABORATORY**  
TRANSFORMING DEMENTIA CARE

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# Diagnosed Dementia in Medicare

*Benchmarking for Study Planning and Equity*



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# Housekeeping

- All participants will be muted
- Enter **all questions** in the Zoom **Q&A/chat box** and send to Everyone
- Moderator will review questions from chat box and ask them at the end
- Want to continue the discussion? Associated podcast released about 2 weeks after Grand Rounds
- Visit [impactcollaboratory.org](https://www.impactcollaboratory.org)
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# Learning Objectives

Upon completion of this presentation, you should be able to:

Identify strengths & challenges when using Medicare data for participant identification

Understand characteristics of diagnosed dementia cases across place

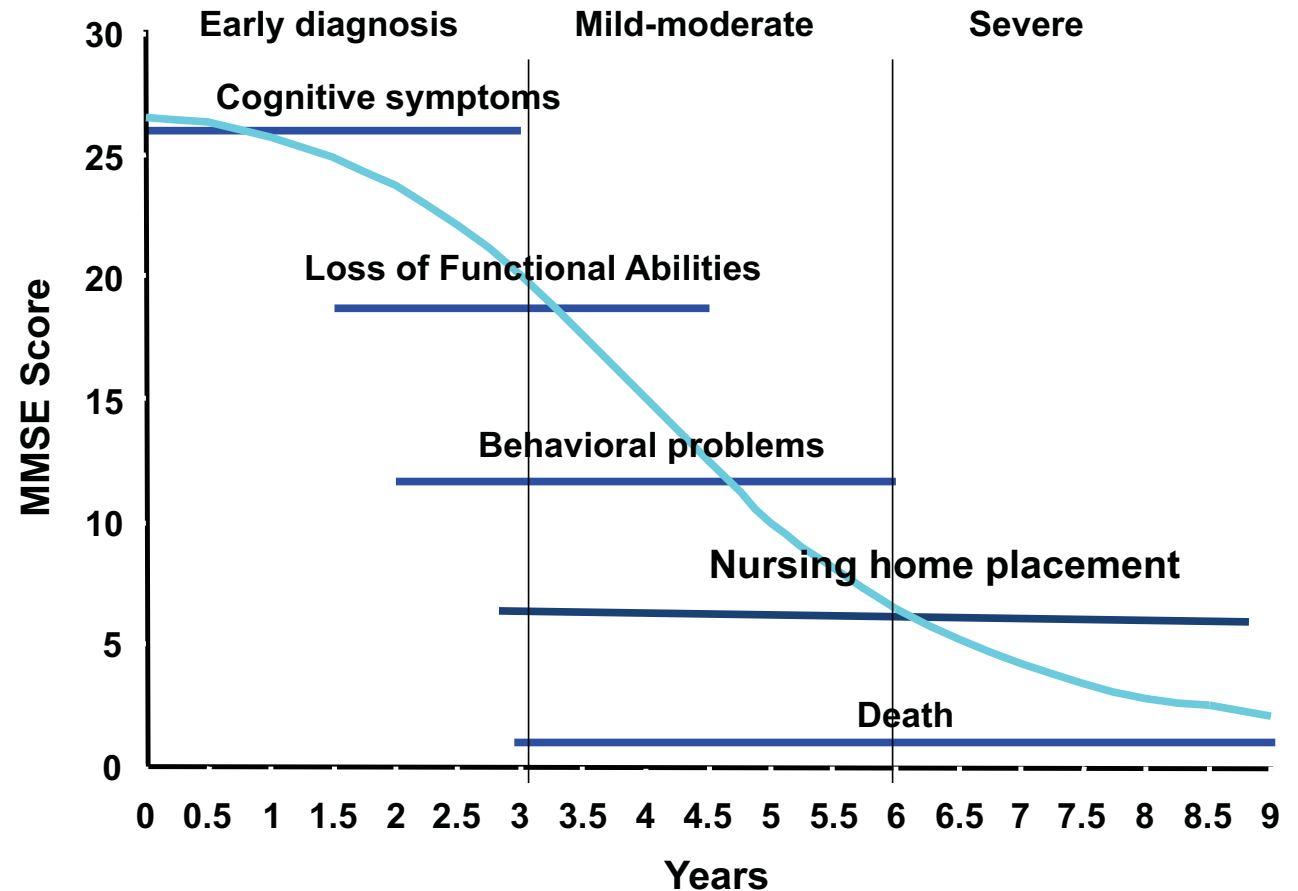
Consider value of using population benchmarks for planning and equity



# Eligibility: *Who is your target population?*

## What is meant by **People Living with dementia?**

*People living with an acquired syndrome of memory loss and other cognitive abilities serious enough to interfere with daily life.*

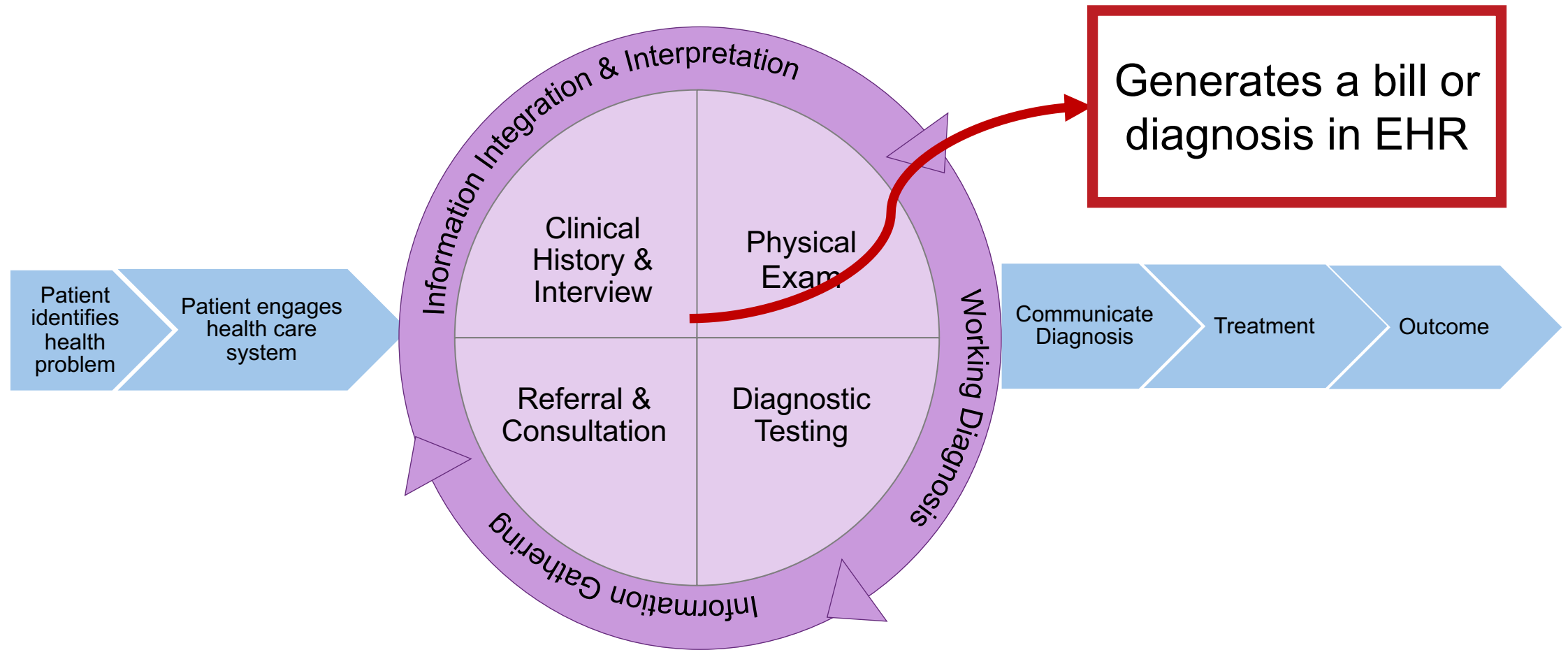


# Healthcare-Generated Data

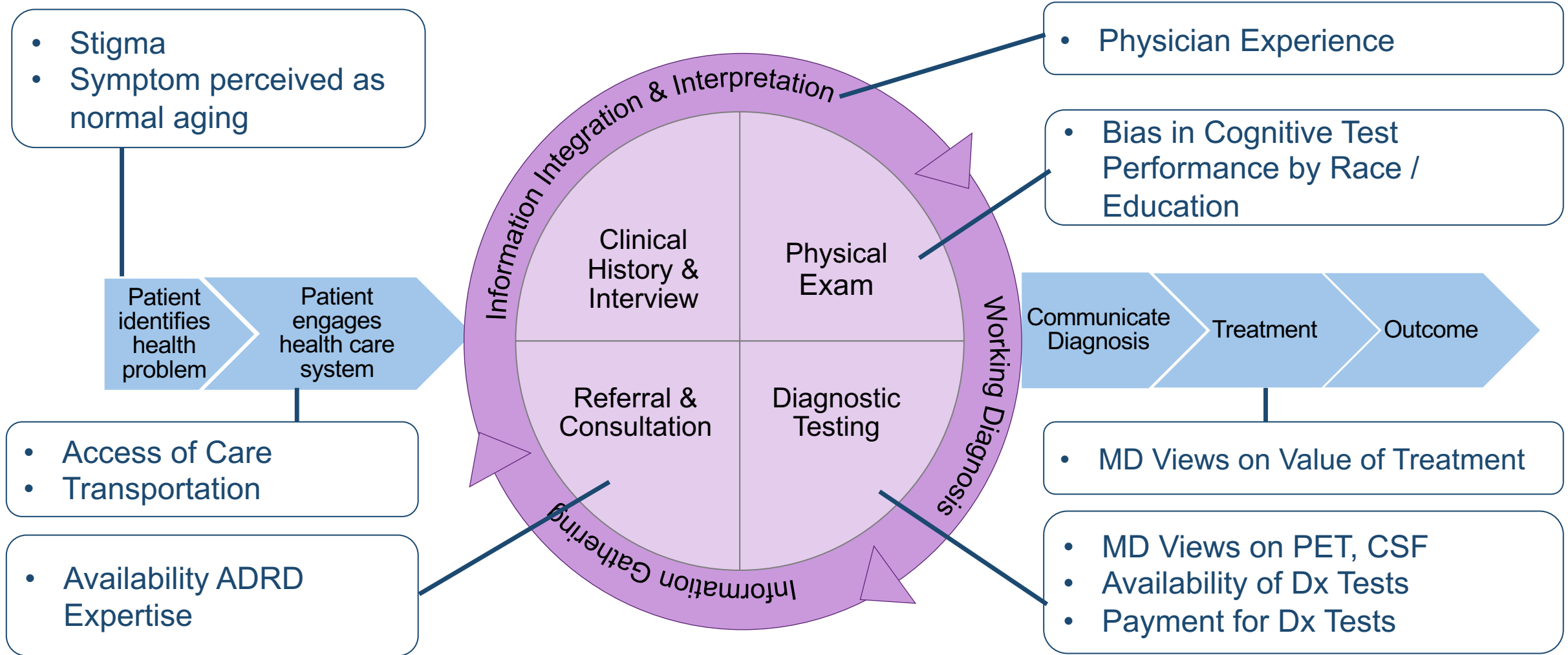
Data collected in the process of health care service delivery for payment or clinical record:

- ✓ Medicare Fee-for-Service (CMS)
- ✓ Medicare Advantage (CMS)
- ✓ Commercial Insurance (OPTUM, Sentinel/DRN, other payers)
- ✓ Medicaid (CMS, state)
- ✓ Minimum Dataset/OASIS (CMS)
- ✓ Electronic Health Record

# Process of Obtaining a Diagnosis

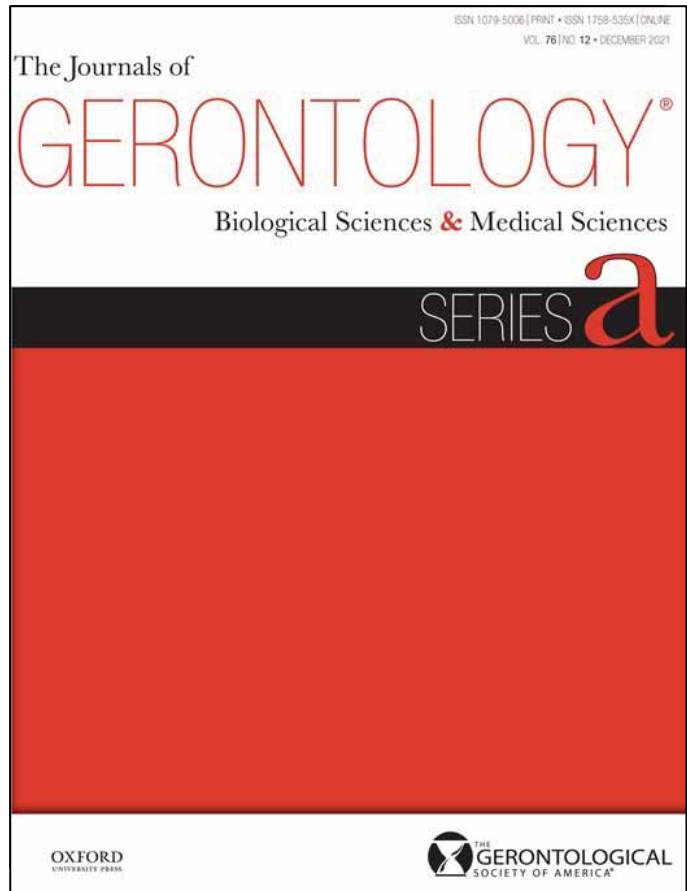


# Many Challenges Obtaining a Diagnosis



# Diagnostic accuracy

## Example of Participants Identified in Medicare Claims



### **Validation of Claims Algorithms to Identify Alzheimer's Disease and Related Dementias**

Ellen P McCarthy, Ph.D., MPH, Chiang-Hua Chang, Ph.D., MS, Nicholas Tilton, Ph.D., Mohammed U Kabeto, MS, Kenneth M Langa, MD, Ph.D, Julie P W Bynum, MD, MPH

*The Journals of Gerontology: Series A*, glab373, <https://doi-org.proxy.lib.umich.edu/10.1093/gerona/glab373>

### **Identification Of Dementia In Recent Medicare Claims Data, Compared To Rigorous Clinical Assessments**

Francine Grodstein, ScD ✉, Chiang-Hua Chang, PhD, Ana W Capuano, PhD, Melinda C Power, ScD, David X Marquez, PhD, Lisa L Barnes, PhD, David A Bennett, MD, Bryan D James, PhD, Julie P W Bynum, MD Author Notes

*The Journals of Gerontology: Series A*, glab377, <https://doi-org.proxy.lib.umich.edu/10.1093/gerona/glab377>



# Claims-based ADRD Diagnostic Accuracy

## Interpretation of results

- Use of 1 year of data with algorithm and 2 claims, standard used for other diseases, performs well. Compared to 3 yrs and 1 claim.
- Sensitivity is the weakness of claims data
- PLWD identified in claims are in later stage disease (20% 1-yr mortality)
- Certain subgroups when flagged with ADRD are more likely to be accurately identified (older, uses a proxy, Black race, more severe disease)
- False positives are not normal cognitively or functionally
- False negatives more likely to be non-White and less functionally impaired.

# Medicare Claims for Participant Identification

## Strengths

- Participants and non-participants included
- Uniform data elements allow use same algorithm across sites with ease
- Uniform data use agreement across all sites if CMS source
- Validated algorithms



## Weaknesses

- Inherent biases and equity issues present in usual care
- Depends on quality of diagnosis in usual care
- Managed care?  
Encounter data not yet validated
- Issues of timeliness are dissipating with VRDC

# Regional Data Created by Technical Data Core

## Methods

- ✓ Age 65+
- ✓ In Medicare Parts A & B (no HMO)
- ✓ Algorithm in:  
McCarthy E.P et al (2022)  
Validation of Claims Algorithms to Identify Alzheimer's Disease and Related Dementias. *J. Gerontol.*
- ✓ Based on zip code of residence



We identify the number of beneficiaries with diagnosed dementia by age, sex, race for each:

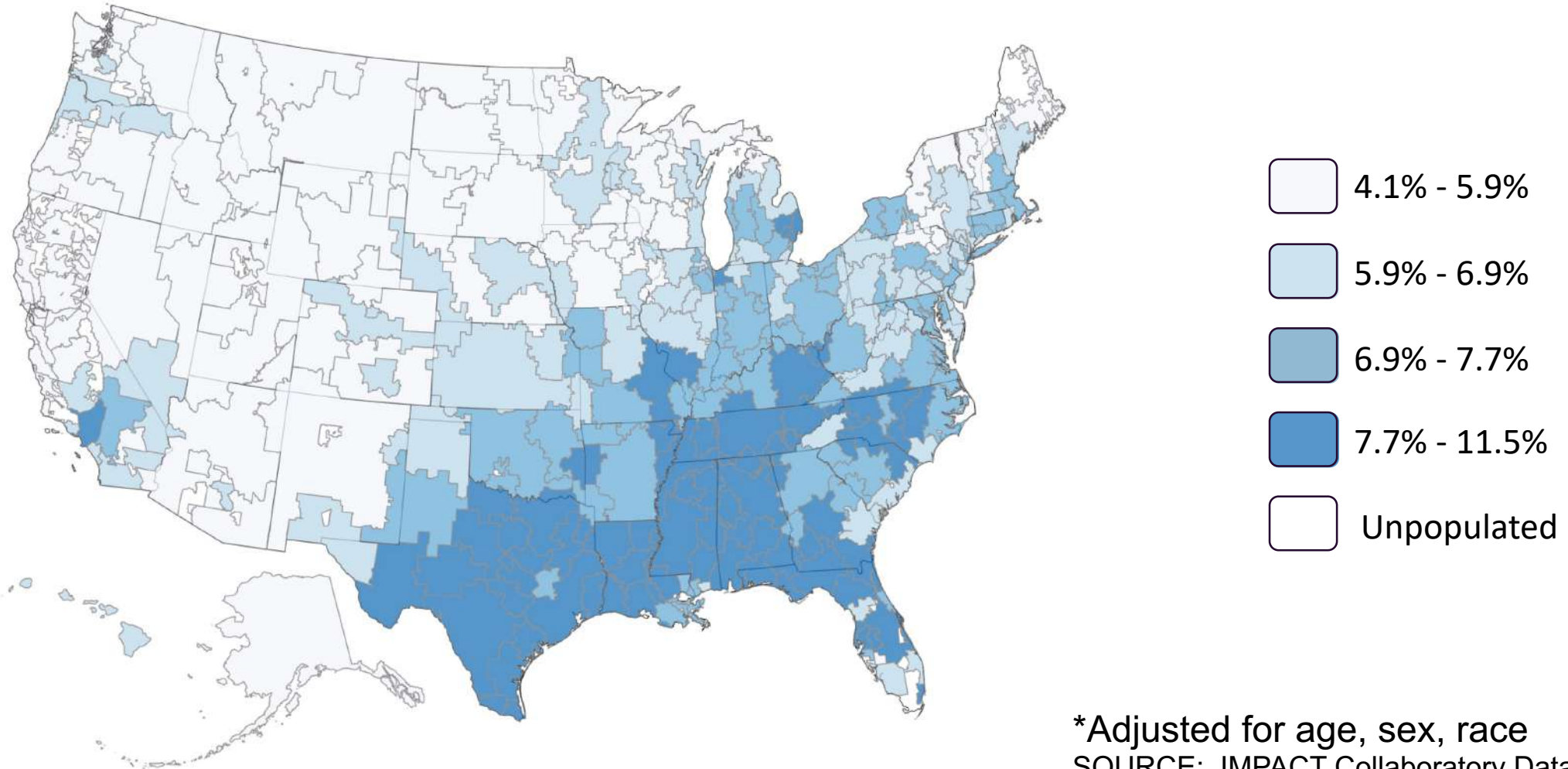
- ✓ State
- ✓ Hospital Referral Region (HRR)
- ✓ Hospital Service Area
- ✓ Primary Care Service Area

**NOTE:** We can query this data for investigators interested in knowing potential sample sizes



# Geographic Differences in Diagnosed ADRD Prevalence

*Adjusted\* Percentage Diagnosed ADRD in FFS Medicare (2019)  
by Hospital Referral Region (HRR)*

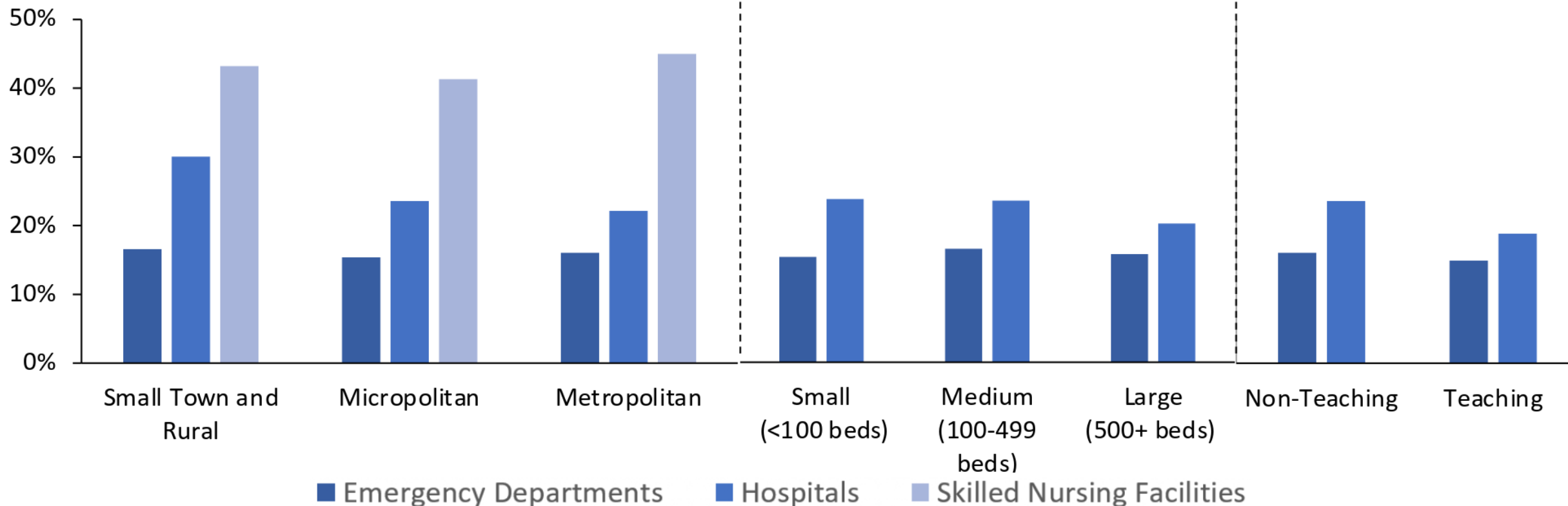


\*Adjusted for age, sex, race  
SOURCE: IMPACT Collaboratory Data Analysis (2024)

# Setting-Specific Data Created by Technical Data Core

## ADRD Distribution across ED, Hospital, SNF:

Mean Percent of Events from ADRD Patients Across Provider-Level Characteristics



# New Data: Interesting facts about the population with ADRD worth considering for study designs

- Differences in ADRD prevalence in epidemiological data vs claims identified diagnosed populations
- Variation in percentage diagnosed ADRD residing in nursing homes
- Geographic distribution of diagnosed ADRD by race/ethnic groups
- Adding Medicare Advantage enrolled
  - Difference between MA & FFS ADRD populations
  - Variation in MA across US
  - Impact of MA on observed racial distribution

Bonus – COVID changes in ADRD population MA & FFS

# Key Features of the Dementia Population at the National Level in Epidemiological Study vs. Medicare Claims

	OVERALL	AGE (Years)						SEX		RACE & ETHNICITY			
		65 -69	70-74	75-79	80-84	85-89	≥ 90	Female	Male	Black	Hispanic	White	Other
HCAP National Estimates (2016)* <b>Dementia % (95% CI)</b>	10% (9-11)	3% (1-4)	4% (2-6)	9% (6-11)	18% (14-22)	26% (20-31)	35% (28-43)	10% (9-11)	10% (8-11)	15% (10-19)	10% (7-13)	11% (10-13)	26% (13-39)
IMPACT Collaboratory 100% FFS Medicare (2019) <b>Dementia %**</b>	6.2%	1.3%	2.5%	5.6%	10.8%	18.1%	27.0%	7.2%	5.1%	8.5%	7.2%	6.1%	4.5%

# What Benchmark to Use for Assessing Representation by Race?

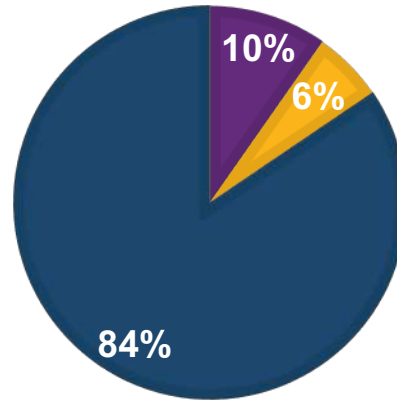
## What percent of people have ADRD within racial/ethnic group?

Black	Hispanic	White
8.5%	7.2%	6.1%

## What percent of people with ADRD in Medicare are in each racial/ethnic group?

DIAGNOSED ADRD FFS 65+ (2019)

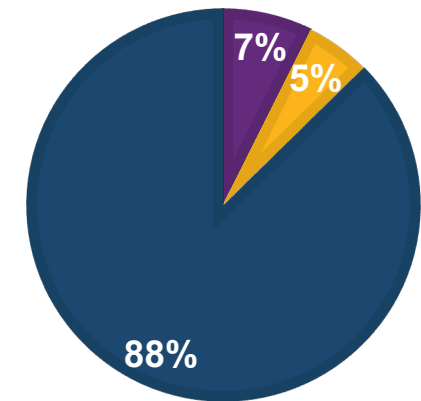
■ Black ■ Hispanic ■ White



## What percent of people in Medicare are in each racial/ethnic group?

ALL FFS MEDICARE 65+ (2019)

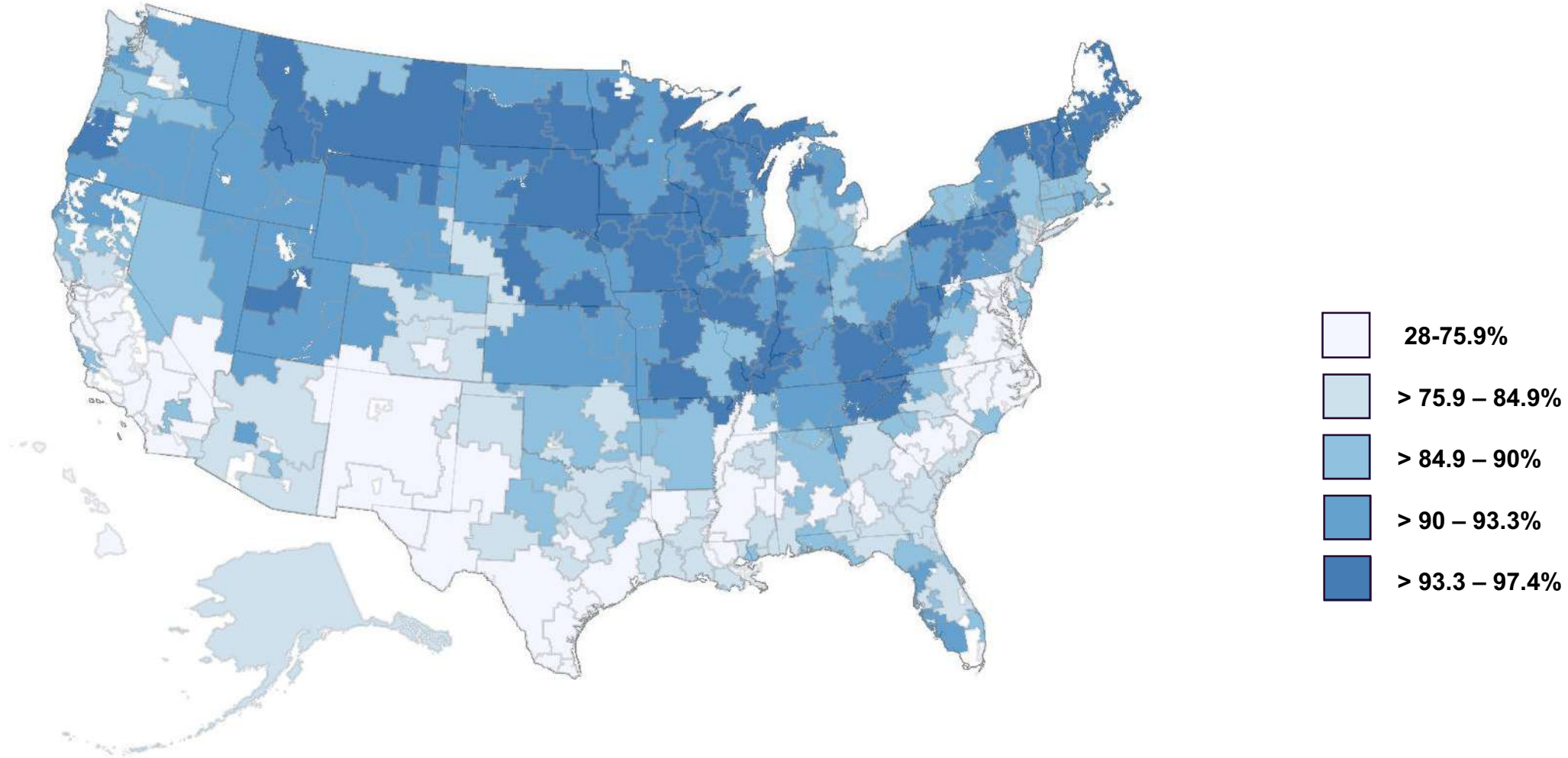
■ Black ■ Hispanic ■ White



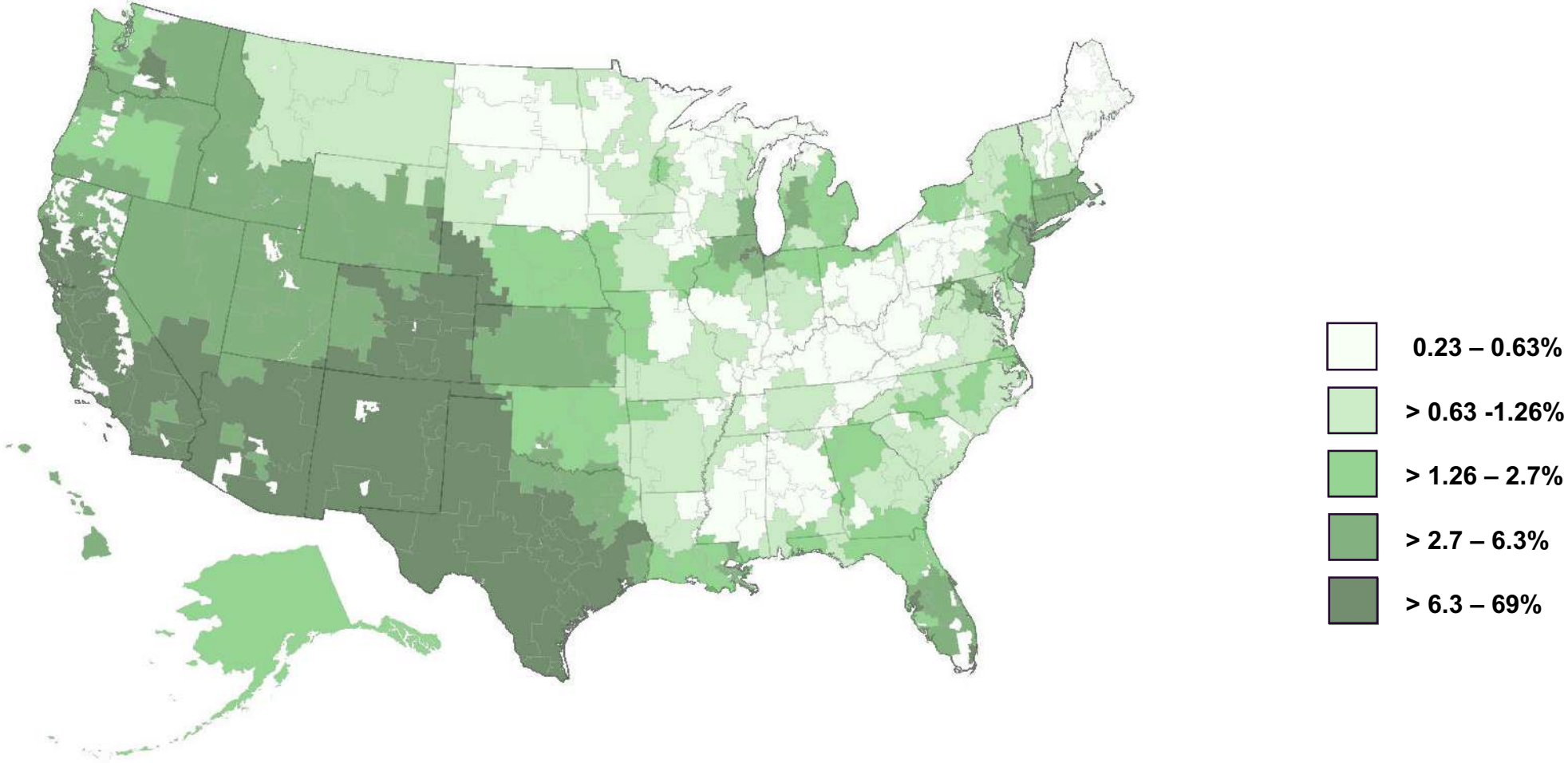
**IMPACT Collaboratory**  
**100% FFS Medicare**  
**(2019)**



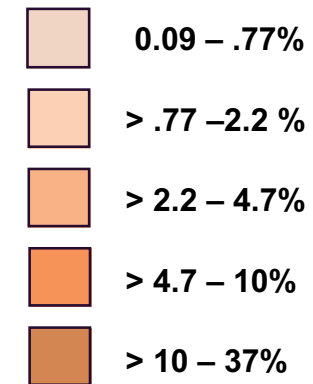
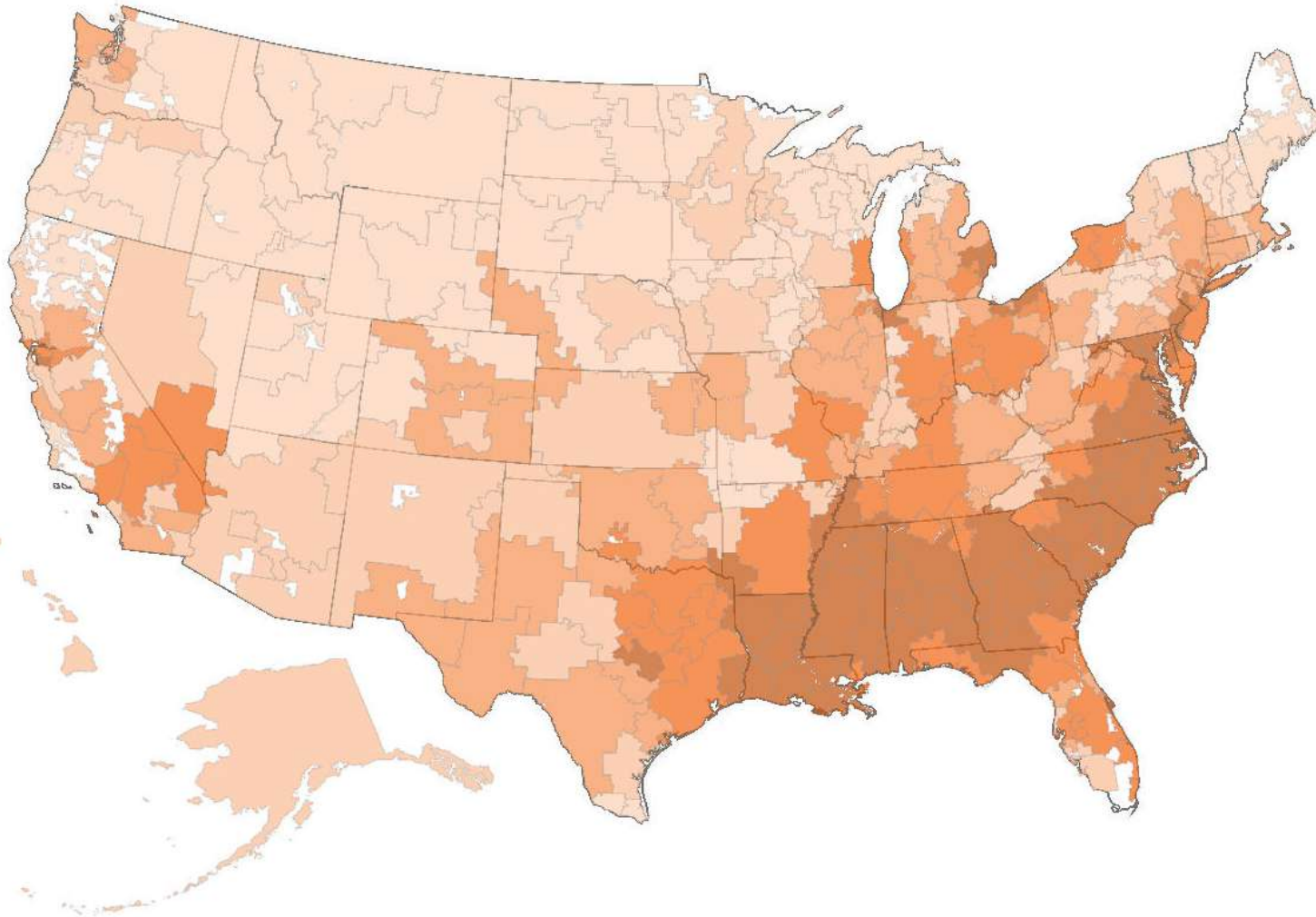
# Percent White FFS Medicare Beneficiaries Age 65+ by HRR (2019)



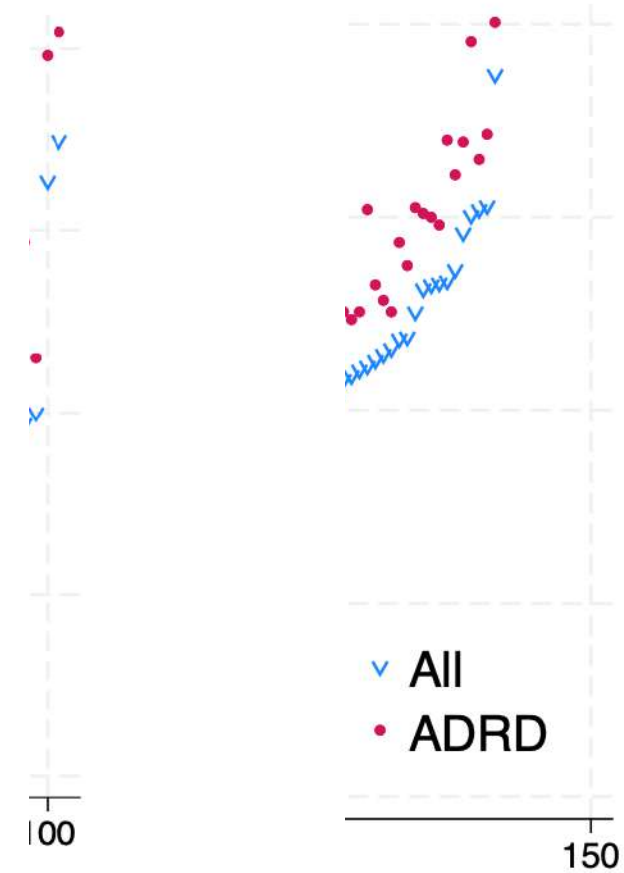
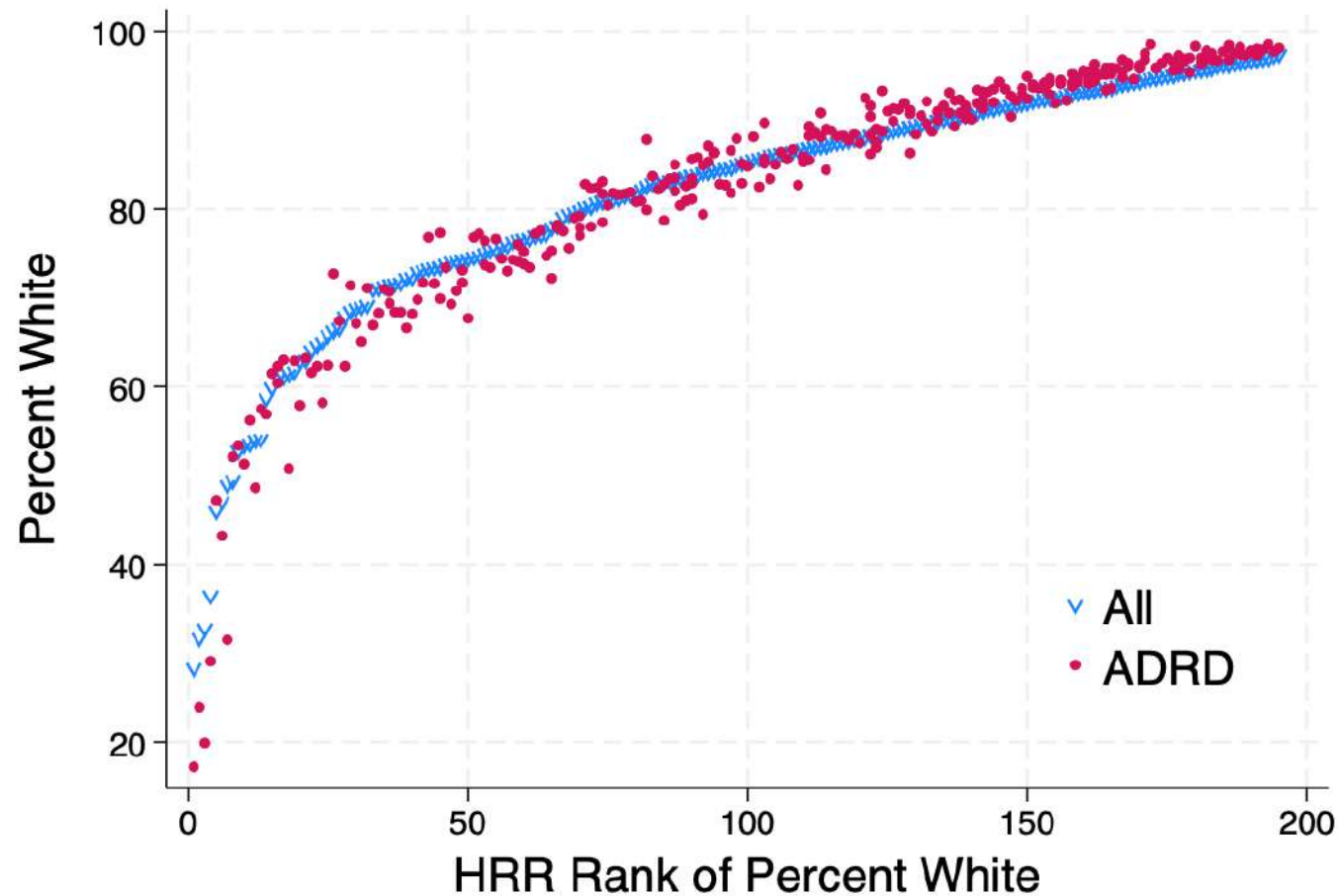
# Percent Hispanic FFS Medicare Beneficiaries Age 65+ by HRR (2019)



# Percent Black FFS Medicare Beneficiaries Age 65+ by HRR (2019)



# Percent by Race for All FFS Medicare compared ADRD



## What Benchmark to Use for Assessing Long Term Nursing Home Residence?

### From Perspective of Nursing home

- 42% of nursing home residents have ADRD-CI<sup>1</sup>
- 70% of nursing home residents aged  $\geq 70$  have dementia.<sup>2</sup>

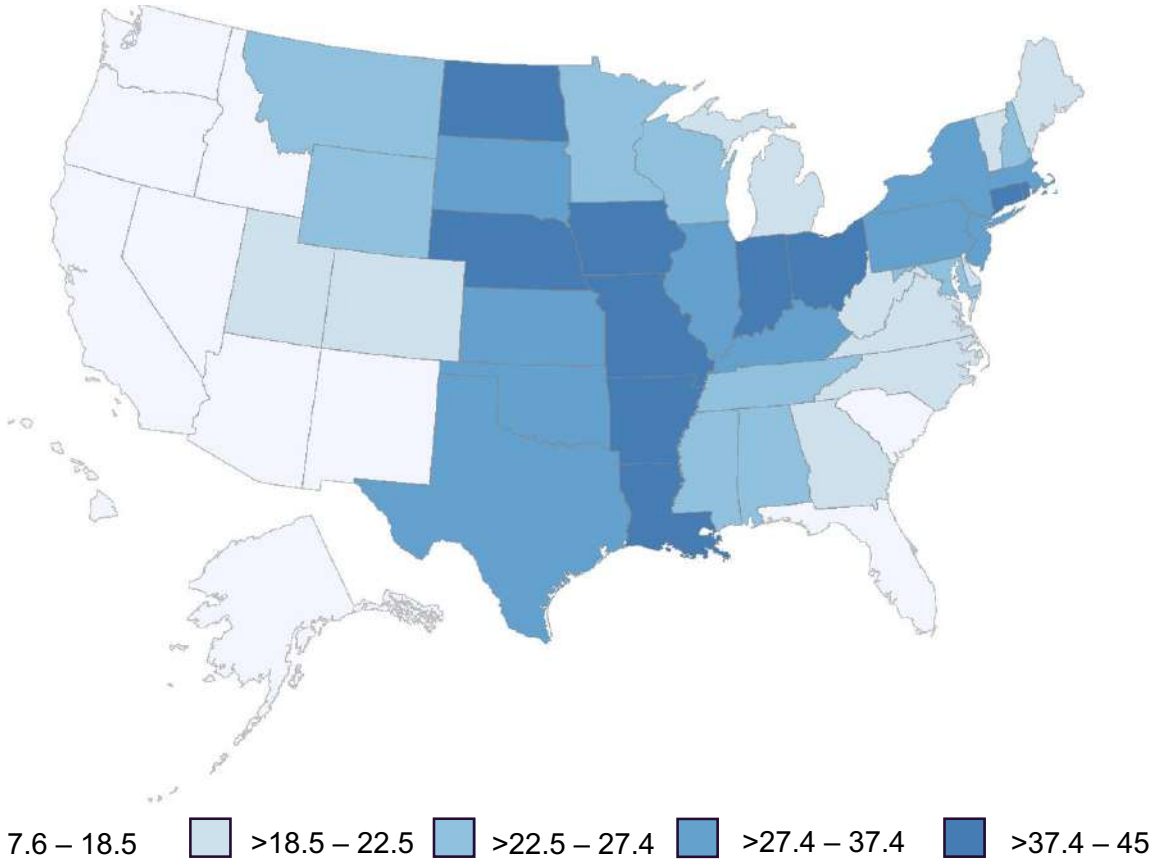
### From Perspective of Population

(using the HRS Nationally representative sample, 2012)<sup>3</sup>

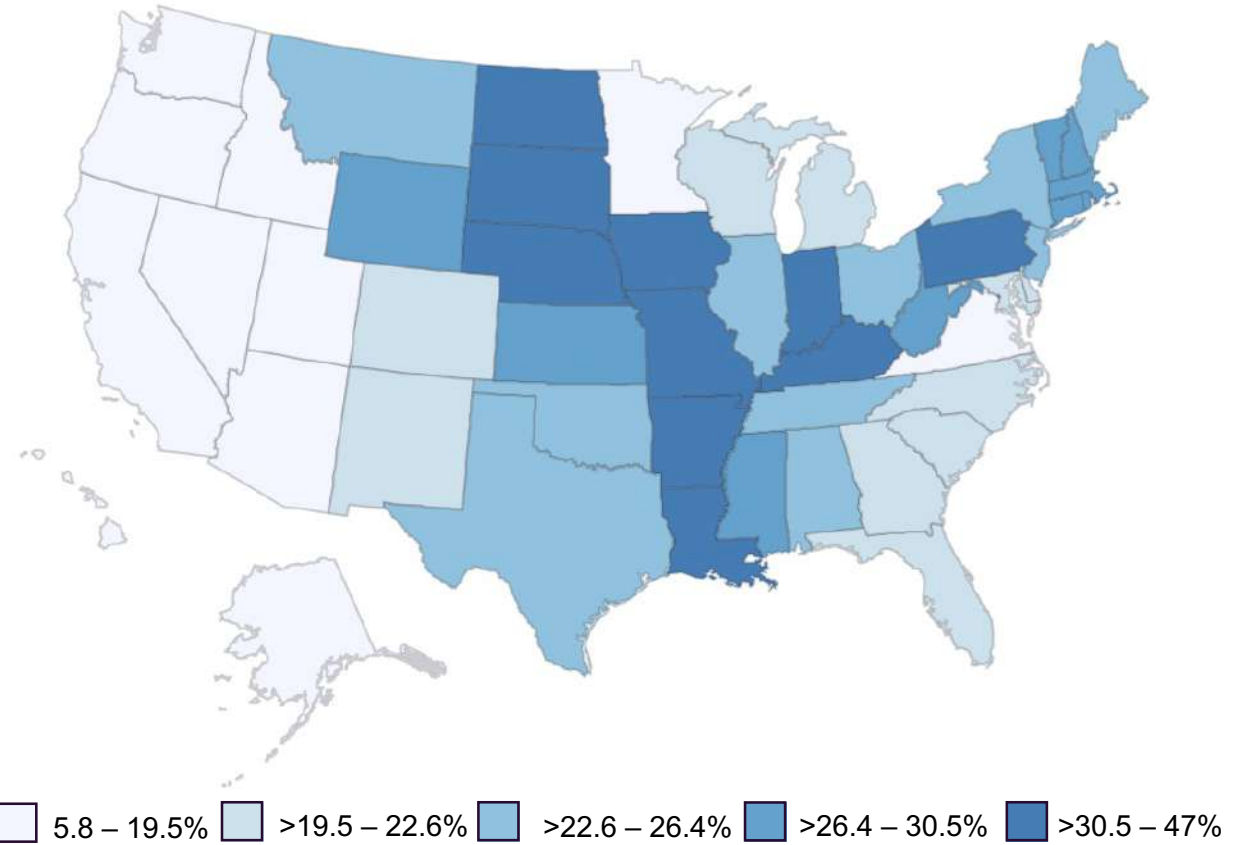
- Participants with identified with Dementia\*:
  - 21% reside in NH or other health care facility

# Nationally 24% Diagnosed ADRD Cases age 65+ in FFS Reside in Nursing Homes (2019)

## Certified NH Beds per 1000 Medicare FFS Enrollees (2019)

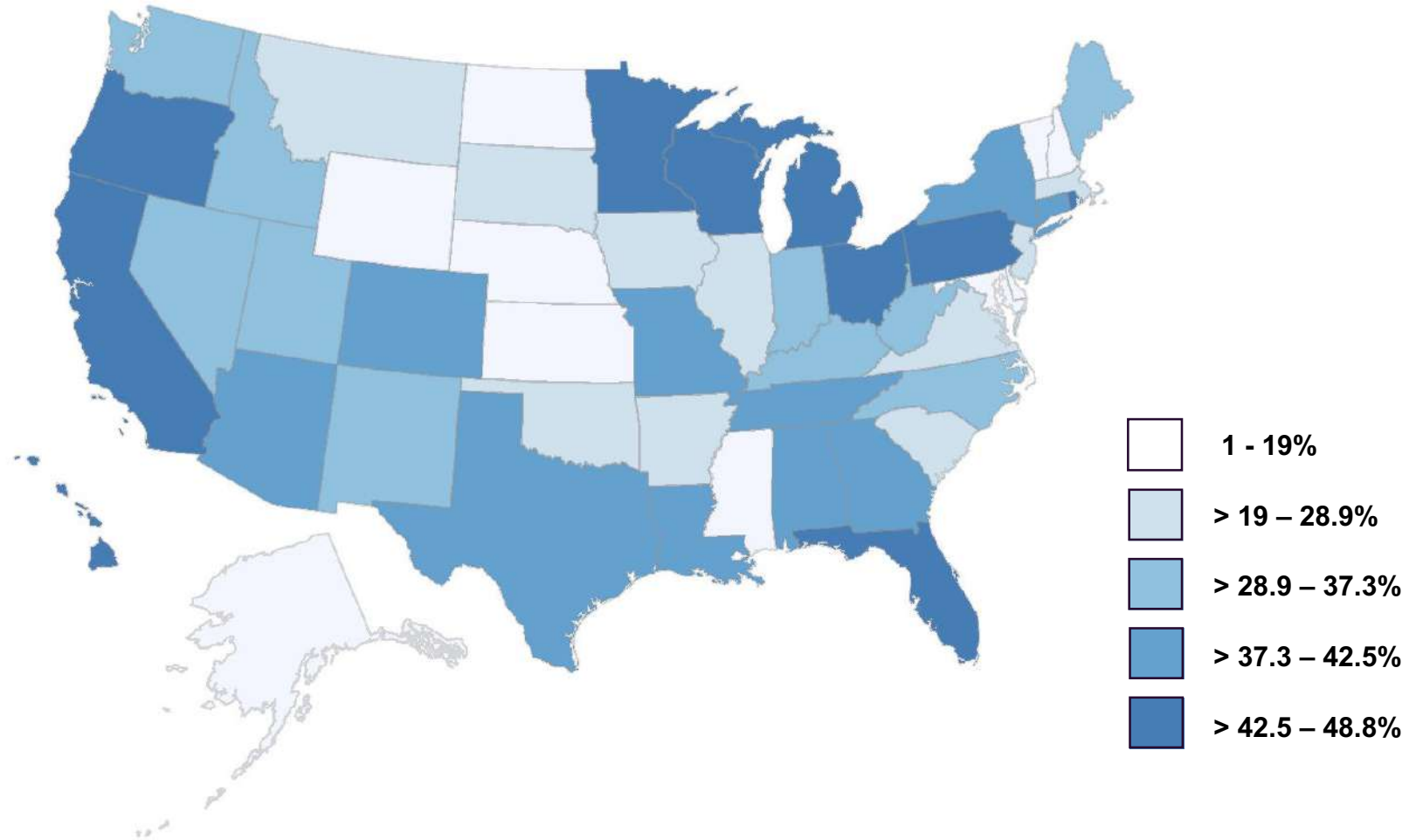


## Percent Diagnosed ADRD in Long-stay Nursing Home (2019)



# What Benchmark to Use for in Medicare Advantage vs Fee-for-Service?

## Percent of Medicare Beneficiaries aged 65+ Enrolled in MA by State (2019)



	Medicare Population 65+ (2019)
	All
FFS	52.7%
MA	36.7%
Partial Yr	10.6%

# What Benchmark to Use for in Medicare Advantage vs Fee-for-Service?

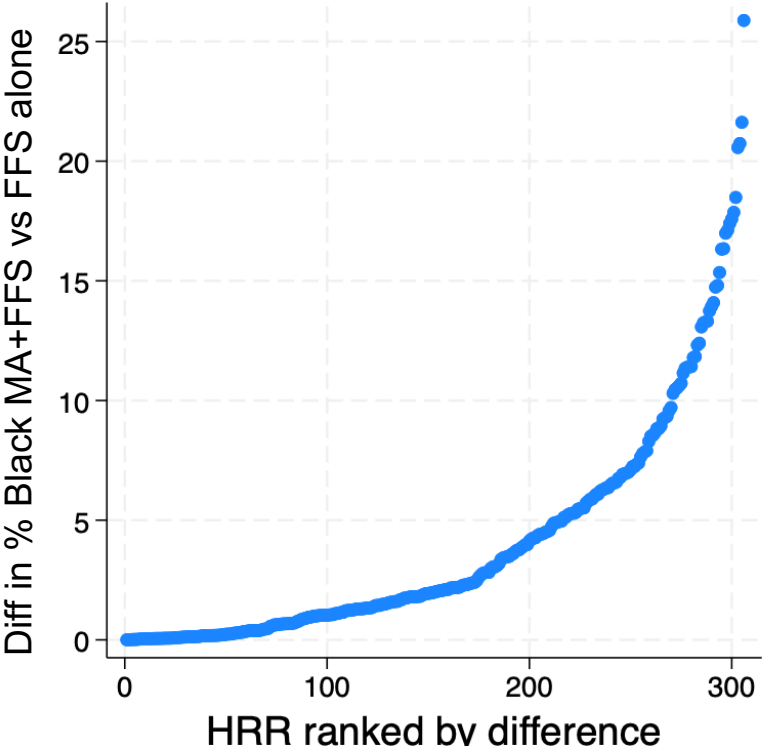
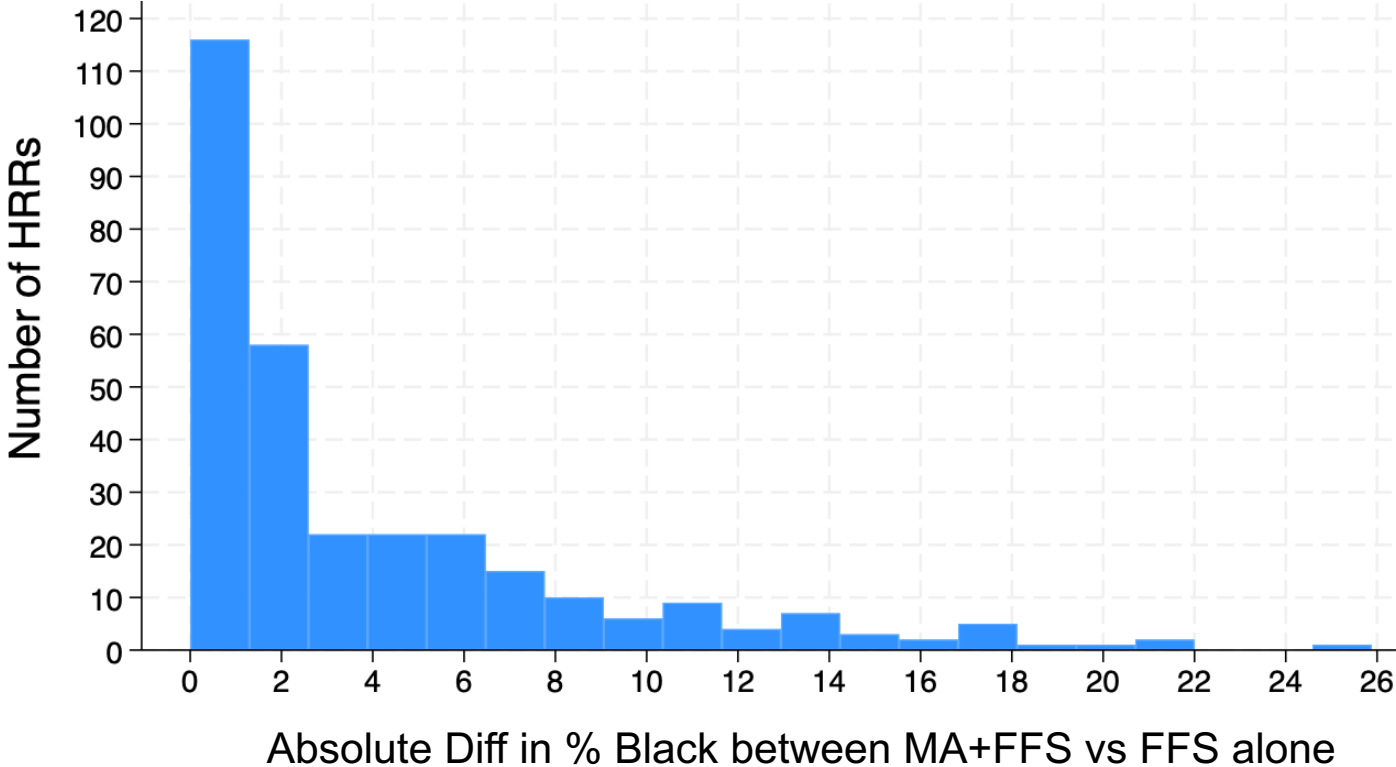
	Medicare Population 65+ (2019)	
	All	Diagnosed ADRD
FFS	52.7%	59.7%
MA	36.7%	35.7%
Part	10.6%	5.0%

	Medicare Population 65+ (2019)			
	All		Diagnosed ADRD	
	FFS	MA	FFS	MA
AGE				
65-74	56%	57%	16%	18%
75 - 84	31%	32%	38%	42%
85 +	13%	11%	46%	40%
SEX				
Female	56%	57%	64%	64%
Male	44%	43%	36%	36%
RACE				
Black	7%	11%	9%	13%
Hispanic	5%	11%	6%	11%
White	82%	71%	81%	71%
Other	6%	7%	4%	5%
DUAL ELIGIBILITY				
	9%	10%	34%	31%



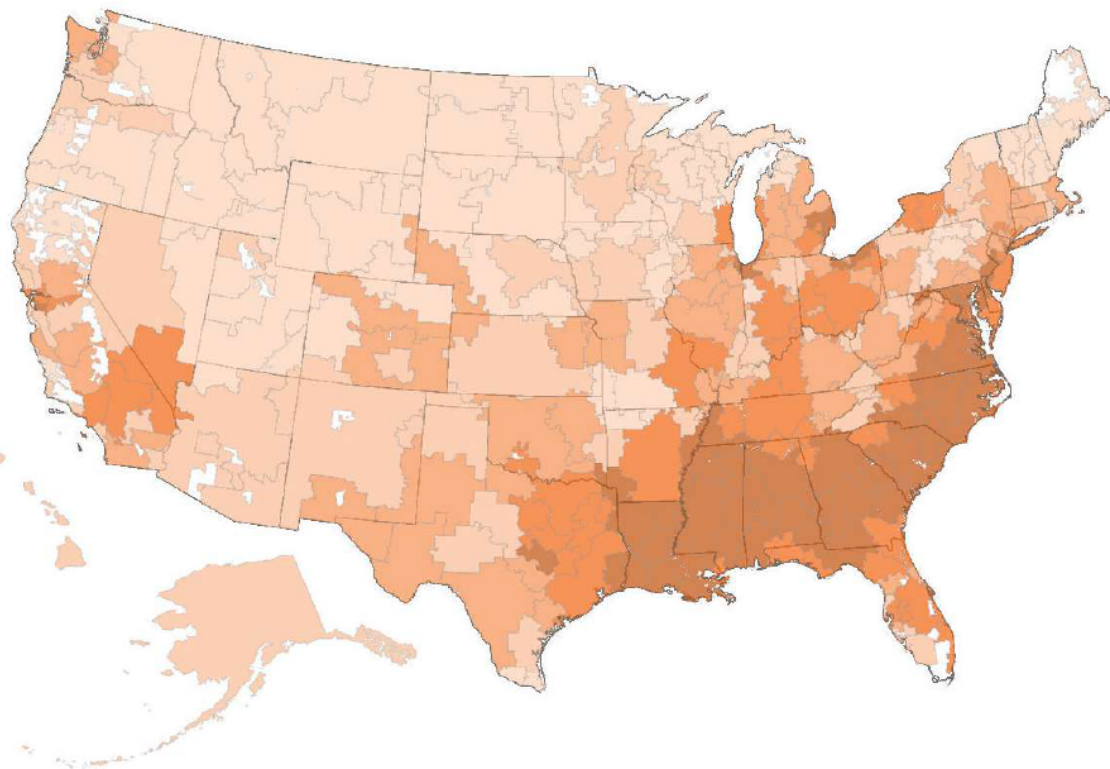
# Impact of MA on Racial Distribution across U.S. in Medicare

## Difference in % Black between using All Medicare (FFS + MA) vs FFS alone



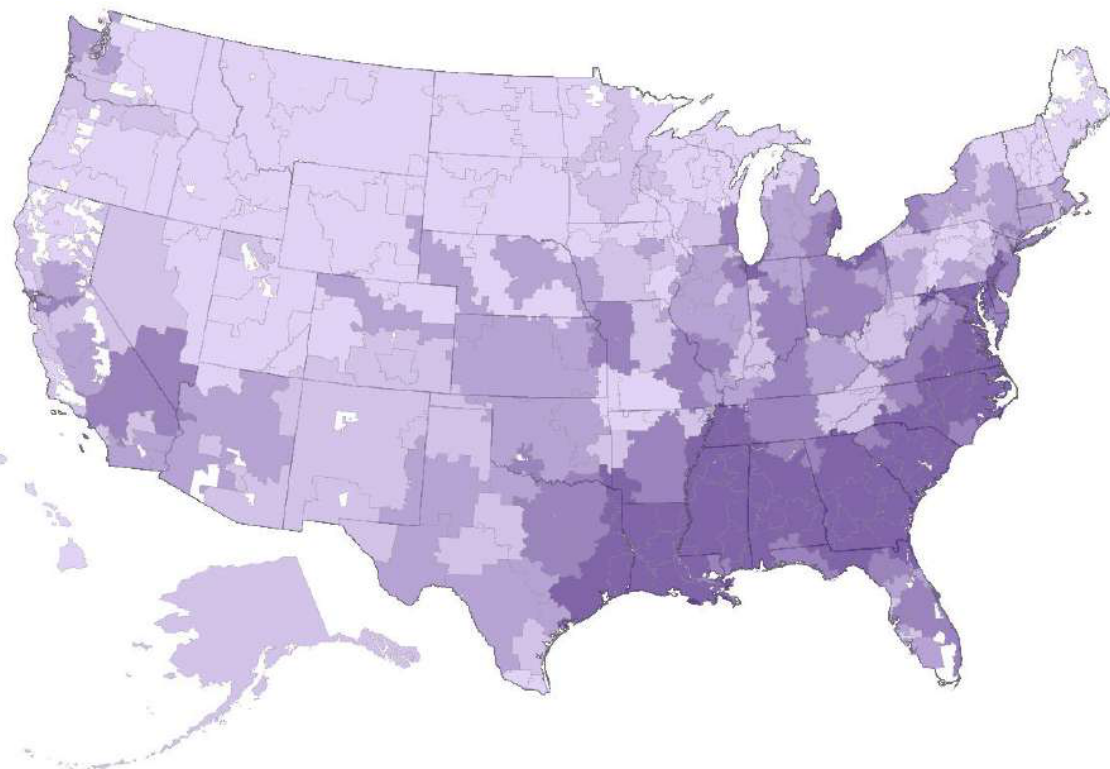
# Percent Black FFS AND Black FFS & MA Medicare Beneficiaries by HRRs (2019)

## Black FFS Medicare Beneficiaries (2019)



0.09–0.77%   >0.77–2.2%   >2.2–4.7%   >4.7–10%   > 10–37%

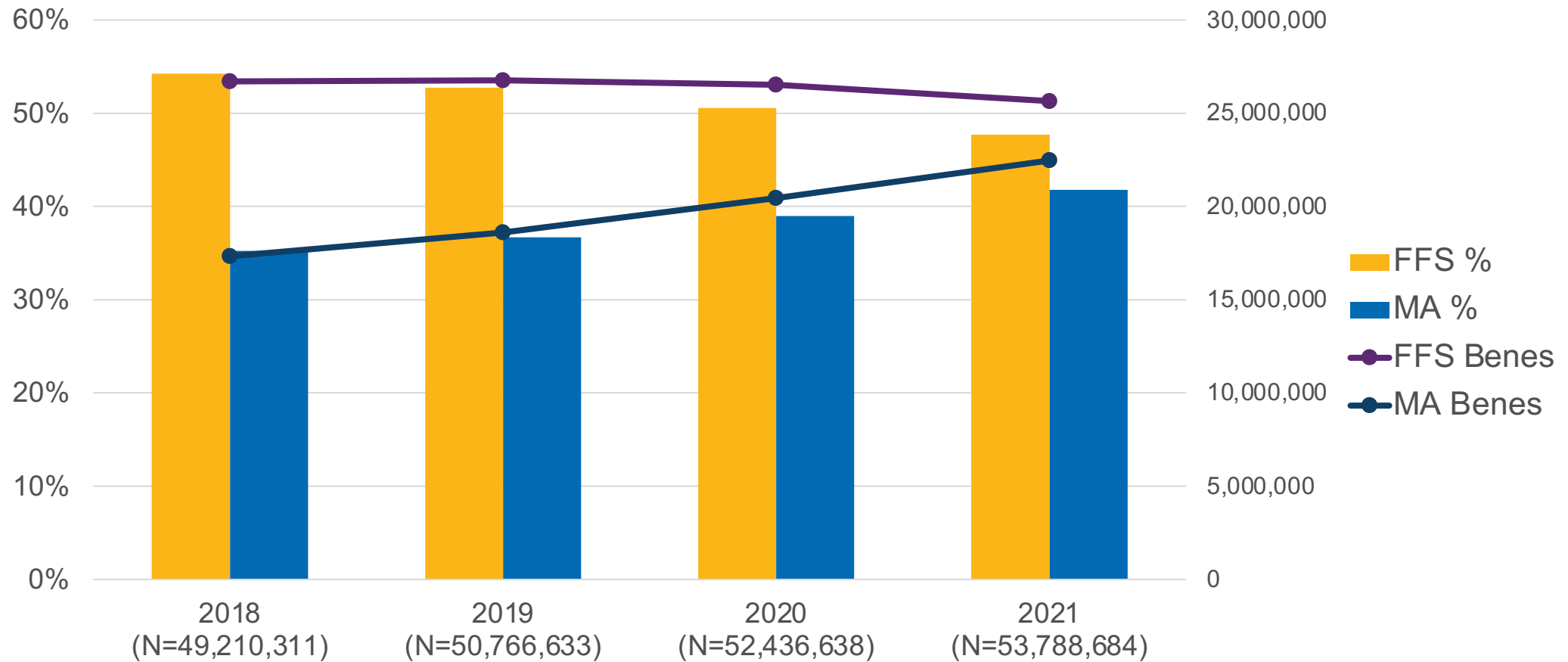
## Black FFS Medicare & MA Beneficiaries (2019)



0.09–0.85%   >0.85–2.7%   >2.7–5.6%   >5.6–12.8%   > 12.8–42%

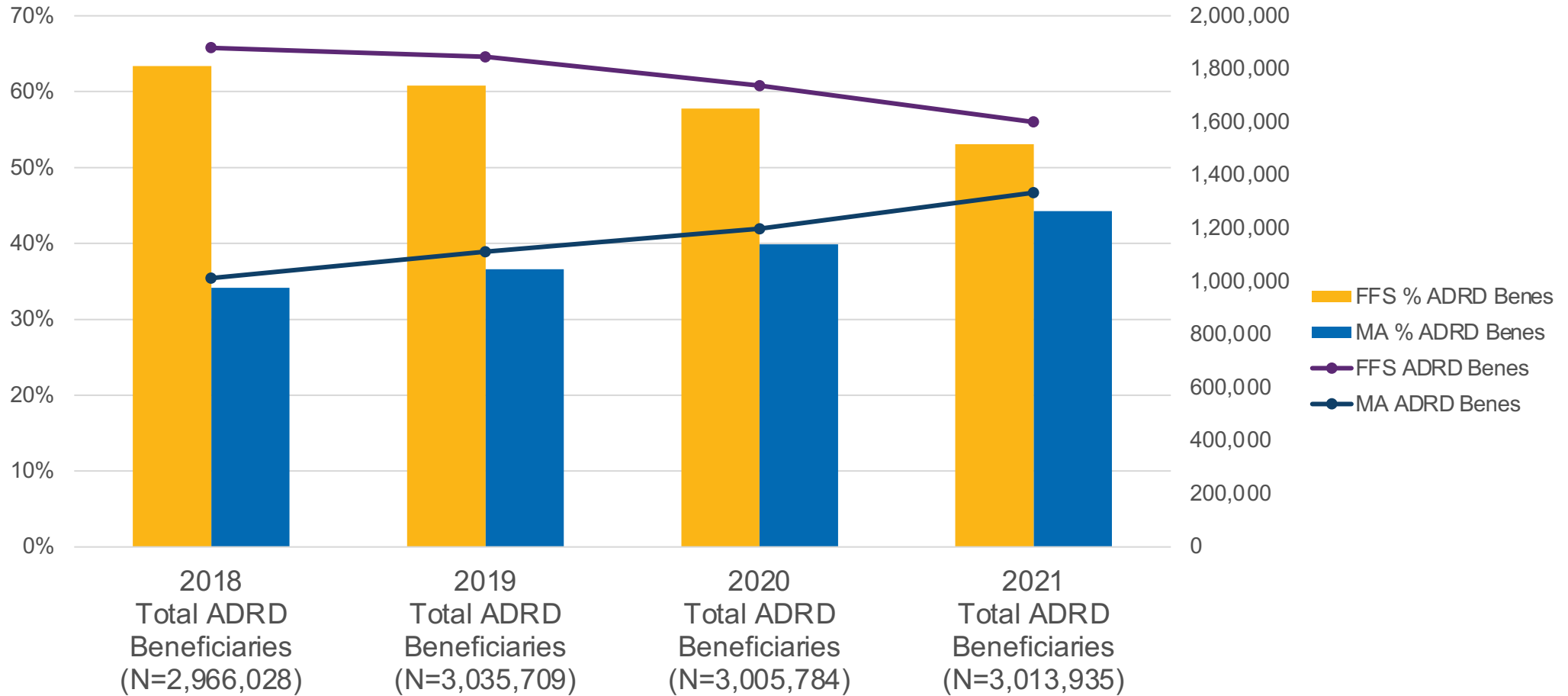
# Changes Across Covid Period in FFS and MA

## Number & Percent Beneficiaries in FFS vs. MA (2018-2021)



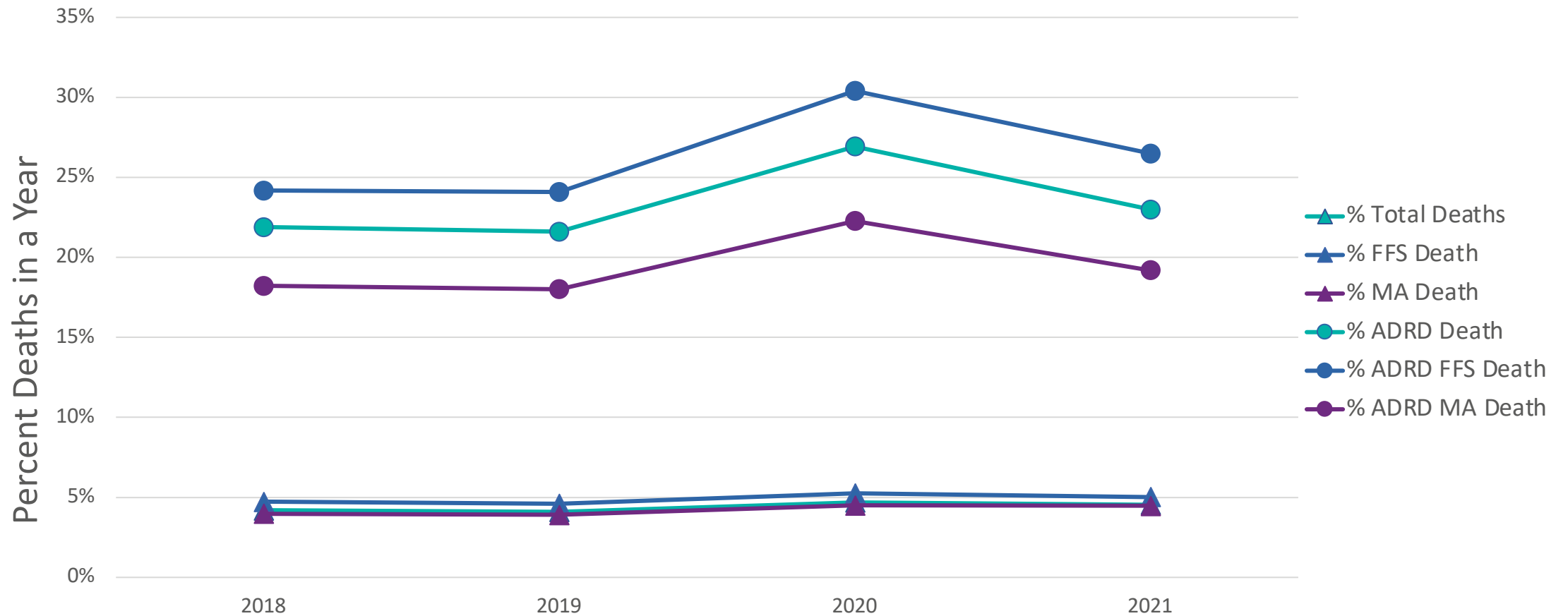
# Changes Across Covid Period in FFS and MA in ADRD Population

## Number & Percent ADRD Beneficiaries FFS vs. MA (2018-2021)



# Changes Across Covid Period in FFS and MA in Pre and Post Covid on ADRD Population

Percent of Beneficiaries Died by ADRD and FFS/MA Status (2018-2021)



# Why pay attention to these population data or benchmarks?

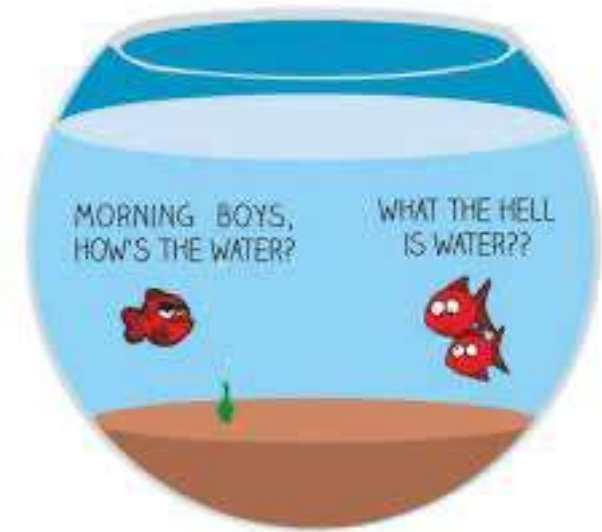
Feasibility

Power

Planning for health equity

Assess potential bias

*Getting Outside One's  
Localized Perspective*



# Closing

- Medicare data identifies fewer people with dementia than epidemiological data with known biases; most important of which is more severe/late stage of disease
  - Since these data driven by EHRs, same bias likely in other healthcare generated data
- National averages do not reflect local benchmarks
- Intersection of Place with Race - or any other demographic characteristic - important to recognize and address
- Less visible context variables (such as MA vs FFS) can also impact bias

# Thanks

## Team at Michigan

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Ellen McCreedy (Brown)

David Meyers (Brown)

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Richard Platt (Harvard)

Liaisons – Vince Mor &  
Ellen McCarthy





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**Questions?**

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