Research Translation for All Persons:
A Discussion of the ADRC Network Role

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FUNDING DISCLOSURES

NIH/National Institute on Aging

NIH/National Institute on Minority Health and Health Disparities

Alzheimer's Association

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BRAIN HEALTH IS NOT DISTRIBUTED EQUALLY

Solutions Needed

The National Academies of
SCIENCES • ENGINEERING • MEDICINE
CONSENSUS STUDY REPORT
Improving Representation in Clinical Trials and Research
BUILDING RESEARCH EQUITY FOR WOMEN AND UNDERREPRESENTED GROUPS

NATIONAL ACADEMIES REPORT: CONCLUSIONS

1. Improving representation in clinical research is **urgent**.
2. Improving representation in clinical research **requires investment**.
3. Improving representation **requires transparency and accountability**.
4. Improving representation in clinical research is the **responsibility of everyone** involved in the clinical research enterprise.
5. Creating a more equitable future entails a **paradigm shift.**

**NASEM Report, "Improving Representation in Clinical Trials and Research," 2022

AUGUST 2022 – FDA POSITION

"The US is experiencing a decline in life expectancy …. As part of a wider effort to reverse this decline, relationships between FDA and the biomedical ecosystem should be reimagined to **facilitate more effective translation of science into successful health interventions**....the biomedical community should review its priorities so that it can deliver more new therapies… particularly for those suffering most: racial and ethnic minorities, people with less education and wealth, and those living in rural areas."

-- Robert M. Califf, FDA Commissioner (Califf, *Science*, 2022)

RESPONSIBILITY

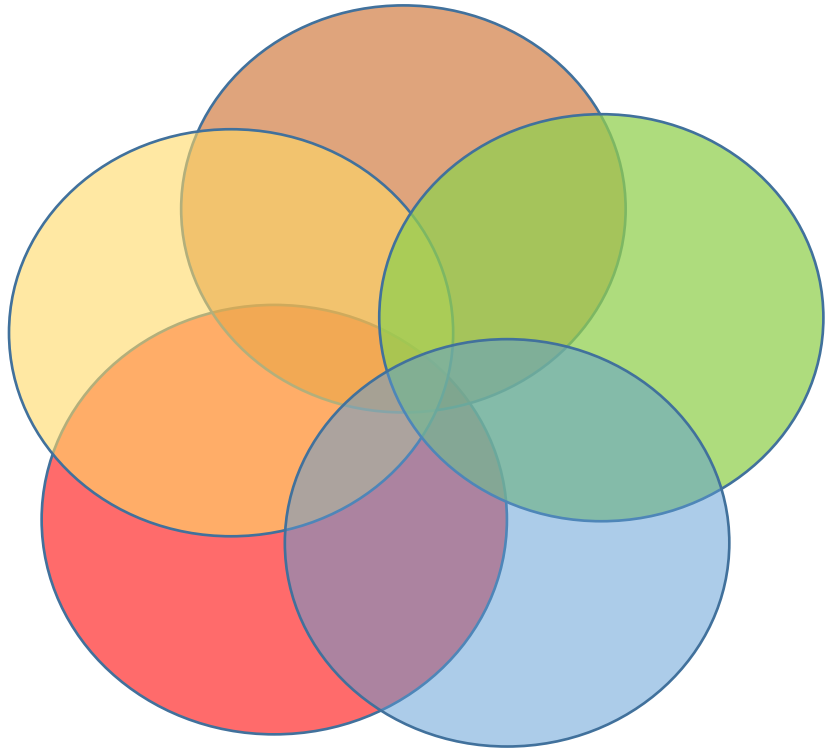
ADRC Role….

"The Alzheimer's Disease Research Centers (ADRC) network is funded by the National Institute on Aging (NIA) to find treatments and prevention strategies for Alzheimer's Disease (AD) and other related dementias, as well as to translate research findings into improved diagnosis and care"… **for all persons.**

*https://www.nia.nih.gov/research/adc

NIH HEALTH DISPARITIES PRIORITY POPULATIONS

- Hispanics/Latinos
- American Indians/Alaskan Natives
- Blacks/African Americans
- Asian Americans
- Native Hawaiians and Other Pacific Islanders
- Socioeconomically Disadvantaged Populations
- Rural Populations
- Disability Populations
- Sexual and Gender Minorities
- Others

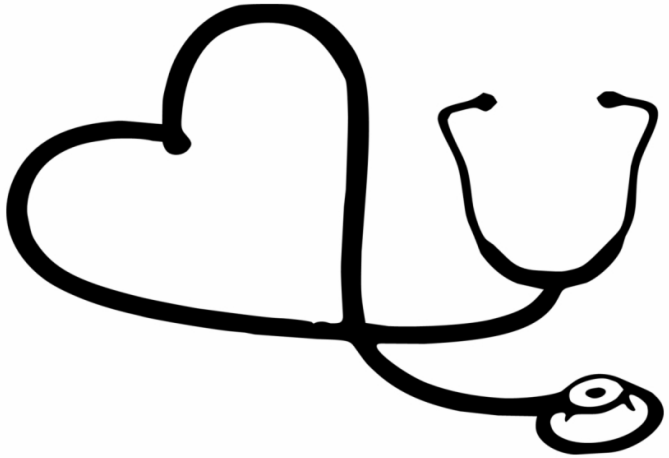


Intersectionality

**Hill, Perez-Stable, Anderson and Bernard, *Ethnicity and Disease*, 2015; https://www.nia.nih.gov/research/osp/framework

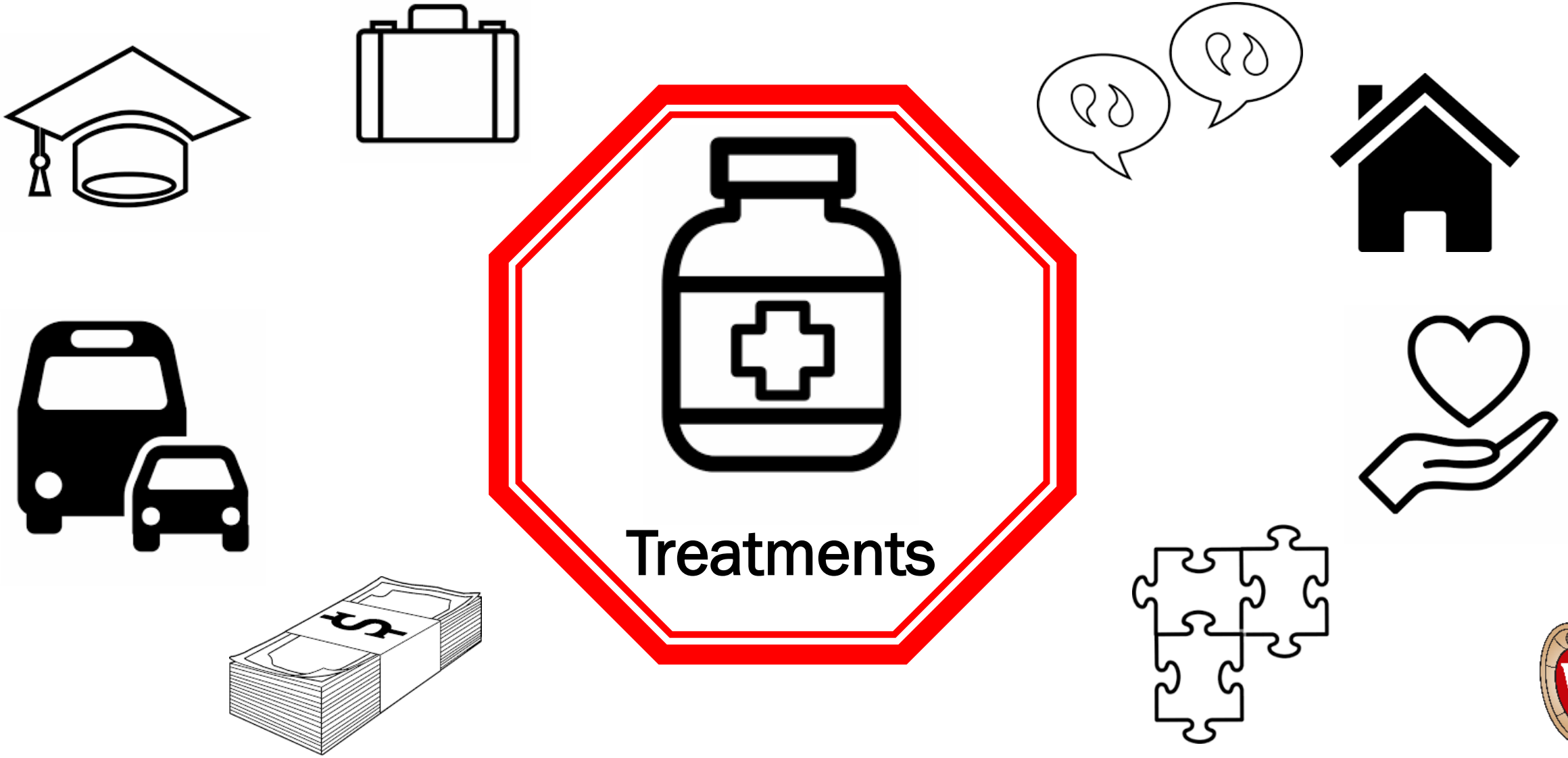
INTERVENTIONS

Treatments



Clinical and Social Interventions

INTERVENTIONS FOR ALL– BARRIERS ARE MANY



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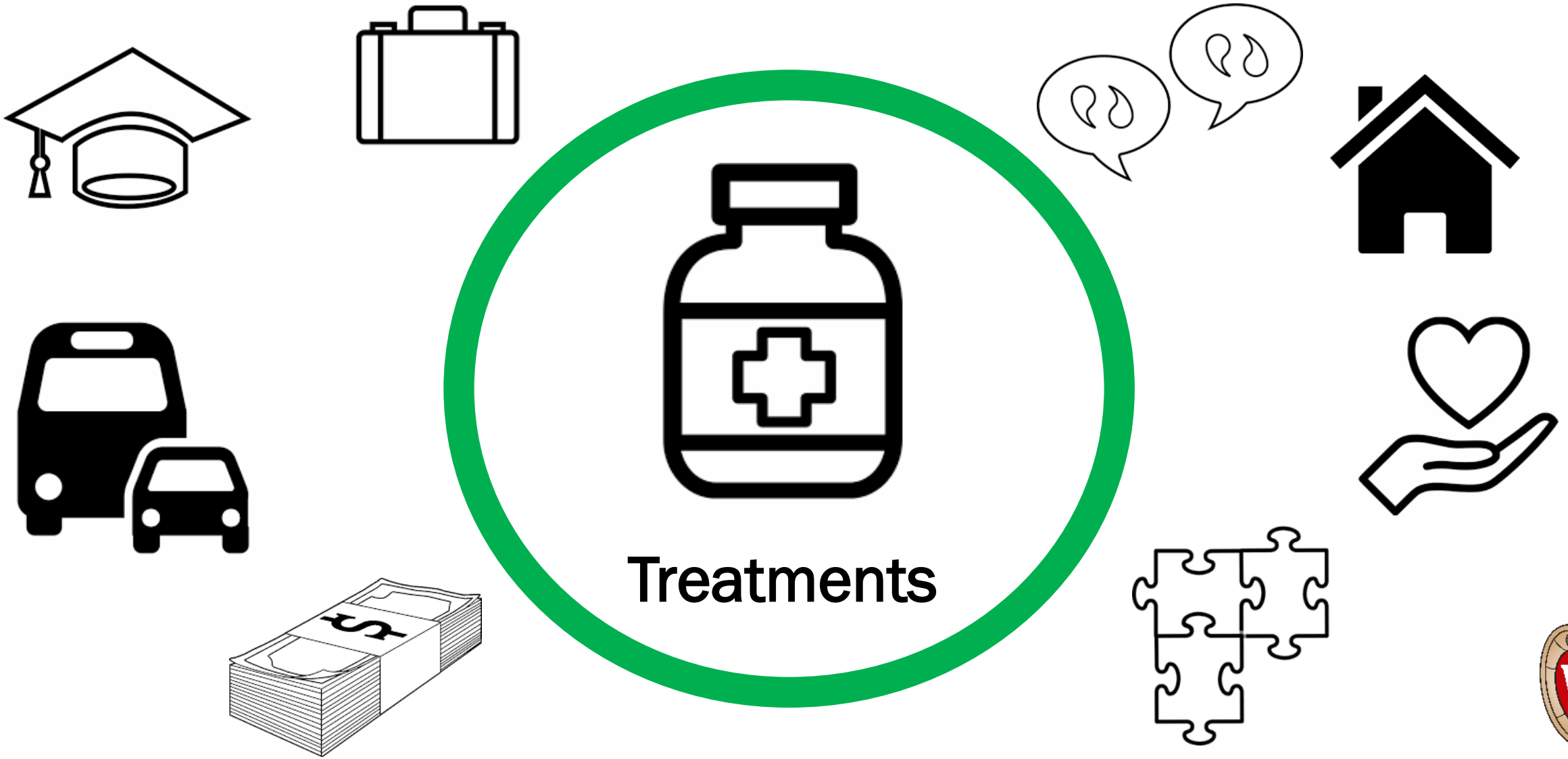
NATIONAL ACADEMIES REPORT CALL: SUBSTANTIAL INVESTMENT OF TIME, MONEY AND EFFORT

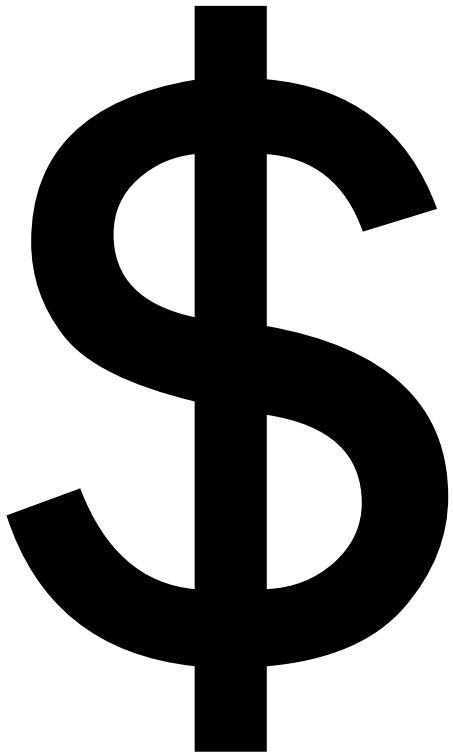
"Investments are needed in the systems and technologies that **reduce burdens to participation** by underrepresented and excluded populations, ***such as*** by **adequately compensating** participants financially for their time when participating in research and by investing resources in making participation more **physically accessible**, and by providing **research materials** that are culturally informed and multilingual."

**NASEM Report, "Improving Representation in Clinical Trials and Research," 2022

INTERVENTIONS FOR ALL REQUIRE SUPPORTS

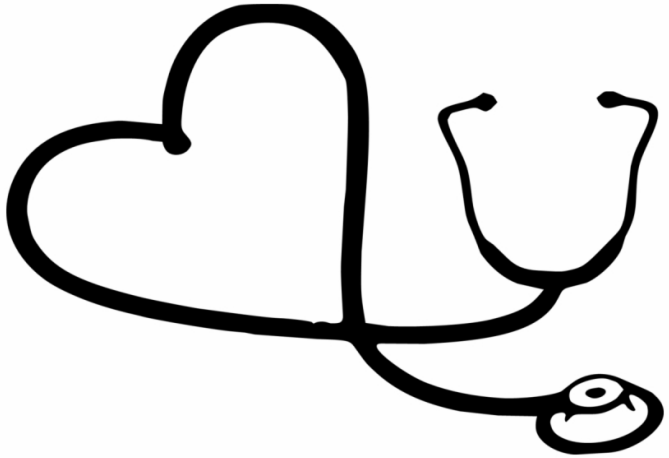


ONE MAJOR BARRIER



INTERVENTIONS

Treatments



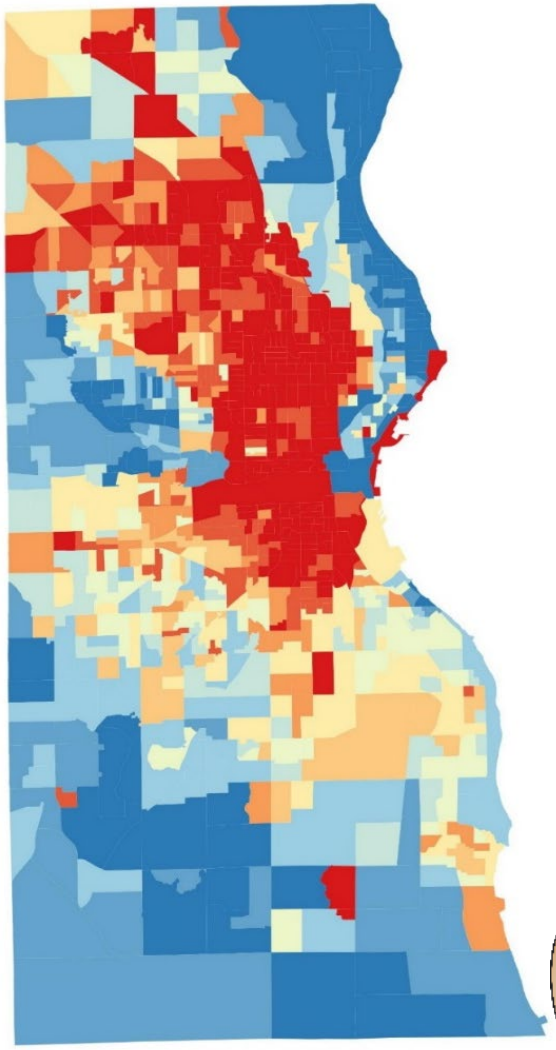
Clinical and Social Interventions

Policy

POWER OF POLICY

AREA DEPRIVATION INDEX (ADI)* - AN EXPOSOME METRIC

- ADI construction
  - 17 measures of social determinants of health across small, population sensitive areas
  - Ranked score
- Current ADI measures for full US available through the Neighborhood Atlas®*
- Similar metrics available in most countries
- ADI in UDS 4.0; launching ADI in ACTC, ADNI and many others



Milwaukee County

*Kind and Buckingham, *New England Journal of Medicine*, 2018

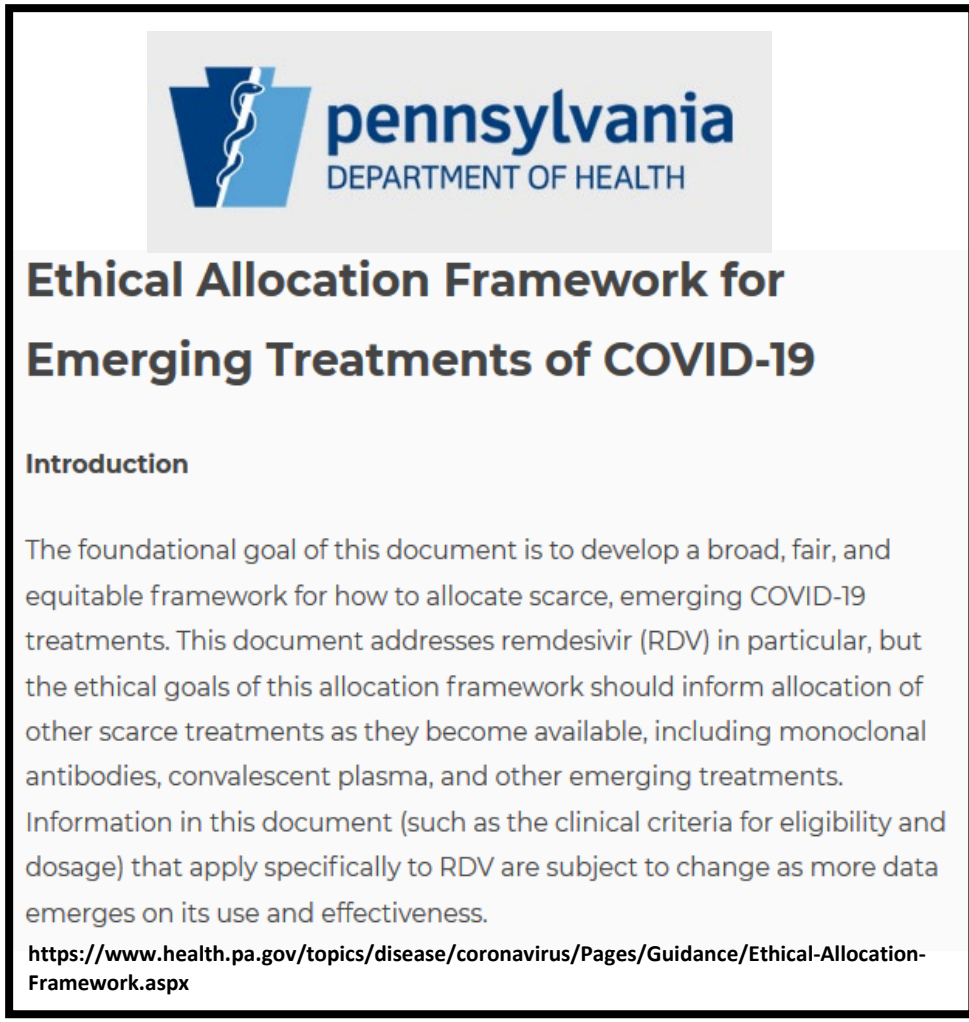
ADI IS NOW LEVERAGED IN US HEALTH POLICY

Ethical Allocation of COVID Therapies

- Example: Pennsylvania

US Centers for Medicare and Medicaid Services (CMS)

- 2023 ACO Realizing Equity, Access, and Community Health (REACH) Model uses ADI to adjust payments



CENTER FOR MEDICARE AND MEDICAID INNOVATION (CMMI)

CMS
CENTERS for MEDICARE & MEDICAID SERVICES

Health Equity Benchmark Adjustment

ACO REACH includes a benchmark adjustment that increases benchmarks for ACOs serving higher proportions of underserved beneficiaries

CMS will stratify all beneficiaries aligned to ACO REACH using a composite measure of underservice that incorporates a combination of[1]:

Area Deprivation Index	Dual Medicaid Status
*Area-level measure of **local socioeconomic factors** correlated with medical disparities and underservice*	*Beneficiary-level measure of economic challenges affecting individuals' ability to access high quality care*
Percentile Score from 1-100	**25 Point Adjustment for Full or Partial Dual Eligibility**

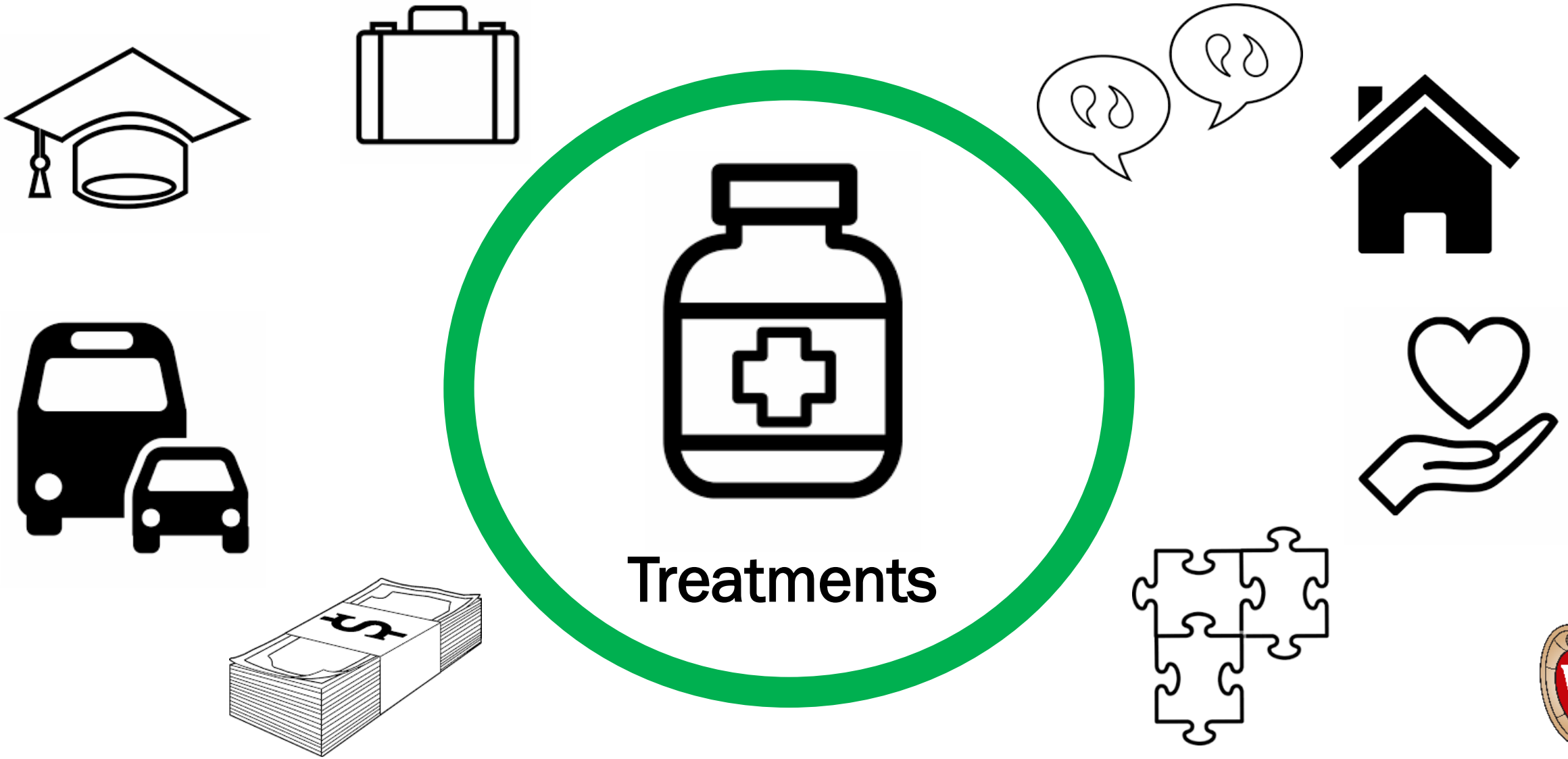
91st – 100th Percentile (Top Decile)	***+$30 PBPM Adjustment***
51st – 90th Percentile (Middle 4 Deciles)	*No Adjustment*
1st – 50th Percentile (Bottom 5 Deciles)	*-$6 PBPM Adjustment*

1. CMS may explore other variables to include in this assessment and will notify applicants prior to the start of PY2023 if any other variables are included.

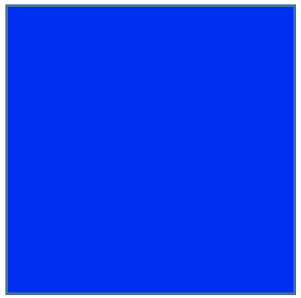
*2022 ACO Realizing Equity, Access, and Community Health (REACH) Model [https://innovation.cms.gov/media/document/aco-reach-fin-meth-webinar-slides}

CMS CENTERS FOR MEDICARE & MEDICAID SERVICES

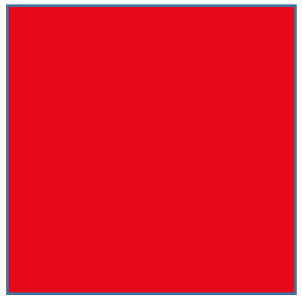
CMS EQUITY APPROACH:
PROVIDES FUNDING TO REMOVE BARRIERS TO TREATMENT



CMS ACO-REACH RESOURCE TARGETING: SIMPLIFIED

 = $

Low ADI

 = $

High ADI

QUESTIONS FOR DISCUSSION

- Should ADRC Network launch efforts towards creating an equity-focused policy standard for interventional trials in alignment with the National Academies report?
- Should financing of interventional research trials be grounded to principles of equity in alignment with CMS payment policy?
- What is the role of the ADRC network in setting equity-aligned standards for industry and other intervention studies?

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