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MEDICAL CENTER

Equitably Including Diverse Participants in Pragmatic Clinical Trials

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NIH Collaboratory Grand Rounds
August 12, 2022

Twitter: @DrCHWilkins

Disclosures as of August 12, 2022:

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Dr. Wilkins currently receives research support from:

- National Institutes of Health (NCATS, NIMHD, NCI, NIA, NHGRI)
- Patient-Centered Outcomes Research Institute
- Robert Wood Johnson Foundation
- American College of Radiology
- Alzheimer's Association

Twitter: @DrCHWilkins

Objectives

- Understand historical, systemic, structural and sociocultural factors that impact diversity in trials
- Identify barriers to racial and ethnic diversity specific to pragmatic trials
- Discuss strategies to enable equitable inclusion of minoritized racial and ethnic groups in pragmatic trials

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The New York Times

F.D.A. Approves Alzheimer's Drug Despite Fierce Debate Over Whether It Works

Aducanumab, or Aduhelm, is the first new Alzheimer's treatment in 18 years and the first to attack the disease process. But some experts say there's not enough evidence it can address cognitive symptoms.

Hispanic/Latino 3% and Black 0.6%

PHARMACEUTICALS & MEDICAL TECHNOLOGY

DOI: 10.1377/hlthaff.2021.01432
HEALTH AFFAIRS 41,
NO. 3 (2022): 368–374

By Angela K. Green, Niti Trivedi, Jennifer J. Hsu, Nancy L. Yu, Peter B. Bach, and Susan Chimonas

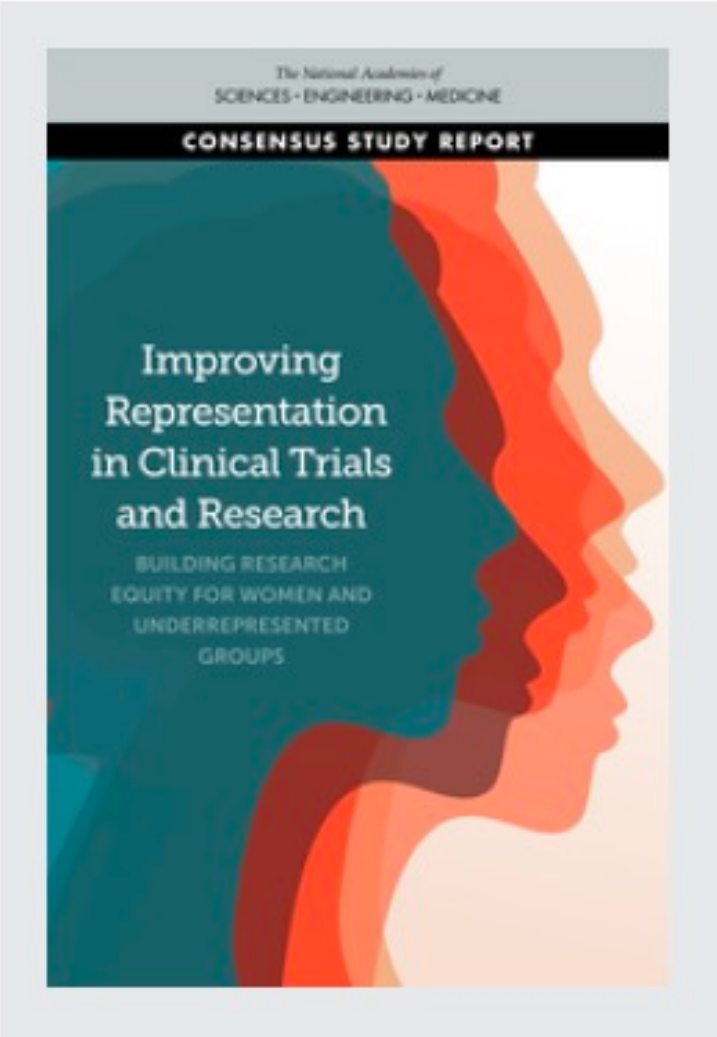
Despite The FDA's Five-Year Plan, Black Patients Remain Inadequately Represented In Clinical Trials For Drugs

STAT

Lack of diversity in clinical trials costs billions of dollars. Incentives can spur innovation

By Dana P. Goldman, Edith A. Perez *and* Carlos del RioAug. 3, 2022

August 12, 2022; @DrCHWilkins



National Academies of Sciences, Engineering, and Medicine 2022. Improving Representation in Clinical Trials and Research: Building Research Equity for Women and Underrepresented Groups. Washington, DC: The National Academies Press. https://doi.org/10.17226/26479.

What is meant by diverse participants?

WHICH POPULATIONS ARE INCLUDED?

NIH-designated U.S. populations:

- Racial and Ethnic Groups
  - American Indian/Alaska Native
  - Asian American
  - Black/African American
  - Hispanic/Latino/x
  - Native Hawaiian and other Pacific Islander
- Sexual and gender minorities
- Socioeconomically disadvantaged populations
- Underserved rural populations

As of May 5, 2021 https://www.nimhd.nih.gov/about/overview/

Race

Artist Angélica Dass rethinks the concept of race by showing the diversity of human skin colors in her global photographic mosaic.
https://www.angelicadass.com/humanae-project

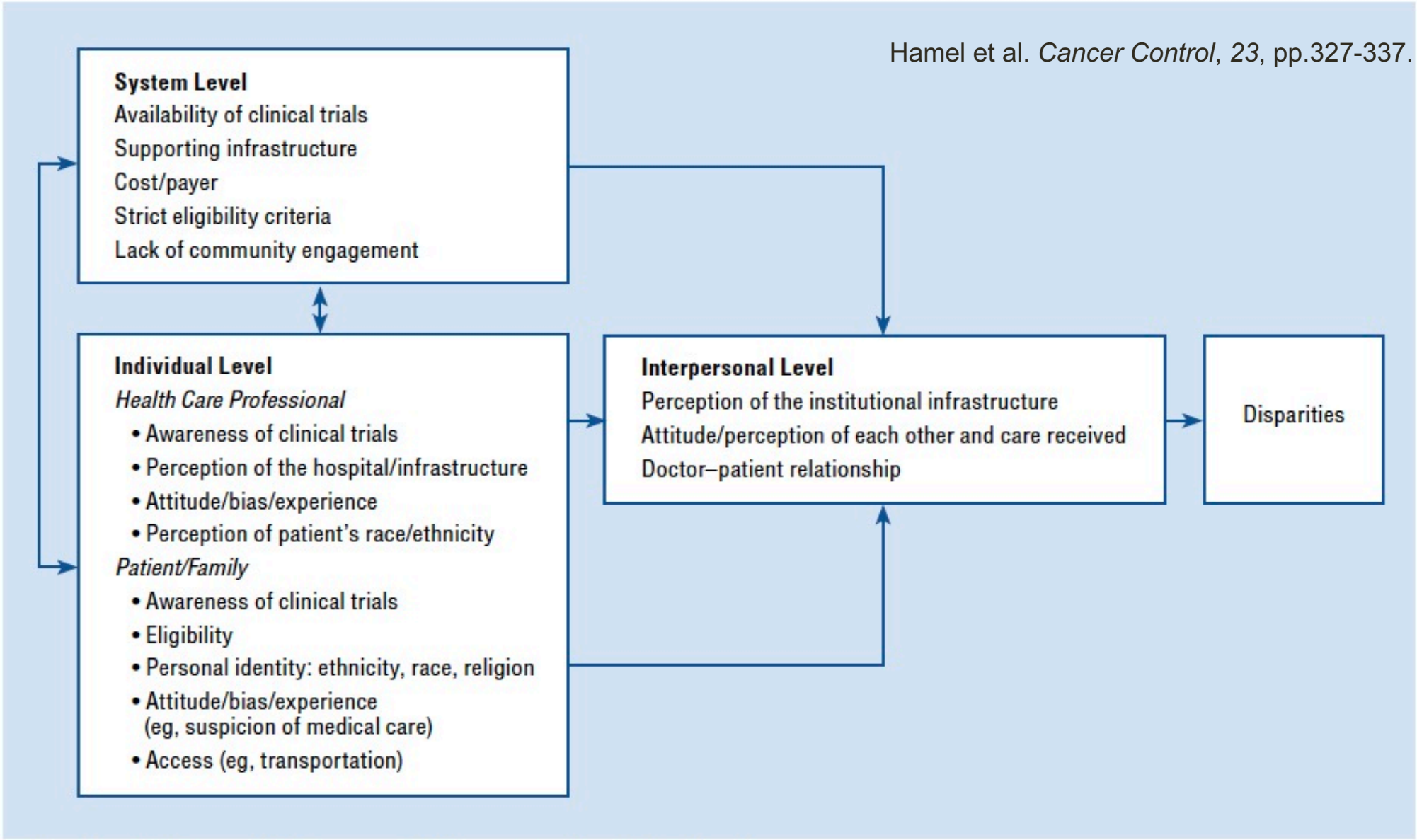
In the United States, the primary purpose of race/ethnicity category is **oppression**

- **Black:** Different rules and limited rights for slaves and eventually descendants, segregation; "one drop" of black blood = Black.
- **American Indian:** Land stolen, massacred; initially didn't have US citizenship; blood quantum used to restrict rights.
- **Hispanic:** only two options for ethnicity per federal categories- Hispanic or not.
- Well into the 20th century, **only White immigrants were eligible** for US citizenship.

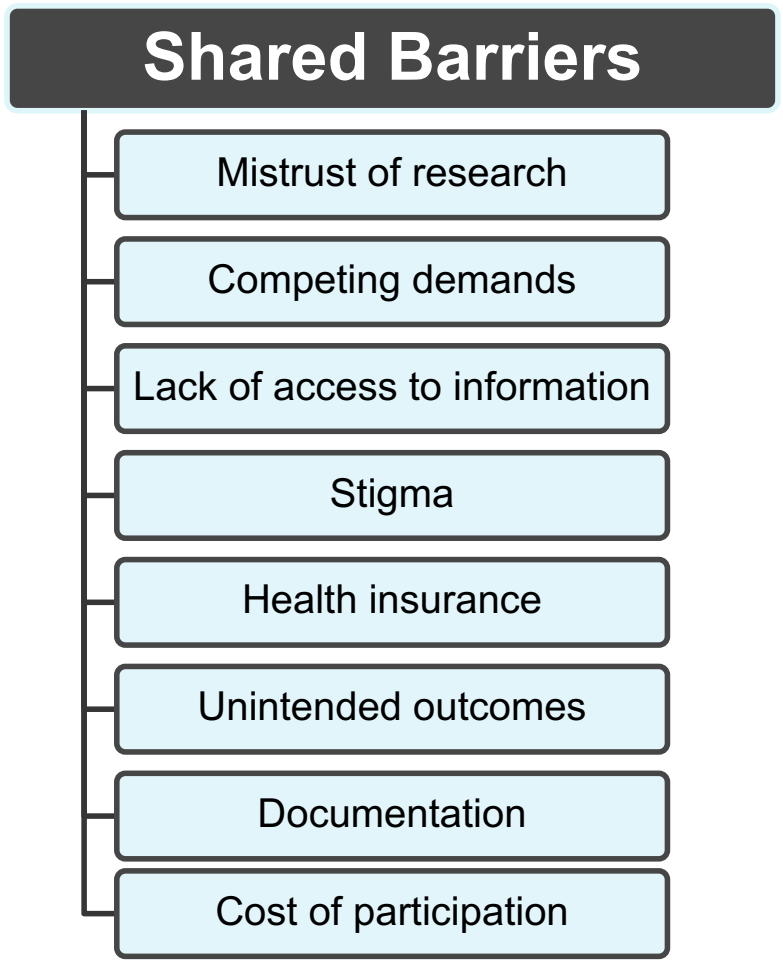
http://i0.wp.com/panafricanalliance.com/wp-content/uploads/2011/05/RacialDifferences.jpg

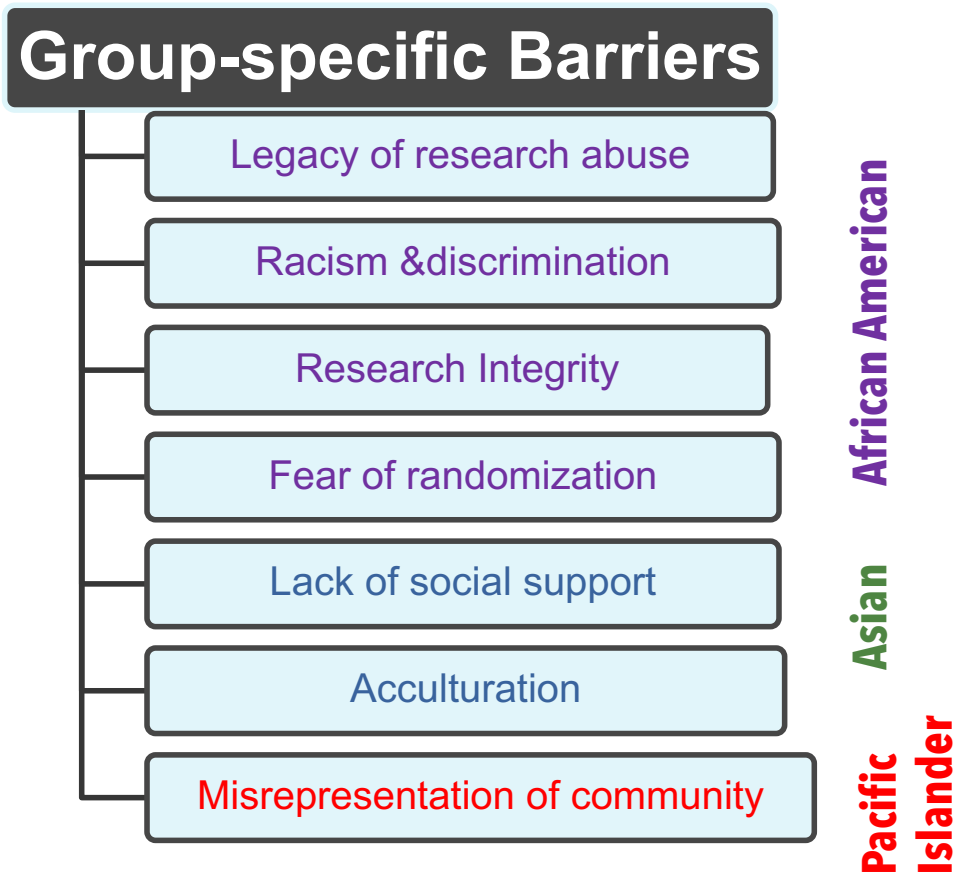
Factors contributing to lack of diversity in clinical trials

Hamel et al. *Cancer Control*, *23*, pp.327-337.



Barriers to clinical trial participation among African American, Hispanic/Latinx, Asian American, and Pacific Islander groups





@DrCHWilkins

George, Duran, Norris. AJPH. 2014;104:16-31.

Study-level Barriers to Recruiting Minoritized Racial and Ethnic Groups

Investigators

- Limited knowledge/experience recruiting diverse groups
- Few, if any, minority researchers
- Little to no experience working with community orgs
- Ineffective communication strategies
- Lack of cultural humility
- Do not demonstrate their trustworthiness

Study-level barriers

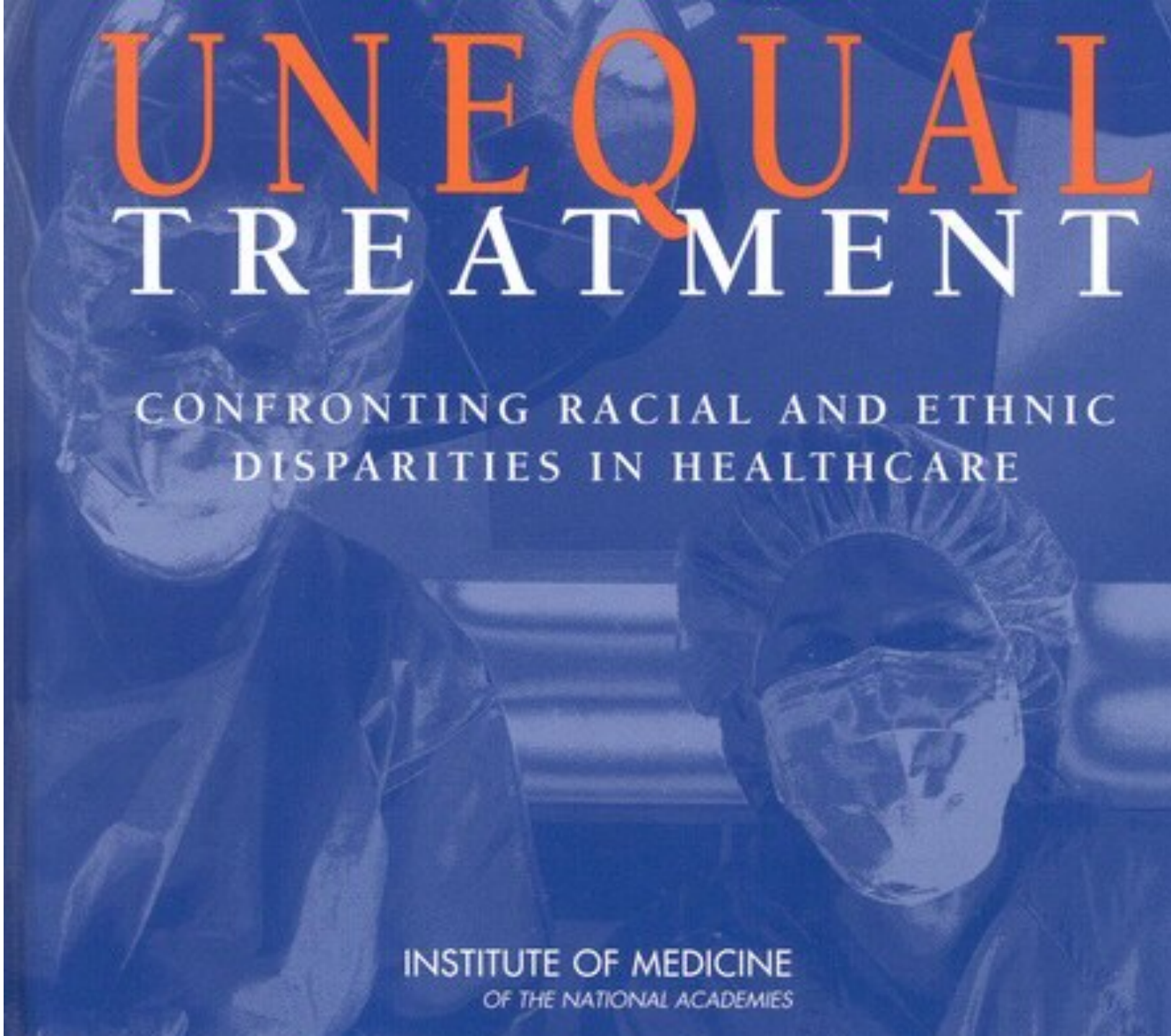
- budgets inadequate for recruitment
- no expertise to culturally adapt tailor documents
- lack of culturally congruent research staff
- No bilingual staff or access to language services

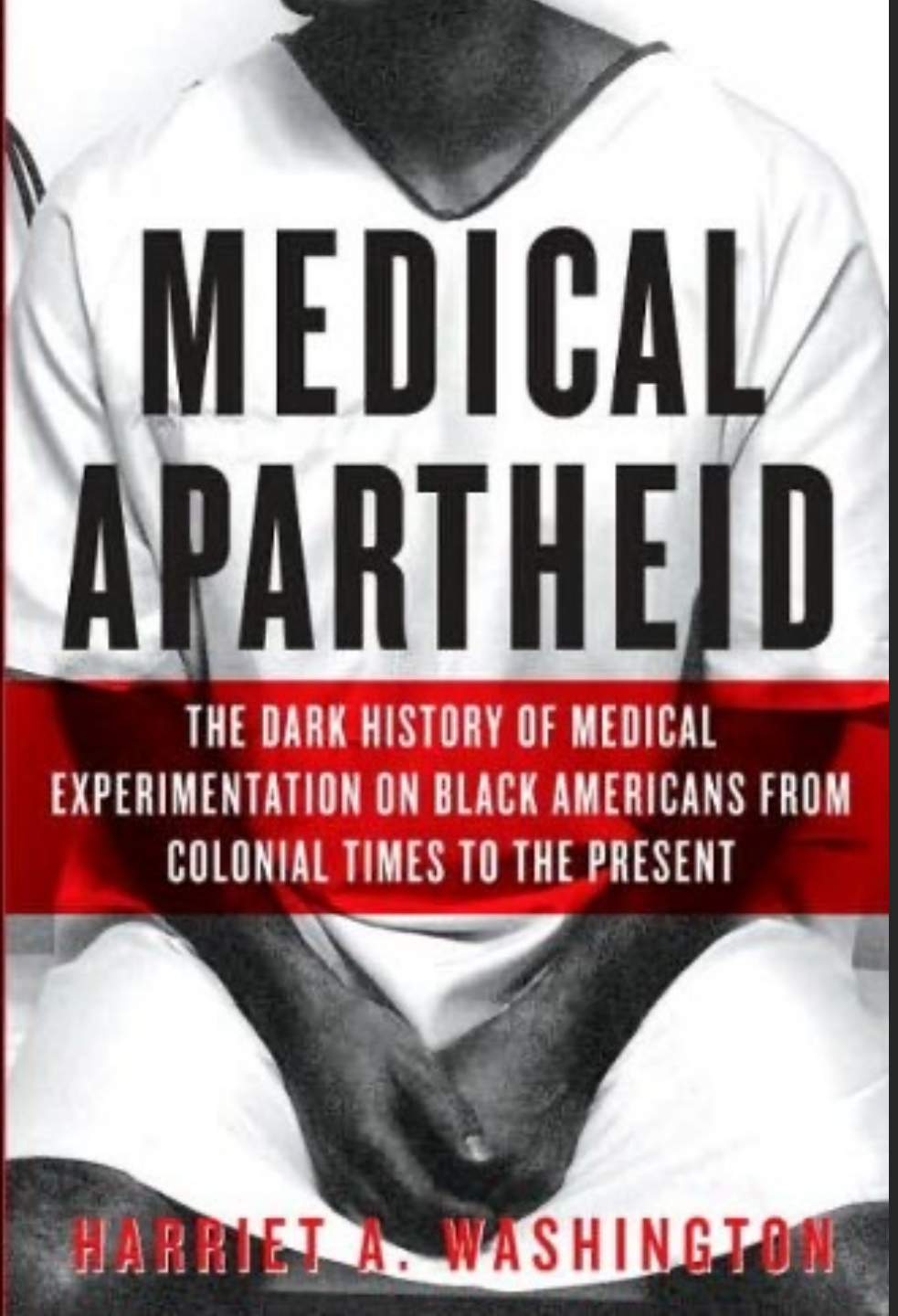
What does pragmatic mean to minoritized racial and ethnic groups?

When we say pragmatic = real world do we understand that health care in the real world is unfair, unjust, racist, discriminatory?

"There hasn't been a lot of progress in 20 years. We are still largely seeing what some would call medical apartheid."

https://www.statnews.com/2022/02/23/landmark-report-systemic-racism-medicine-so-little-has-changed/





From the era of slavery to the present day, the first full history of Black America's shocking mistreatment as unwilling and unwitting experimental subjects at the hands of the medical establishment.

Harriet A. Washington 2006


ROBERT THOM

The Atlantic

POLITICS

America's Health Segregation Problem

Has the country done enough to overcome its Jim Crow health care history?

VANN R. NEWKIRK II MAY 18, 2016

A doctor's office in Merigold, Mississippi in 1939 (MARION POST WOLCOTT / LIBRARY OF CONGRESS)

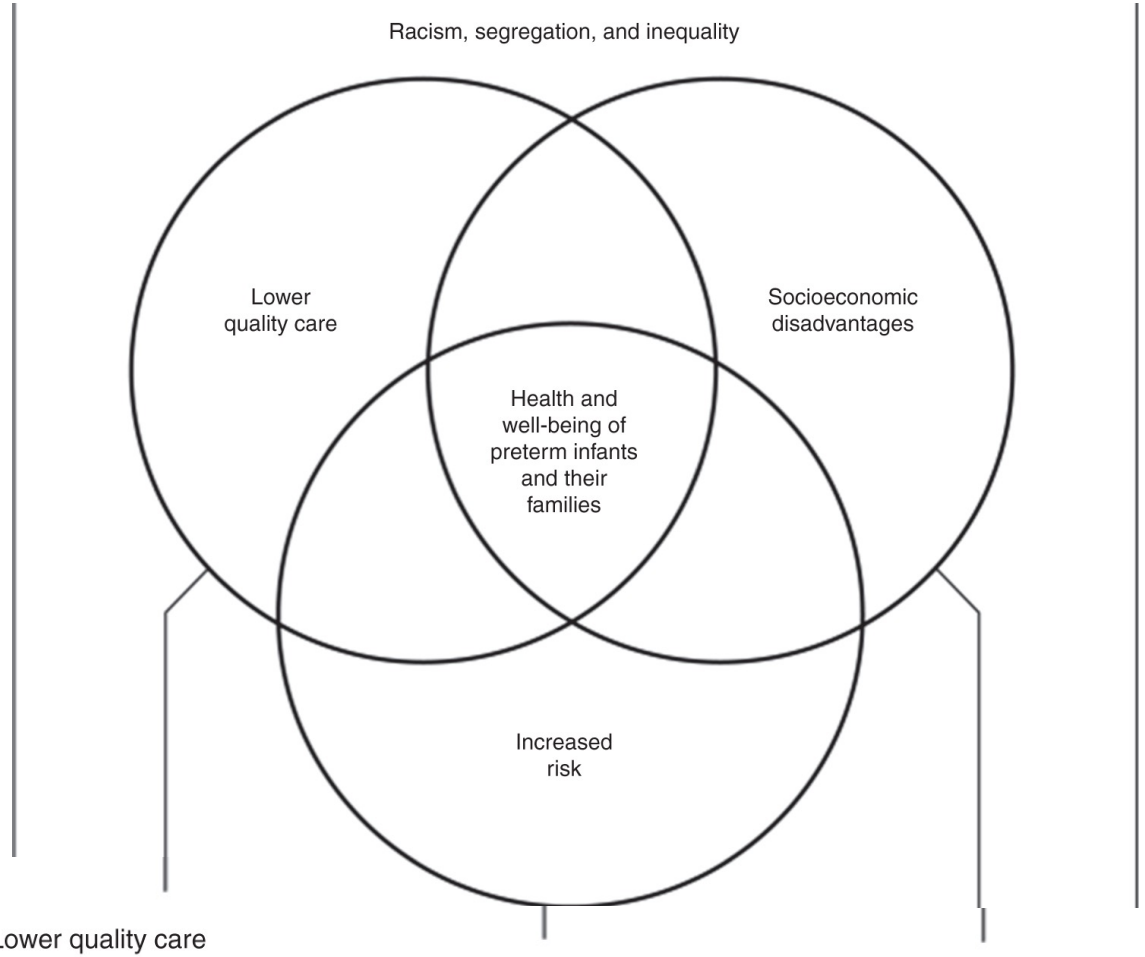
Wilkins CH. Slide created April 2018.

Legacy of racial segregation endures at many U.S. hospitals

Andis Robeznieks 2021

The color of health: how racism, segregation, and inequality affect health

Beck et al 2020



Lower quality care

- Disparities dashboard
- Implicit bias education
- Quality improvement to eliminate modifiable disparities
- SDH screening
- Structured discharge process with coordinated follow-through services
- Culture of equity

Increased risk

- Access to quality prenatal and interconception care
- Increased interpregnancy intervals
- 17-alpha hydroxyprogest-erone access and adherence
- Cerclage placement in high risk women
- Screening and treatment of specific genital infections

Socioeconomic disadvantages

- Meaningful clinical-community partnerships
- Early intervention and intensive early education programs
- Quality health care across the lifespan for infants and families
- EHR data for population-level pattern recognition

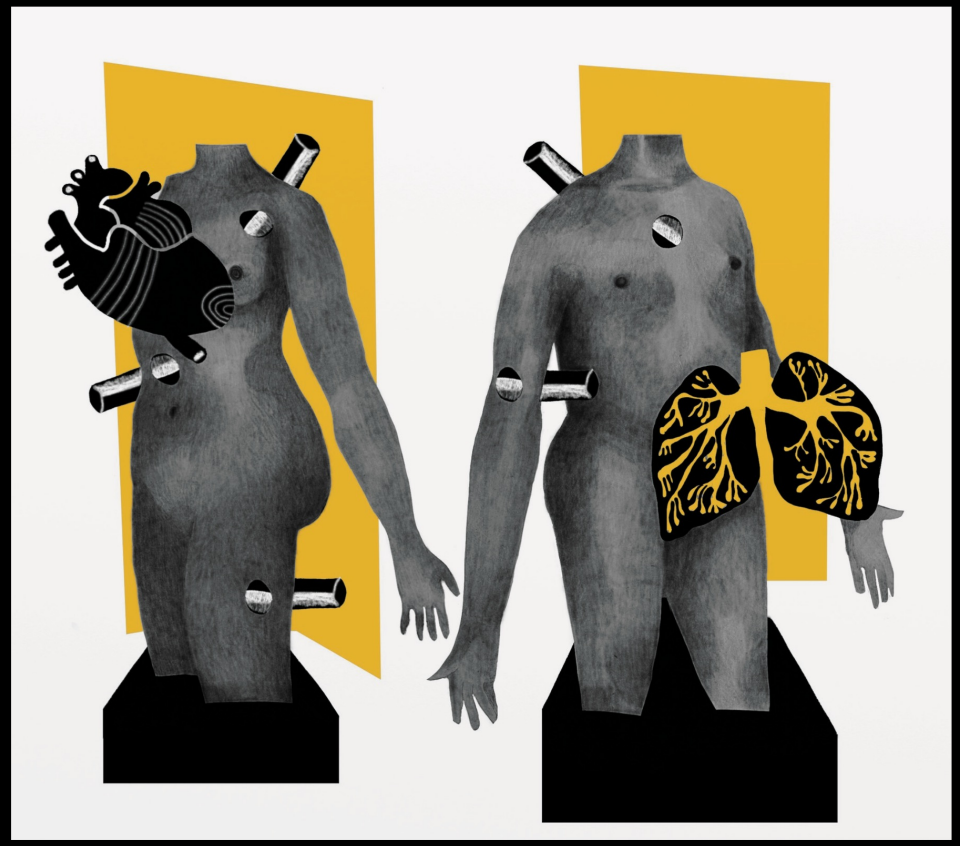


ILLUSTRATION BY DIANA EJAITA

Myths about physical racial differences were used to justify slavery — and are still believed by doctors today.

By Linda Villarosa

AUG. 14, 2019

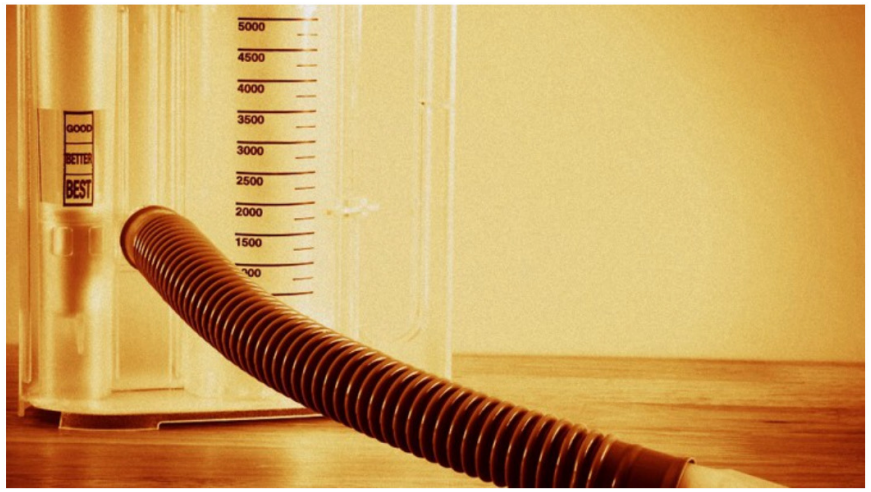
The Atlantic Sign In Subscribe

HEALTH

How Racism Creeps Into Medicine

The history of a medical instrument reveals the dubious science of racial difference.

HAMZA SHABAN AUGUST 29, 2014



GLENDA/SHUTTERSTOCK

In 1864, the year before the Civil War ended, a massive study was launched to quantify the bodies of Union soldiers. One key finding in what would become a 613-page report was that soldiers classified as "White" had a higher lung capacity than those labeled "Full Blacks" or "Mulattoes." The study relied on the spirometer—a medical instrument that measures lung capacity. This device was previously used by plantation physicians to show that black slaves had weaker lungs than white citizens.

- In 1864, Samuel Cartwright, a physician and slaveholder, reported 20% lower lung capacity among Blacks.

It is the red vital blood sent to the brain that liberates their minds when under the white man's control, and it is the want of sufficiency of red vital blood that chains their minds to ignorance and barbarism when in freedom (7, 8).

From History of Spirometer, Lujan and DiCarlo; Adv Physiol Educ 42: 163–165, 2018.

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The NEW ENGLAND JOURNAL of MEDICINE

MEDICINE AND SOCIETY

Debra Malina, Ph.D., *Editor*

Hidden in Plain Sight — Reconsidering the Use of Race Correction in Clinical Algorithms

Darshali A. Vyas, M.D., Leo G. Eisenstein, M.D., and David S. Jones, M.D., Ph.D.

Table 1. Examples of Race Correction in Clinical Medicine.*

Tool and Clinical Utility	Input Variables	Use of Race
Cardiology		
The American Heart Association's Get with the Guidelines–Heart Failure[3] (https://www.mdcalc.com/gwtg-heart-failure-risk-score) *Predicts in-hospital mortality in patients with acute heart failure. Clinicians are advised to use this risk stratification to guide decisions regarding initiating medical therapy.*	Systolic blood pressure Blood urea nitrogen Sodium Age Heart rate History of COPD Race: black or nonblack	Adds 3 points to the risk score if the patient is identified as nonblack. This addition increases the estimated probability of death (higher scores predict higher mortality).

JAMA The Journal of the American Medical Association

VIEWPOINT

Addressing Bias in Artificial Intelligence in Health Care

Parikh RB, Teeple S, Navathe AS. JAMA. 2019;322(24):2377-2378

Table. Artificial Intelligence Bias in Health Care

Example of Bias	Type of Bias	Potential Reasons for Bias	Methods to Address Bias
Low sensitivity of Framingham Risk Score in minority subgroups	Statistical	Algorithm training sample differs significantly from the population of interest	Oversample minority subgroups in training sample; tailor predictions or scores for specific subgroups
Delayed diagnosis of lung cancer in patients with low socioeconomic status or who lack transportation access to clinic	Social	Underlying disparities in diagnosis	Create flags for model uncertainty in predictions for certain high-risk subgroups
Missing data in electronic health record–based data sets due to lack of patient follow-up	Statistical and social	Missing data	Base predictions on "upstream" data at presentation of illness, not on subsequent follow-up data

JAMA Network Open

Invited Commentary | Health Informatics

Algorithmovigilance—Advancing Methods to Analyze and Monitor Artificial Intelligence–Driven Health Care for Effectiveness and Equity

Peter J. Embi, MD, MS

May 2021
@DrCHWilkins

What strategies might enable diversity in pragmatic trials?

Trial Innovation Network

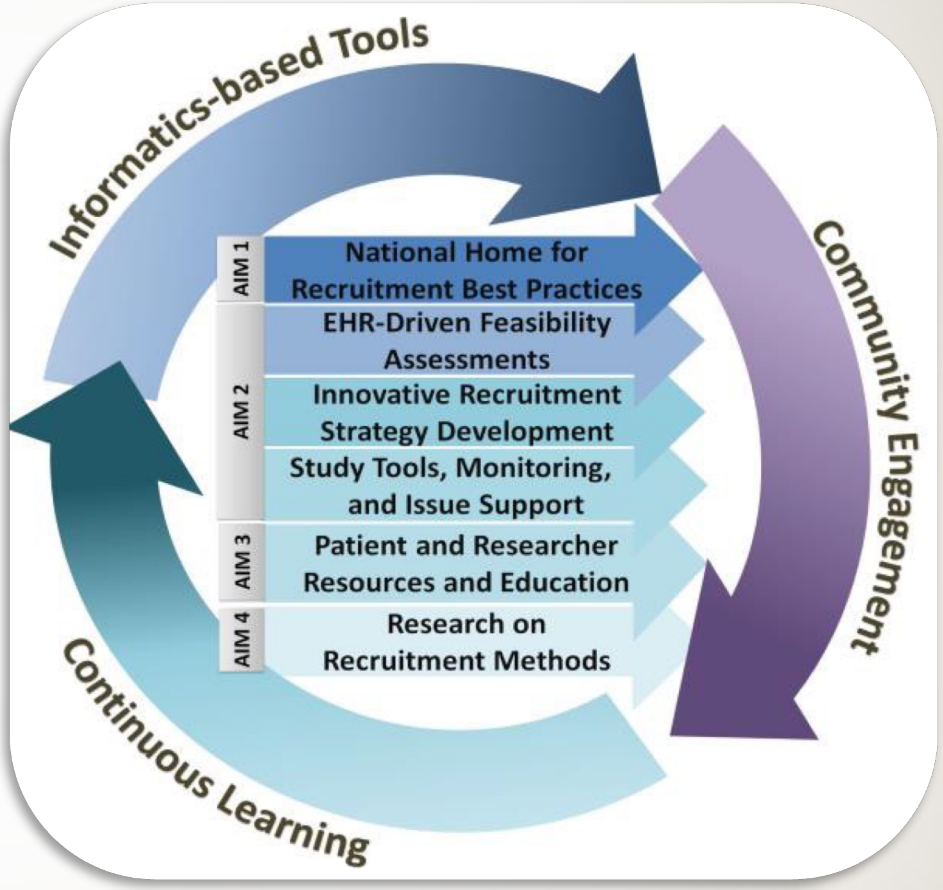
RECRUITMENT INNOVATION CENTER

Paul Harris, PhD and Consuelo H. Wilkins, MD, MSCI
Vanderbilt University Medical Center

Vision and purpose

Our goal is to positively impact human health by **improving participant enrollment and retention in multi-center clinical trials**.

Achieving this goal will require sophisticated **informatics-based recruitment tools** and **novel engagement approaches** to accelerate recruitment and retention.



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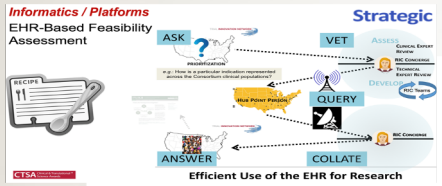
RIC Areas of Support



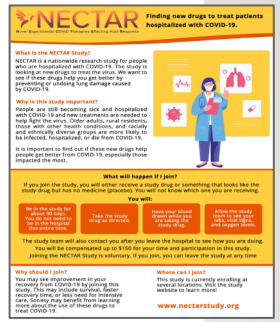
Cohort Assessment & EOI

Community Engagement Studios

Enhancing Diversity

REDCap-based eConsent

Supporting Consent



Return of Value

Clinician Study App

*Wilkins, C., Edwards, T., Stroud, M., Kennedy, N., Jerome, R., Lawrence, C., . . . Harris, P. (2021). The Recruitment Innovation Center: Developing novel, person-centered strategies for clinical trial recruitment and retention. *Journal of Clinical and Translational Science, 5*(1), E194. doi:10.1017/cts.2021.841

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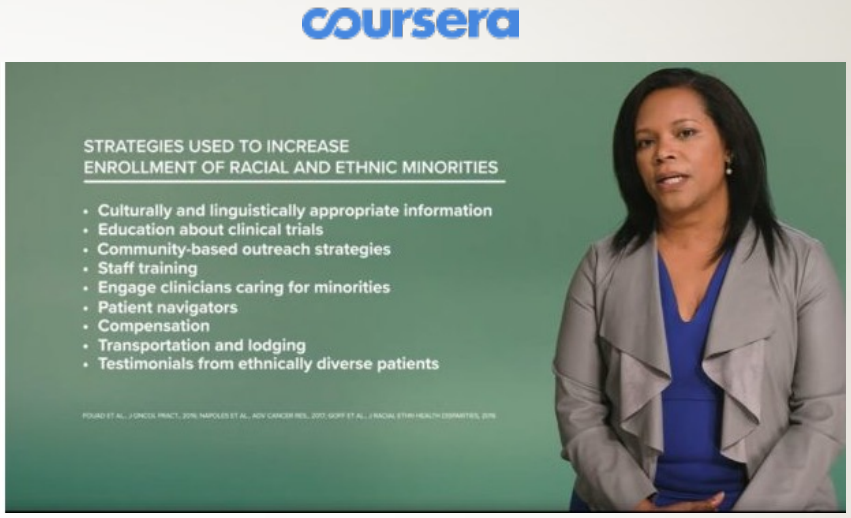
Research Environment

Foster a diverse, anti-racist research environment:

- **Study team members should be educated and trained** on implicit bias and best practices for working with diverse populations

Example: "Faster Together, Enhancing the Recruitment of Minorities in Clinical Research"

- **Goal:** To teach individuals how to enhance the recruitment of racial and ethnic minoritized communities in clinical research



Modules:

1. Understanding the need to increase minority recruitment in clinical trials
2. Key principles of community engagement
3. Reaching out into the community: effective communications
4. Educating potential research participants
5. Outreach with community healthcare providers
6. Effective screening, education, and decision support
7. Managing an effective, person-centered consent process
8. Person-centered retention

Kusnoor SV, et al. Design and implementation of a massive open online course on enhancing the recruitment of minorities in clinical trials - Faster Together. BMC Med Res Methodol. 2021 Mar 5;21(1):44.

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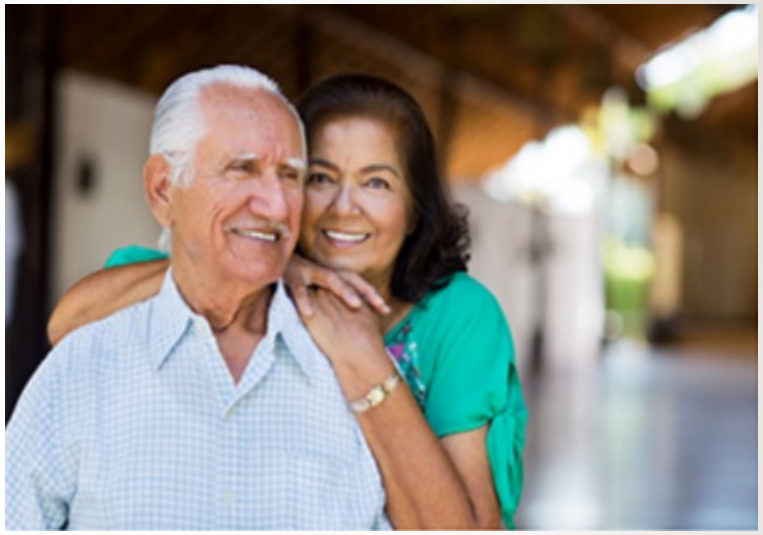
Recruitment & Retention Approach

Ensure recruitment approach and study materials are accessible, tailored, and culturally appropriate

- **Research team is trained on best practices in recruitment**
  - **Example:** Art of Recruitment
- **Study materials are tailored and accessible**
- **Identify opportunities** to raise awareness and reach potential participants – thinking "outside the box"
  - Support groups on social media
  - Hashtag searches
  - Connecting with other care providers (e.g., social workers)
  - Build community awareness through Facebook live events, attending Church events, and other community gatherings



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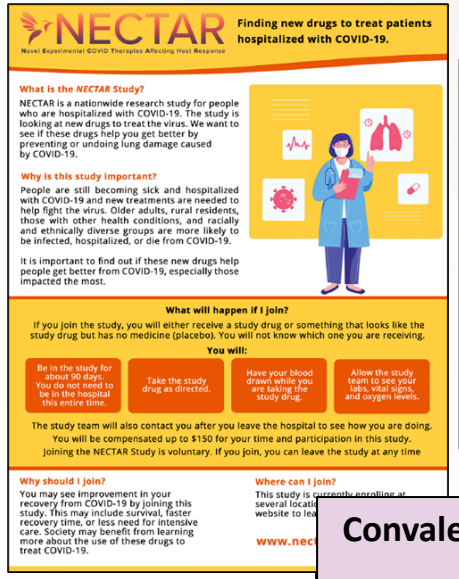
Study materials are tailored and accessible

- Provide supplemental information and educational materials that are approachable – ***the consent form is not enough***
- ***Content should be comprehensive*** and outline study purpose, procedures, end-goal of the study, expectations, and present potential side effects, risks, and benefits
  - Visuals can be useful tools for research procedures
  - Address fears about participation
- Materials are easy to understand ***for all literacy levels***
- Language is transparent, clear, and trust-building
- Available in multiple languages with images that are relatable


NECTAR

Novel Experimental COVID Therapies Affecting Host Response

Finding new drugs to treat patients hospitalized with COVID-19.

What is the *NECTAR* Study?

NECTAR is a nationwide research study for people who are hospitalized with COVID-19. The study is looking at new drugs to treat the virus. We want to see if these drugs help you get better by preventing or undoing lung damage caused by COVID-19.

Why is this study important?

People are still becoming sick and hospitalized with COVID-19 and new treatments are needed to help fight the virus. Older adults, rural residents, those with other health conditions, and racially and ethnically diverse groups are more likely to be infected, hospitalized, or die from COVID-19.

It is important to find out if these new drugs help people get better from COVID-19, especially those impacted the most.

What will happen if I join?

If you join the study, you will either receive a study drug or something that looks like the study drug but has no medicine (placebo). You will not know which one you are receiving.

You will:

- Be in the study for about 90 days. You do not need to be in the hospital this entire time.
- Take the study drug as directed.
- Have your blood drawn while you are taking the study drug.
- Allow the study team to see your labs, vital signs, and oxygen levels.

The study team will also contact you after you leave the hospital to see how you are doing.
You will be compensated up to $150 for your time and participation in this study.
Joining the NECTAR Study is voluntary. If you join, you can leave the study at any time

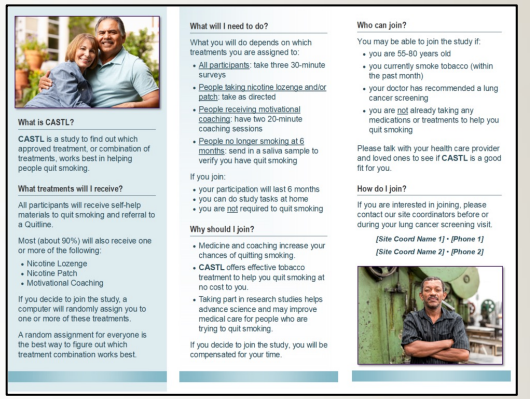
Why should I join?

You may see improvement in your recovery from COVID-19 by joining this study. This may include survival, faster recovery time, or less need for intensive care. Society may benefit from learning more about the use of these drugs to treat COVID-19.

Where can I join?

This study is currently enrolling at several locati
website to lea

www.nec


What is CASTL?

CASTL is a study to find out which approved treatment, or combination of treatments, works best in helping people quit smoking.

What treatments will I receive?

All participants will receive self-help materials to quit smoking and referral to a Quitline.

Most (about 90%) will also receive one or more of the following:

- Nicotine Lozenge
- Nicotine Patch
- Motivational Coaching

If you decide to join the study, a computer will randomly assign you to one or more of these treatments.

A random assignment for everyone is the best way to figure out which treatment combination works best.

What will I need to do?

What you will do depends on which treatments you are assigned to:

- All participants: take three 30-minute surveys
- People taking nicotine lozenge and/or patch: take as directed
- People receiving motivational coaching: have two 20-minute coaching sessions
- People no longer smoking at 6 months: send in a saliva sample to verify you have quit smoking

If you join:

- your participation will last 6 months
- you can do study tasks at home
- you are not required to quit smoking

Why should I join?

- Medicine and coaching increase your chances of quitting smoking.
- **CASTL** offers effective tobacco treatment to help you quit smoking at no cost to you.
- Taking part in research studies helps advance science and may improve medical care for people who are trying to quit smoking.

If you decide to join the study, you will be compensated for your time.

Who can join?

You may be able to join the study if:

- you are 55-80 years old
- you currently smoke tobacco (within the past month)
- your doctor has recommended a lung cancer screening
- you are not already taking any medications or treatments to help you quit smoking

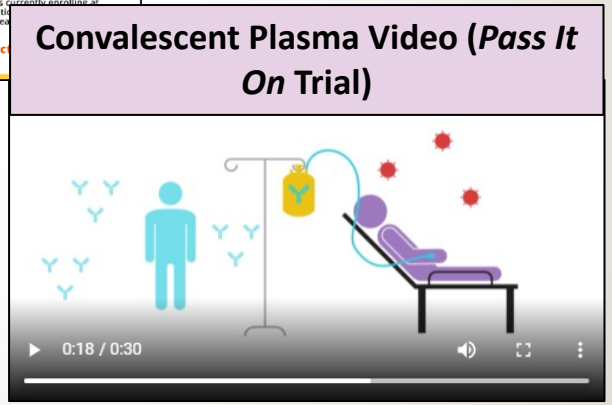
Please talk with your health care provider and loved ones to see if **CASTL** is a good fit for you.

How do I join?

If you are interested in joining, please contact our site coordinators before or during your lung cancer screening visit.

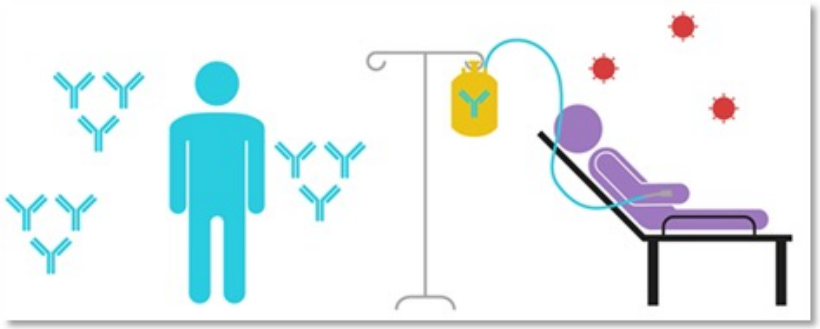
[Site Coord Name 1] - [Phone 1]

[Site Coord Name 2] - [Phone 2]



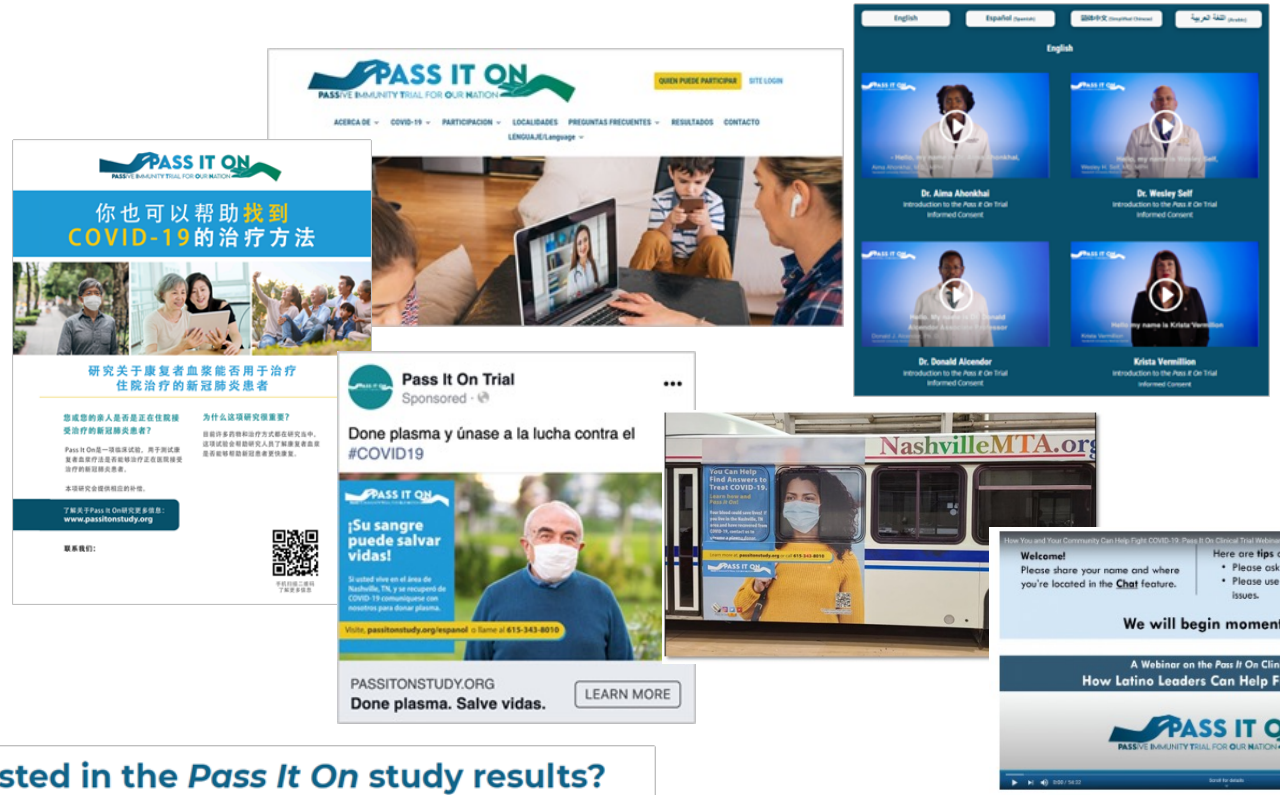
PassITON Trial

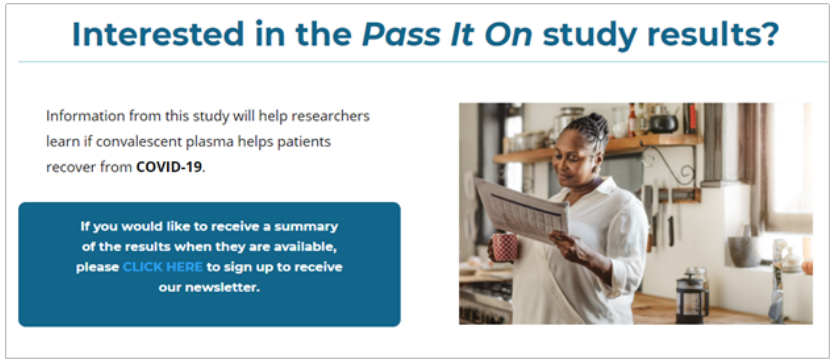
- A multi-center, randomized, placebo-controlled trial to determine if anti-SARS-CoV-2 convalescent plasma is safe and effective in adult hospitalized COVID-19 patients
- Enrollment goal: 1,000 participants across 26 sites
- Partnered with a multi-cultural marketing agency (Culture Shift Team)
  - Develop a comprehensive strategy to raise national awareness at the onset of the trial
  - Broadly share results of trial
  - Emphasis on inclusivity, equity, and diversity
- 40% of study participants identified as Black, Hispanic, Asian, American Indian or Alaska Native, Native Hawaiian, or Multiracial
- The informed consent document was translated into over 20 different languages including Spanish, Arabic, Chinese, and Hindi
- The study website was culturally tailored and was available in 4 different languages



PASS IT ON
PASSIVE IMMUNITY TRIAL FOR OUR NATION

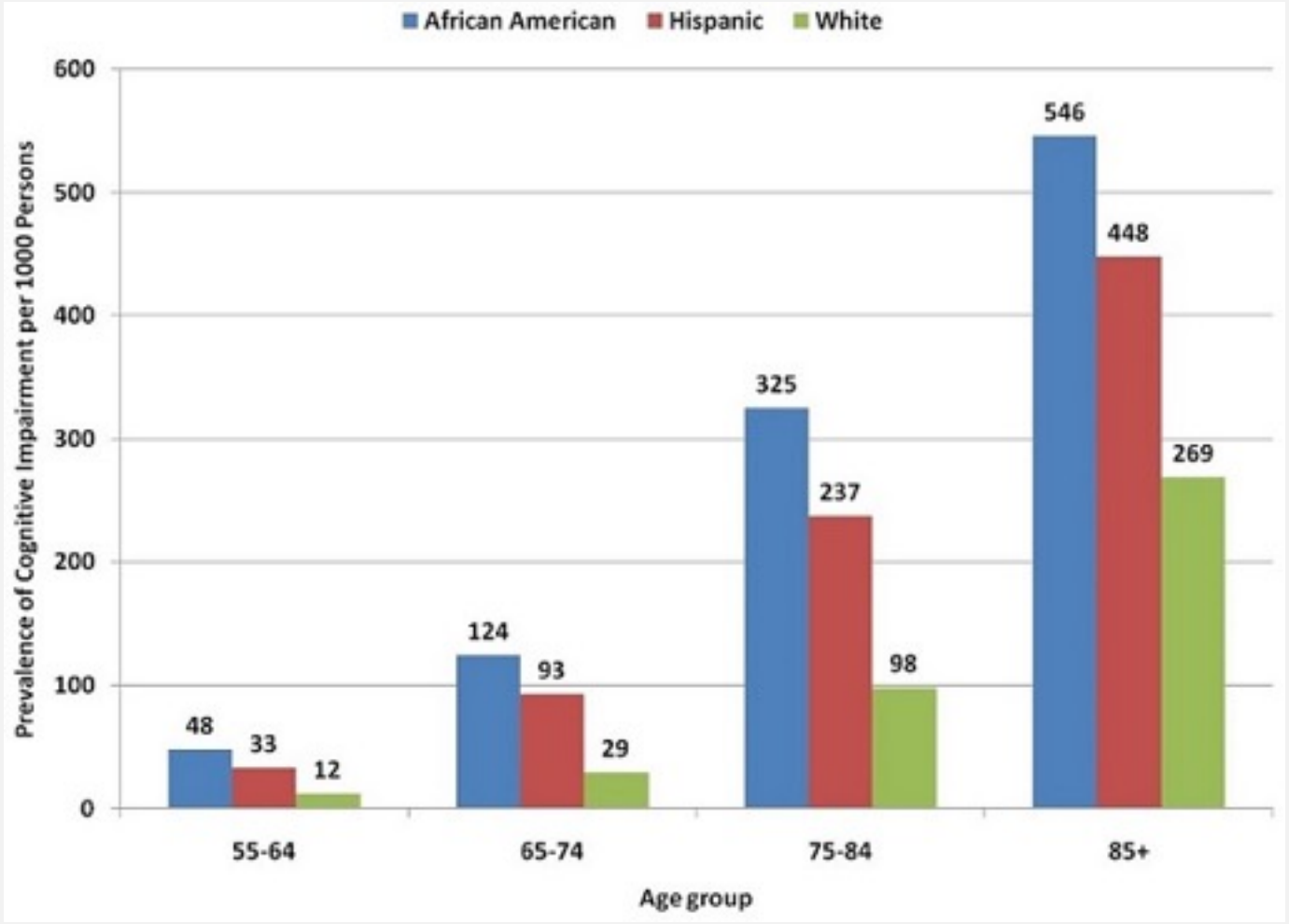
- Study materials
- Outreach efforts
- Broad dissemination of findings





https://passitonstudy.org/results/

Alzheimer Disease Disparities



Alzheimer's Association 2020

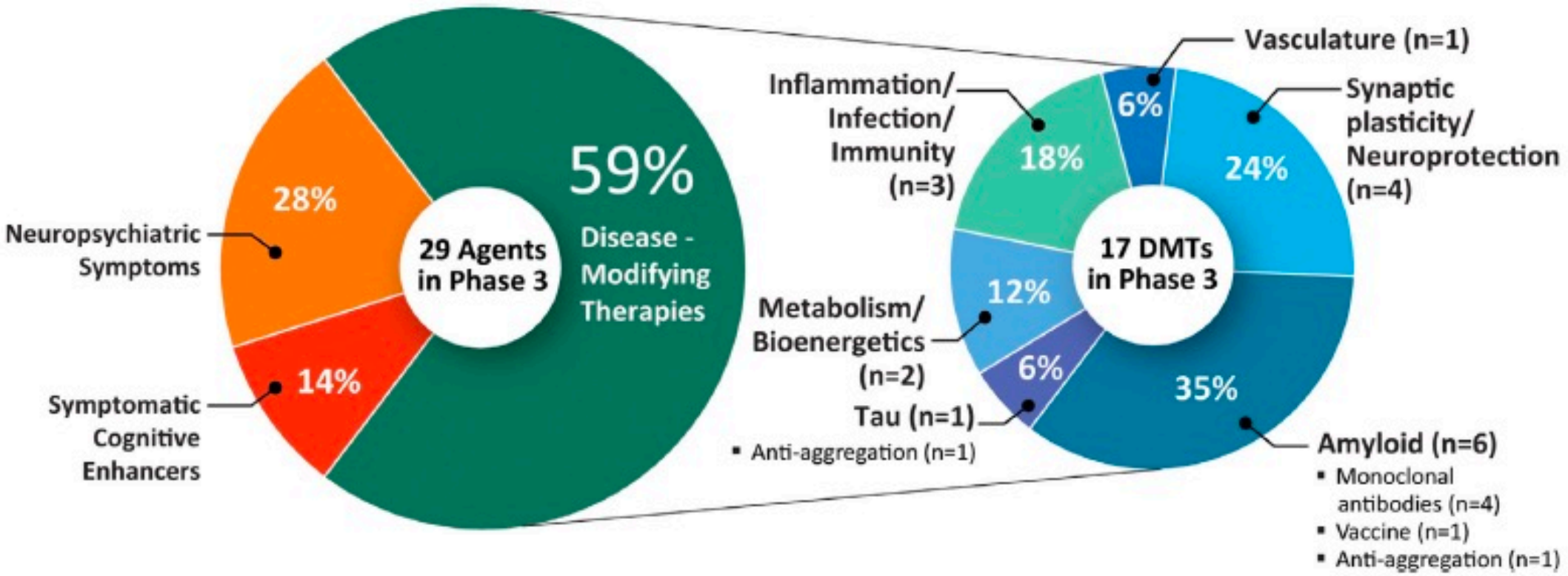


FIGURE 2 Mechanisms of action of agents in Phase 3 of the Alzheimer's disease drug development pipeline (ClinicalTrials.gov accessed February 27, 2020) (Figure by Mike de la Flor)

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Culturally Tailored Materials

Four sets of recruitment materials were reviewed by community members

- General (across all audiences)
- Black/African American Community
- Hispanic/Latinx (English) Community
- Hispanic/Latinx Community (Spanish)
  - Transcreation: Adaptation of Content from one language to another to ensure that messaging is culturally adopted to and resonates with your audience.
  - Used in creative writing and marketing materials

Have you or a loved one noticed changes in your memory and thinking?

Partner with us on our journey to improve medical care for people with memory loss.

New IDEAS is a research study looking for better ways to diagnose and care for people with memory loss by using FDA-approved brain imaging.

You may be able to join if:

- You or a loved one has noticed some changes in your memory and thinking.
- You are seeing a doctor who is participating in the New IDEAS Study.
- You have Medicare as your primary insurance.

Taking part in New IDEAS is up to you. If you join, you can leave the study at any time.

Potential benefits:

- Joining New IDEAS could lead to better care for you, your family, and many others dealing with memory loss.
- With the PET scan, your doctor can better diagnose and treat your memory loss or that of your loved one.
- The New IDEAS Study gives you the opportunity to have Medicare cover the cost of your amyloid PET scan.

For more information, please contact:

866-507-7254

newideas-participant@alz.org

or visit us at:

Ideas-Study.org/PatientHome

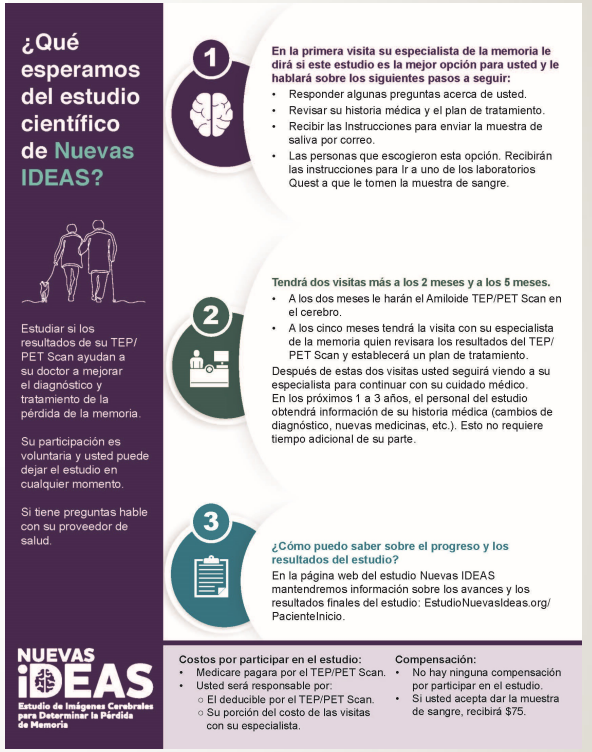
Scan here with smartphone camera

NEW iDEAS Brain Imaging Study for Memory Loss

Directed by: alzheimer's association

Sponsored and Managed by: ACR American College of Radiology

Advised by: Centers for Medicare & Medicaid Services (CMS)



¿Qué esperamos del estudio científico de Nuevas IDEAS?

Estudiar si los resultados de su TEP/PET Scan ayudan a su doctor a mejorar el diagnóstico y tratamiento de la pérdida de la memoria.

Su participación es voluntaria y usted puede dejar el estudio en cualquier momento.

Si tiene preguntas hable con su proveedor de salud.

1

En la primera visita su especialista de la memoria le dirá si este estudio es la mejor opción para usted y le hablará sobre los siguientes pasos a seguir:

- Responder algunas preguntas acerca de usted.
- Revisar su historia médica y el plan de tratamiento.
- Recibir las Instrucciones para enviar la muestra de saliva por correo.
- Las personas que escogieron esta opción. Recibirán las instrucciones para Ir a uno de los laboratorios Quest a que le tomen la muestra de sangre.

2

Tendrá dos visitas más a los 2 meses y a los 5 meses.

- A los dos meses le harán el Amiloide TEP/PET Scan en el cerebro.
- A los cinco meses tendrá la visita con su especialista de la memoria quien revisara los resultados del TEP/PET Scan y establecerá un plan de tratamiento.

Después de estas dos visitas usted seguirá viendo a su especialista para continuar con su cuidado médico. En los próximos 1 a 3 años, el personal del estudio obtendrá información de su historia médica (cambios de diagnóstico, nuevas medicinas, etc.). Esto no requiere tiempo adicional de su parte.

3

¿Cómo puedo saber sobre el progreso y los resultados del estudio?

En la página web del estudio Nuevas IDEAS mantendremos información sobre los avances y los resultados finales del estudio: EstudioNuevasIdeas.org/PacienteInicio.

NUEVAS iDEAS Estudio de Imágenes Cerebrales para Determinar la Pérdida de Memoria

Costos por participar en el estudio:

- Medicare pagara por el TEP/PET Scan.
- Usted será responsable por:
  - El deducible por el TEP/PET Scan.
  - Su porción del costo de las visitas con su especialista.

Compensación:

- No hay ninguna compensación por participar en el estudio.
- Si usted acepta dar la muestra de sangre, recibirá $75.

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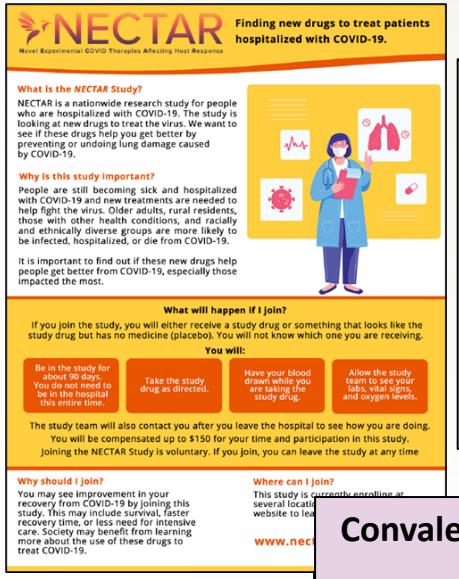
Study materials are tailored and accessible

- Provide supplemental information and educational materials that are approachable – ***the consent form is not enough***
- ***Content should be comprehensive*** and outline study purpose, procedures, end-goal of the study, expectations, and present potential side effects, risks, and benefits
  - Visuals can be useful tools for research procedures
  - Address fears about participation
- Materials are easy to understand ***for all literacy levels***
- Language is transparent, clear, and trust-building
- Available in multiple languages with images that are relatable


NECTAR

Novel Experimental COVID Therapies Affecting Host Response

Finding new drugs to treat patients hospitalized with COVID-19.

What is the *NECTAR* Study?

NECTAR is a nationwide research study for people who are hospitalized with COVID-19. The study is looking at new drugs to treat the virus. We want to see if these drugs help you get better by preventing or undoing lung damage caused by COVID-19.

Why is this study important?

People are still becoming sick and hospitalized with COVID-19 and new treatments are needed to help fight the virus. Older adults, rural residents, those with other health conditions, and racially and ethnically diverse groups are more likely to be infected, hospitalized, or die from COVID-19.

It is important to find out if these new drugs help people get better from COVID-19, especially those impacted the most.

What will happen if I join?

If you join the study, you will either receive a study drug or something that looks like the study drug but has no medicine (placebo). You will not know which one you are receiving.

You will:

- Be in the study for about 90 days. You do not need to be in the hospital this entire time.
- Take the study drug as directed.
- Have your blood drawn while you are taking the study drug.
- Allow the study team to see your labs, vital signs, and oxygen levels.

The study team will also contact you after you leave the hospital to see how you are doing.
You will be compensated up to $150 for your time and participation in this study.
Joining the NECTAR Study is voluntary. If you join, you can leave the study at any time

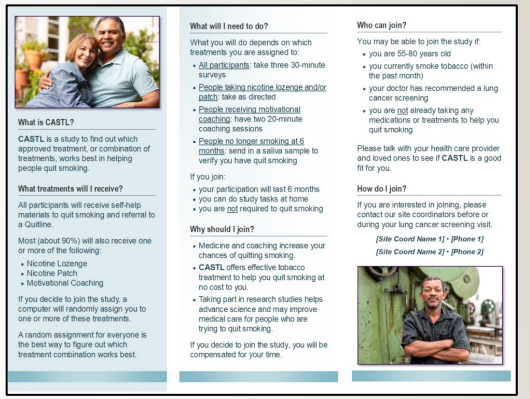
Why should I join?

You may see improvement in your recovery from COVID-19 by joining this study. This may include survival, faster recovery time, or less need for intensive care. Society may benefit from learning more about the use of these drugs to treat COVID-19.

Where can I join?

This study is currently enrolling at several locati
website to lea

www.nec


What is CASTL?

CASTL is a study to find out which approved treatment, or combination of treatments, works best in helping people quit smoking.

What treatments will I receive?

All participants will receive self-help materials to quit smoking and referral to a Quitline.

Most (about 90%) will also receive one or more of the following:

- Nicotine Lozenge
- Nicotine Patch
- Motivational Coaching

If you decide to join the study, a computer will randomly assign you to one or more of these treatments.

A random assignment for everyone is the best way to figure out which treatment combination works best.

What will I need to do?

What you will do depends on which treatments you are assigned to:

- All participants: take three 30-minute surveys
- People taking nicotine lozenge and/or patch: take as directed
- People receiving motivational coaching: have two 20-minute coaching sessions
- People no longer smoking at 6 months: send in a saliva sample to verify you have quit smoking

If you join:

- your participation will last 6 months
- you can do study tasks at home
- you are not required to quit smoking

Why should I join?

- Medicine and coaching increase your chances of quitting smoking.
- **CASTL** offers effective tobacco treatment to help you quit smoking at no cost to you.
- Taking part in research studies helps advance science and may improve medical care for people who are trying to quit smoking.

If you decide to join the study, you will be compensated for your time.

Who can join?

You may be able to join the study if:

- you are 55-80 years old
- you currently smoke tobacco (within the past month)
- your doctor has recommended a lung cancer screening
- you are not already taking any medications or treatments to help you quit smoking

Please talk with your health care provider and loved ones to see if **CASTL** is a good fit for you.

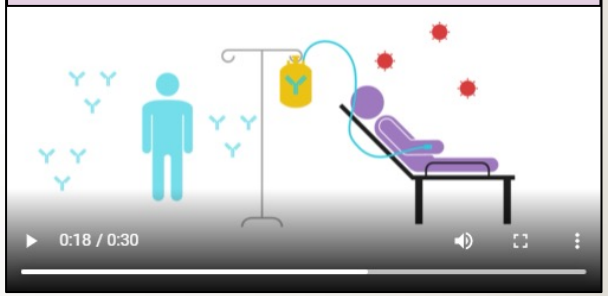
How do I join?

If you are interested in joining, please contact our site coordinators before or during your lung cancer screening visit.

[Site Coord Name 1] - [Phone 1]

[Site Coord Name 2] - [Phone 2]

Convalescent Plasma Video (*Pass It On* Trial)



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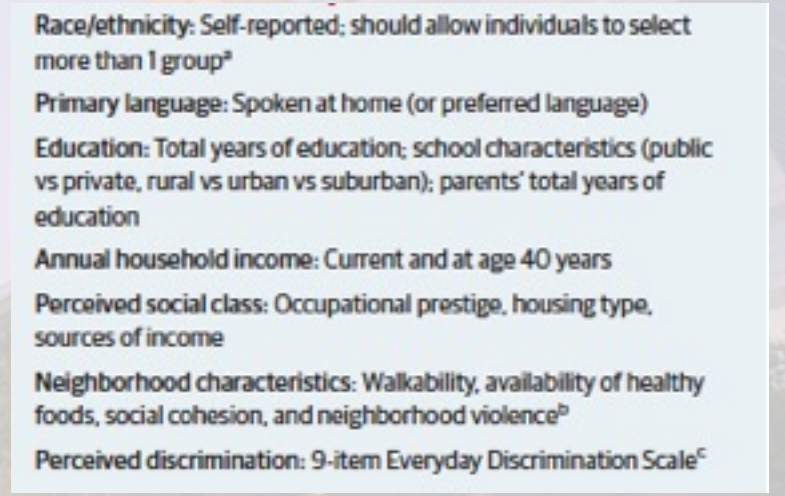
Designing Scientifically Just Research

- Does the study population reflect the burden of the disease?
- Has race been defined? Is it clear how race will be used?
- Are social and structural determinants of health included?
- If White people are the control, why? Is this justified?

Example of demographic data to collect



Race/ethnicity: Self-reported; should allow individuals to select more than 1 group[a]

Primary language: Spoken at home (or preferred language)

Education: Total years of education; school characteristics (public vs private, rural vs urban vs suburban); parents' total years of education

Annual household income: Current and at age 40 years

Perceived social class: Occupational prestige, housing type, sources of income

Neighborhood characteristics: Walkability, availability of healthy foods, social cohesion, and neighborhood violence[b]

Perceived discrimination: 9-item Everyday Discrimination Scale[c]

Wilkins, Schindler, Morris. JAMA Neurol. 2020 Sep 1;77(9): 1063-1064.

Consuelo H. Wilkins, MD, MSCI; Senior Vice President and Senior Associate Dean for Health Equity; Professor of Medicine; Vanderbilt University Medical Center

@DrCHWilkins

January 20, 2202

The Urgency of Justice in Research

Andrea Gilmore-Bykovskyi, Jonathan D. Jackson, Consuelo H. Wilkins

"Despite good intentions, we propagate and maintain a system where non-white populations bear the burden of disease but do not reap the benefits of research advances."

Proposed actions the scientific community should adopt:

- **Strengthen compliance, transparency and accountability in clinical research enrollment**
- **Address exclusionary research practices**
- **Invest in sustained, reciprocal relationships with marginalized communities**
- **Ensure enrollment goals are scientifically valid and reflect burden of disease**
- **Develop evidence-based guidance to inform inclusive research participation**

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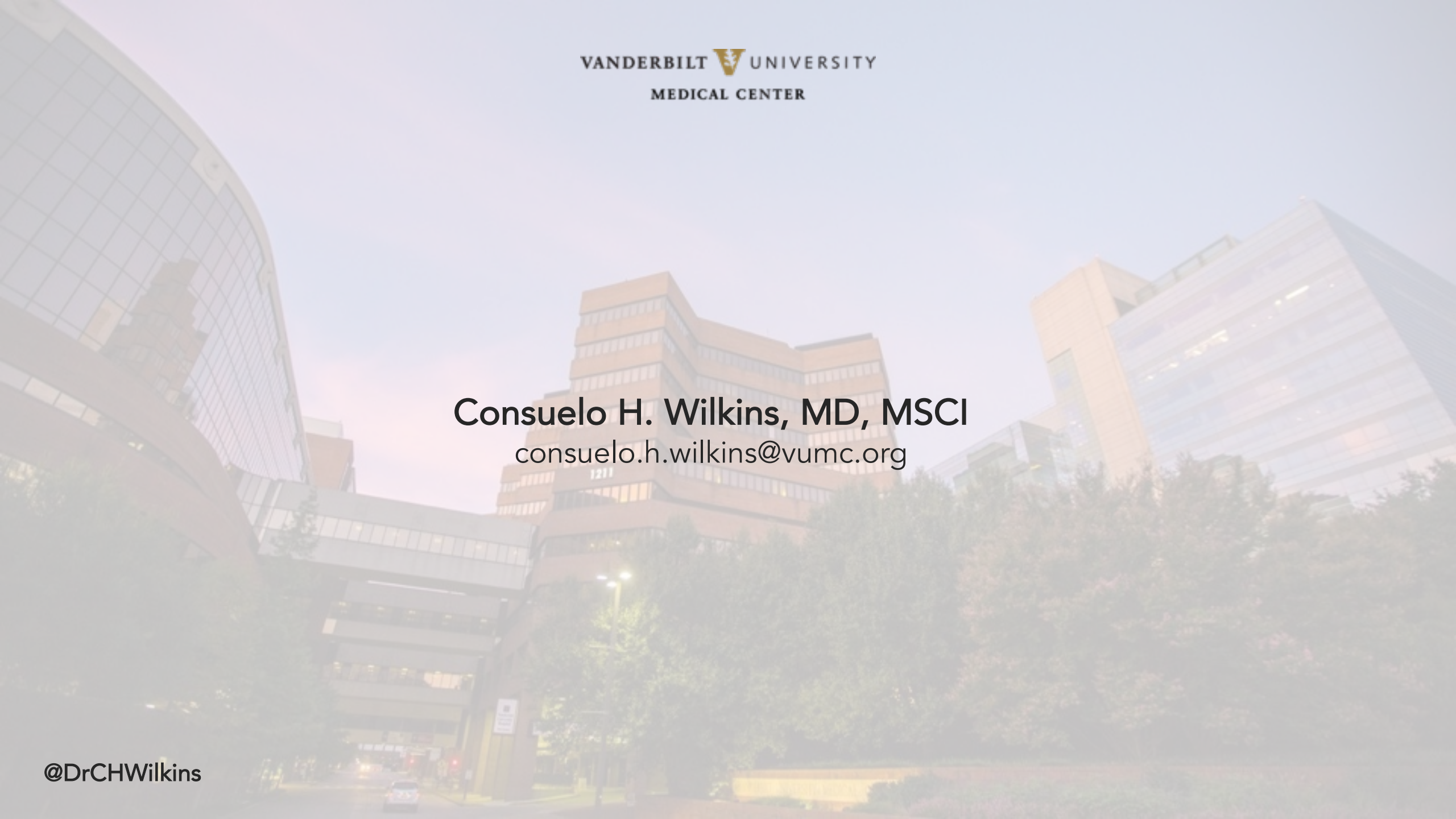
Trends in Molecular Medicine, 2020. https://doi.org/10.1016/j.molmed.2020.11.004
http://www.sciencedirect.com/science/article/pii/S1471491420302872



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