

ADVISORY PANEL ON PATIENT ENGAGEMENT MEETING

Via GoToWebinar

Spring 2020 Meeting

Day One, June 4, 2020
11:30am-2:55pm EDT



Welcome

Kristin L. Carman
Director, Public and Patient Engagement

Thomas Scheid
Chair, Advisory Panel on Patient
Engagement



Day One: Thursday



Part I (EDT):

- 11:30 AM – Welcome and Roll Call
- 11:45 AM – Dr. Nakela Cook, Executive Director, PCORI
- 12:30 PM – COVID-19: PCORI Immediate Commitments and Frontline Perspectives
- 1:45 PM – Break

Part 2 (EDT):

- 2:15 PM – Advisory Panel Discussion: COVID-19
- 2:55 PM – Public Meeting Adjourns
- 3:10 PM – Diversity, Equity and Inclusion Session (CLOSED SESSION)
- 4:30 PM – Diversity, Equity and Inclusion Session Adjourns

Day Two



Part I (EDT):

- 11:30 AM – Welcome
- 11:40 AM – PCORI Reauthorization Activities: Update on National Priorities & Research Agenda
- 12:10 PM – Building Awareness and Encouraging Use of PCORI's Engagement Learnings
- 12:25 – PEAPs in Action: Current Advances in Patient-focused Drug Development
- 1:05 PM – Break

Part 2 (EDT):

- 1:30 PM – Virtual Engagement: Lessons from a Cystic Fibrosis Community
- 2:10 PM – Appreciation and Farewells
- 2:45 PM – Wrap-up
- 3:15 PM – Adjourn (complete post-event survey)

Housekeeping



- Meeting is available to the public and is being recorded
- Members of the public are invited to listen to this teleconference and view the webinar
- No public comment period is scheduled
- A meeting summary and materials will be made available on PCORI's website following the meeting
- Visit www.pcori.org/events for more information on future activities

GoToWebinar Housekeeping

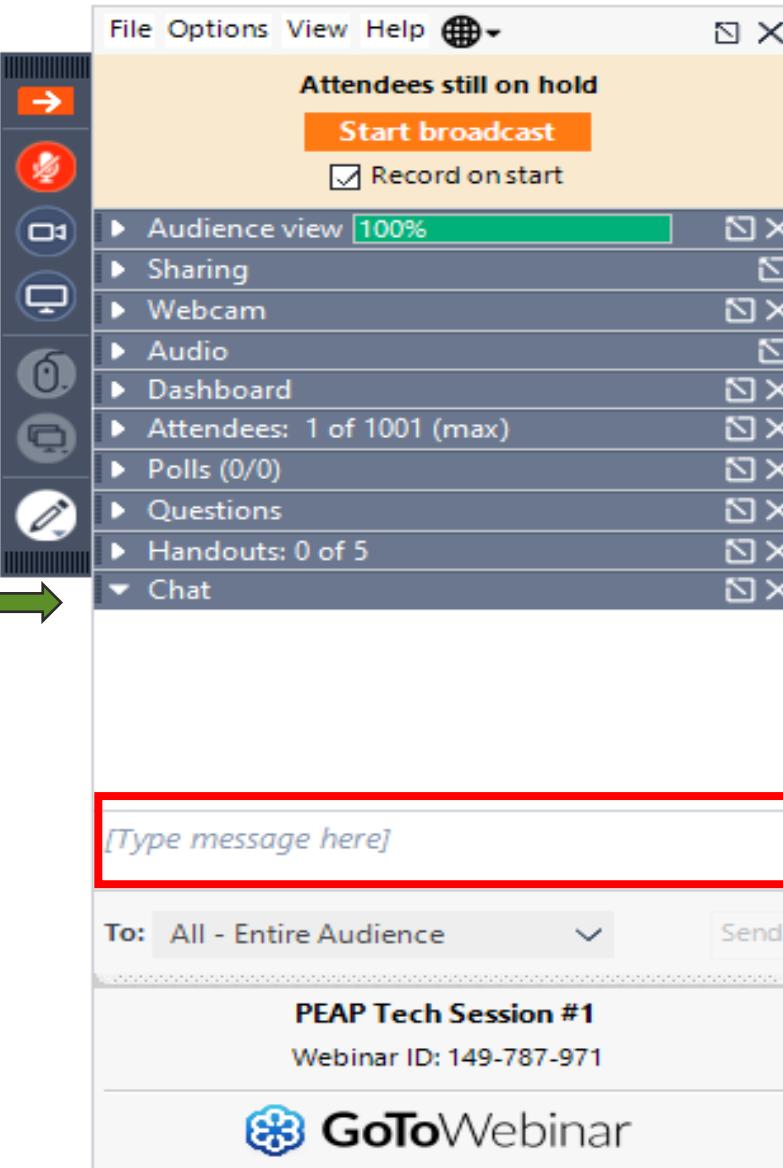


- Attendees are in listen-only mode
- Panelists (PCORI PEAP) can mute/unmute themselves
 - Please keep yourself on mute when not talking
- Submitting questions/comments (PCORI PEAP)
 - Type "I have a question/comment"
- If you need to leave the meeting early, please send Lisa a note so we aren't concerned that you are having connectivity issues

How to Ask Questions – Panelist Instructions

You are muted

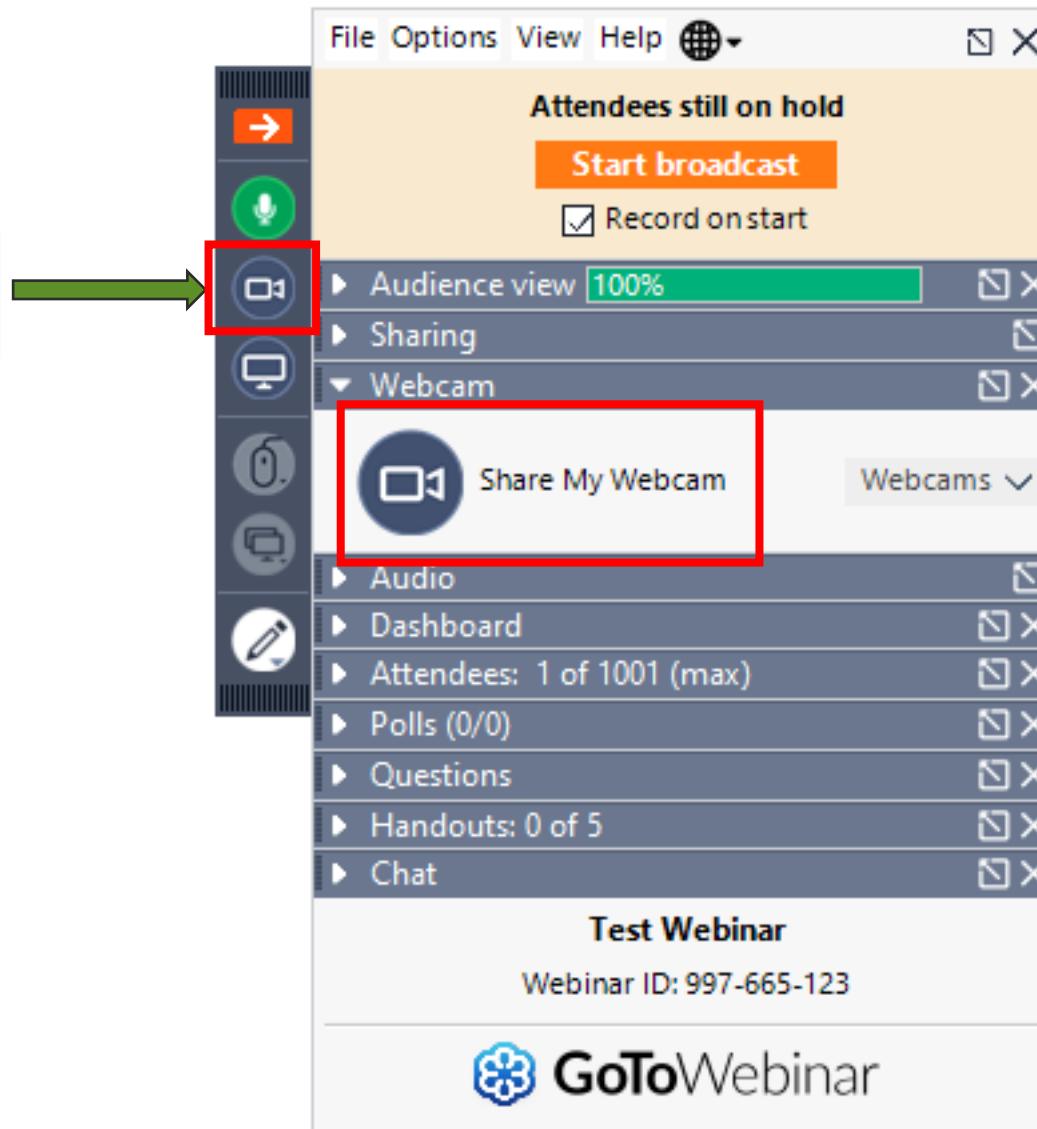
Type “I have a comment” in the chat box



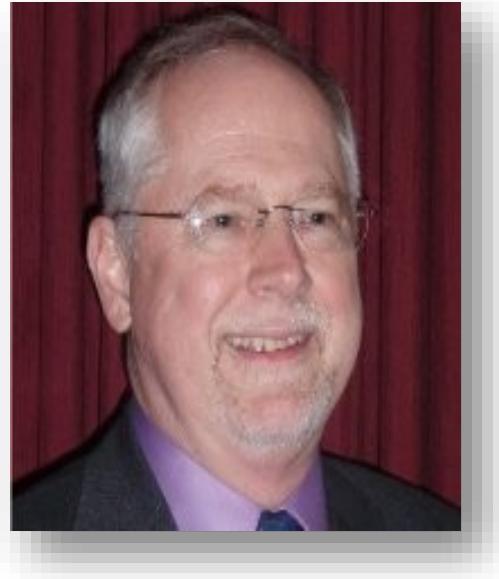
The screenshot shows a software interface for managing a webinar. At the top, a message says "Attendees still on hold" with a "Start broadcast" button and a checked "Record on start" checkbox. On the left, a vertical toolbar has icons for audio, video, and other controls. The main pane lists various session features: Audience view (100% highlighted in green), Sharing, Webcam, Audio, Dashboard, Attendees (1 of 1001 max), Polls (0/0), Questions, Handouts (0 of 5), and Chat. A red box highlights the "Chat" section. Below the list is a text input field with the placeholder "[Type message here]" and a red border. At the bottom, it says "To: All - Entire Audience" and "Send". The footer displays "PEAP Tech Session #1" and "Webinar ID: 149-787-971". The GoToWebinar logo is at the bottom right.

How to Turn on Your Webcam – Panelist Instructions

Click to turn webcam on/off. Icon is green when on.



PEAP Chair and Co-chair



Thomas Scheid, MA

Chair

Founding Board Member

Welcome Home for Life Network

*Representing: Patients, Caregivers,
and Patient Advocates*



Gwen Darien

Co-chair

Executive Vice President, Patient Advocacy

Patient Advocate Foundation

*Representing: Patients, Caregivers, and
Patient Advocates*

The PCORI PEAP Team



Kristin Carman, MA, PhD
Director,
Public and Patient
Engagement



Lisa Stewart, MA
Senior Engagement Officer,
Public and Patient
Engagement



Meghan Berman, MPH
Program Associate,
Public and Patient
Engagement



Aleksandra Modrow
Senior Administrative
Assistant,
Public and Patient
Engagement

Roll Call - Advisory Panel Members



Sonya Ballentine
Patients, Caregivers,
and Advocacy
Organizations



Jennifer Canvasser
Patients, Caregivers,
and Advocacy
Organizations



Katherine Capperella
Industry



Beth Careyva
Researchers



Tracy Carney
Patients, Caregivers,
and Advocacy
Organizations



Gwen Darien
Patients, Caregivers,
and Advocacy
Organizations



Sarah Donelson
Industry



Maureen Fagan
Clinicians



Marilyn Geller
Patients, Caregivers,
and Advocacy
Organizations



Crispin Goytia
Patients, Caregivers,
and Advocacy
Organizations



James Harrison
Researchers



Jill Harrison
Patients, Caregivers,
and Advocacy
Organizations

Roll Call - Advisory Panel Members



Matthew Hudson
*Patients, Caregivers,
and Advocacy
Organizations*



Simon Mathews
Clinicians



Anita Roach
*Patients, Caregivers,
and Advocacy
Organizations*



Brendaly Rodriguez
*Patients, Caregivers,
and Advocacy
Organizations*



Beverly Rogers
*Patients, Caregivers,
and Advocacy
Organizations*



Thomas Scheid
*Patients, Caregivers,
and Advocacy
Organizations*



Norah Schwartz
Researchers



Umair Shah
Policy Makers



Sandy Sufian
*Patients, Caregivers,
and Advocacy
Organizations*



Danny van Leeuwen
*Patients, Caregivers, and
Advocacy Organizations*

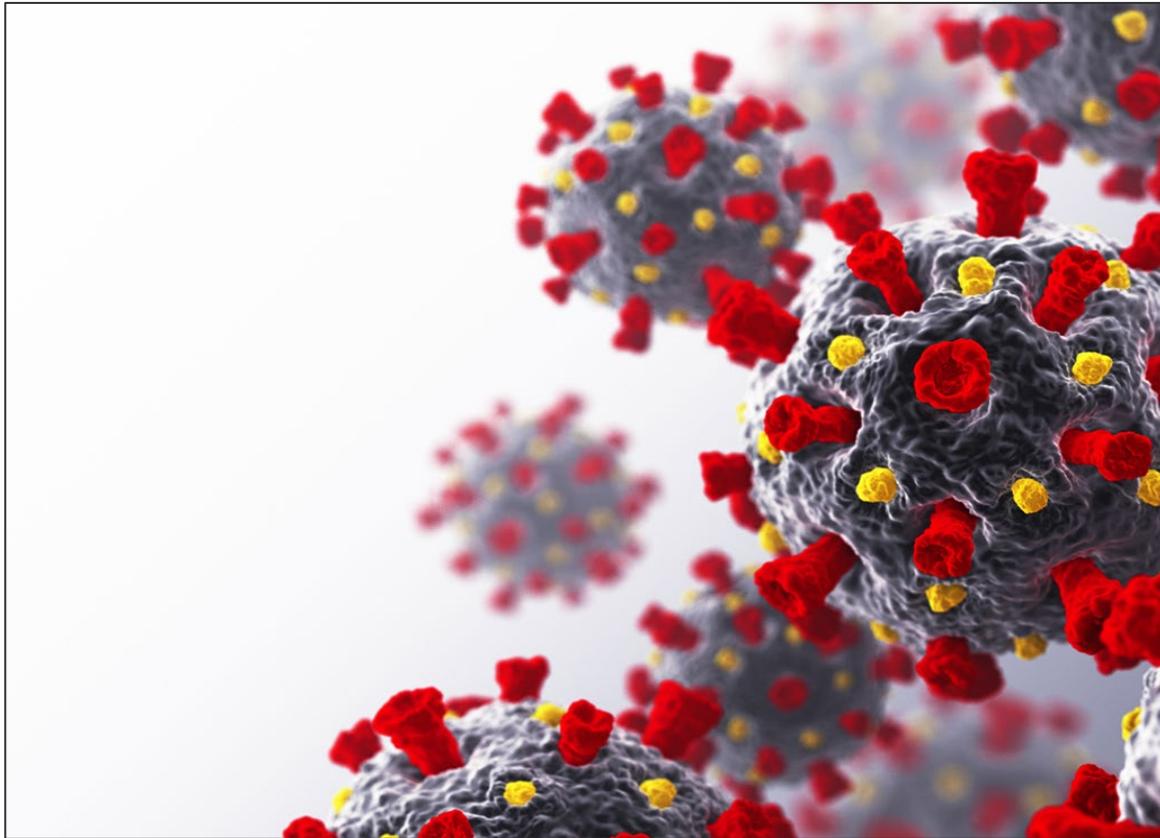


**Freddie White-
Johnson**
*Patients, Caregivers,
and Advocacy
Organizations*



Neely Williams
*Patients, Caregivers,
and Advocacy
Organizations*

Our World. Our Work.



Introduction to Dr. Nakela Cook

Kristin L. Carman
Director, Public & Patient Engagement

*Following presentation, remarks and questions presented by:
Thomas Scheid (Chair) and Gwen Darien (Co-chair)*



Executive Director Report

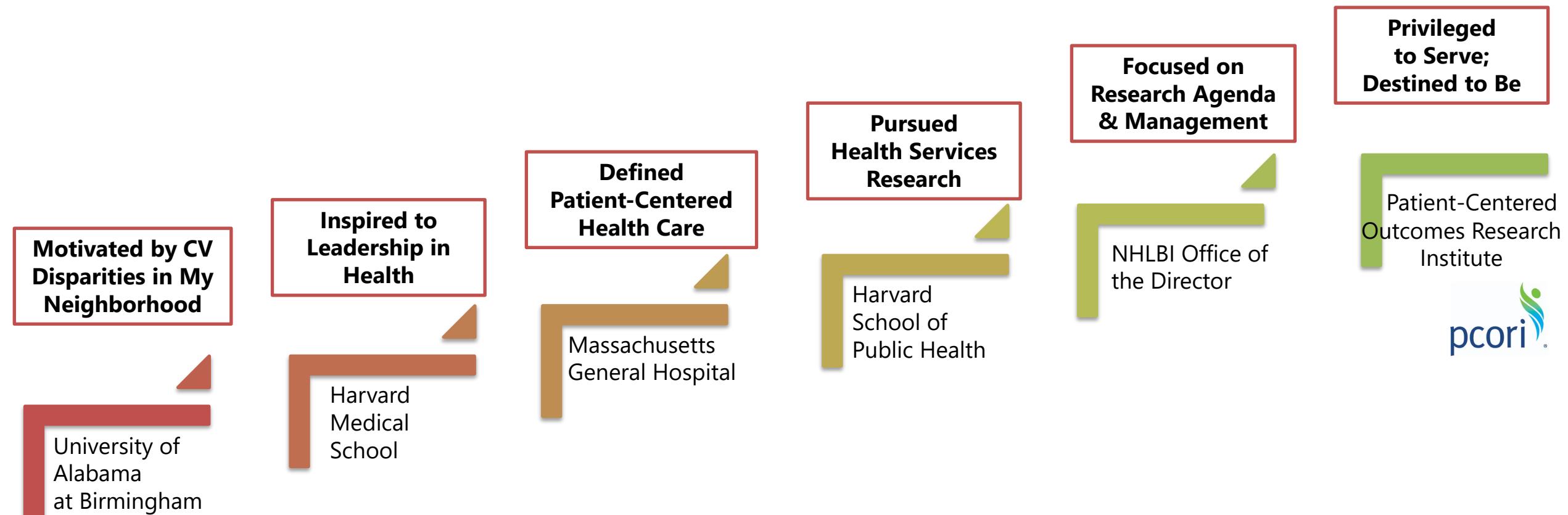
Nakela L. Cook, MD, MPH
Executive Director

Navigating Our Course Together



- **My First Few Months at PCORI**
 - My Personal Journey
 - Early Onboarding
 - Passionate and Mission-Driven PCORI Staff and Board
- **Envisioning PCORI 2.0**
 - Opportunities for the Future
 - Learning in a Public Health Crisis
- **Our Course Together**
 - Year 1 Priorities

My Journey: Fulfilling a Life's Purpose



Outstanding, Resilient Staff and Passionate, Mission-Driven Panels and Committees at the Heart of PCORI



- **Overcoming Challenges in Pursuit of the Mission**

"Courage is simply doing whatever is needed in pursuit of the vision"

— Peter M. Senge, The Fifth Discipline: The Art & Practice of The Learning Organization

- **Dedicated and Mission-Driven**

- Amazing Ambassadors
- Engagement expertise that informs programs and evaluation
- Amplification of the reach of PCORI's mission

A true testament to your efforts



Thank You for Your Service and Contributions



Sonya Ballentine
*Peer Navigator, Illinois
Institute of Technology*



Katherine Capperella
*Global Patient Engagement,
Johnson & Johnson*



Beverly Rogers
*Founder, Bev J Rogers
Enterprises*



Thomas Scheid
*Founding Director, Welcome
Home for Life Network*



Norah Schwartz
*Researcher, El Colegio de la
Frontera Norte*



Brendaly Rodriguez
*Past President, FL Community Health
Worker Coalition; Univ. of Miami CTSA*



Freddie White-Johnson
*Founder, Fannie Lou Hamer Cancer
Foundation; Univ. of Southern Miss.*

We salute our retiring members!

Navigating Our Course Together

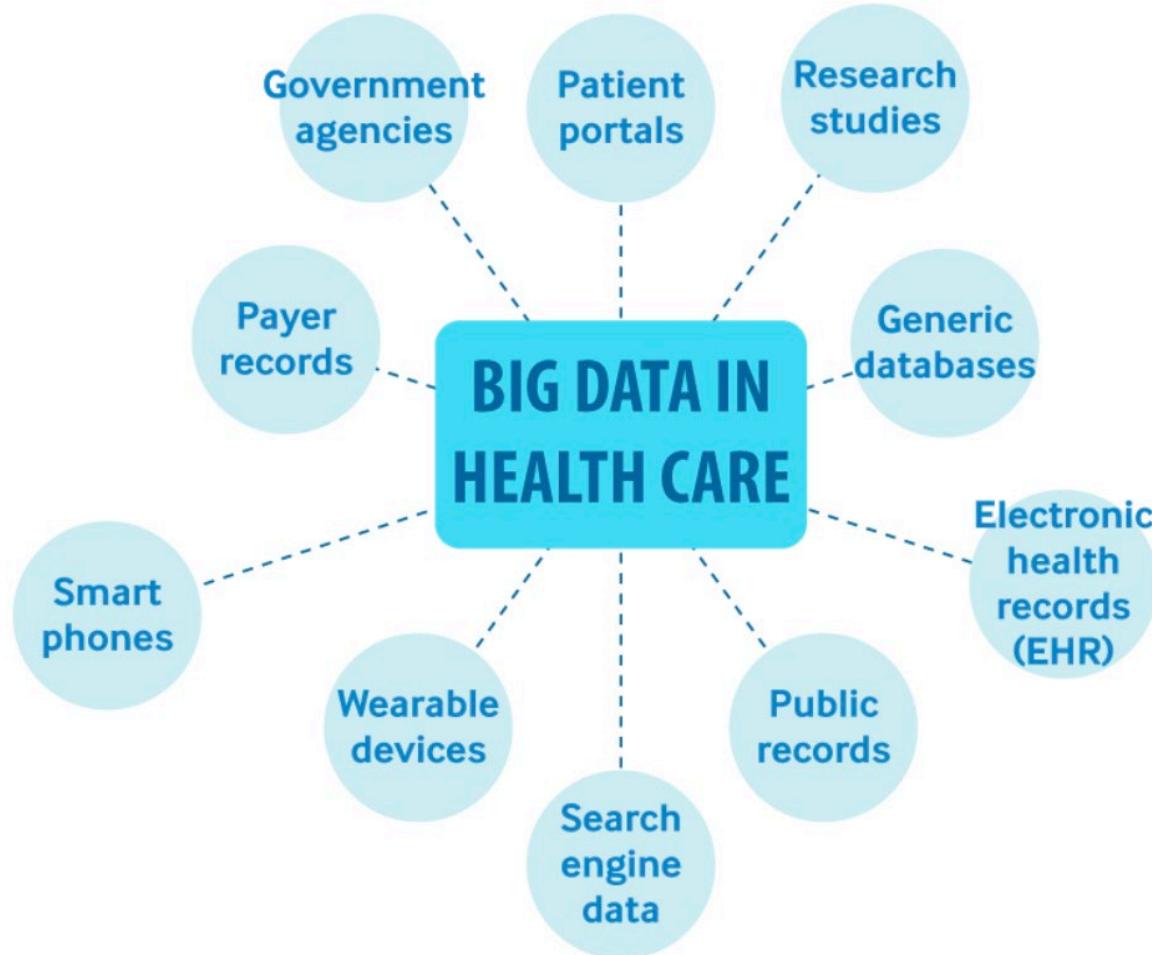


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Evolving Healthcare and Research Landscape in a Big Data Era



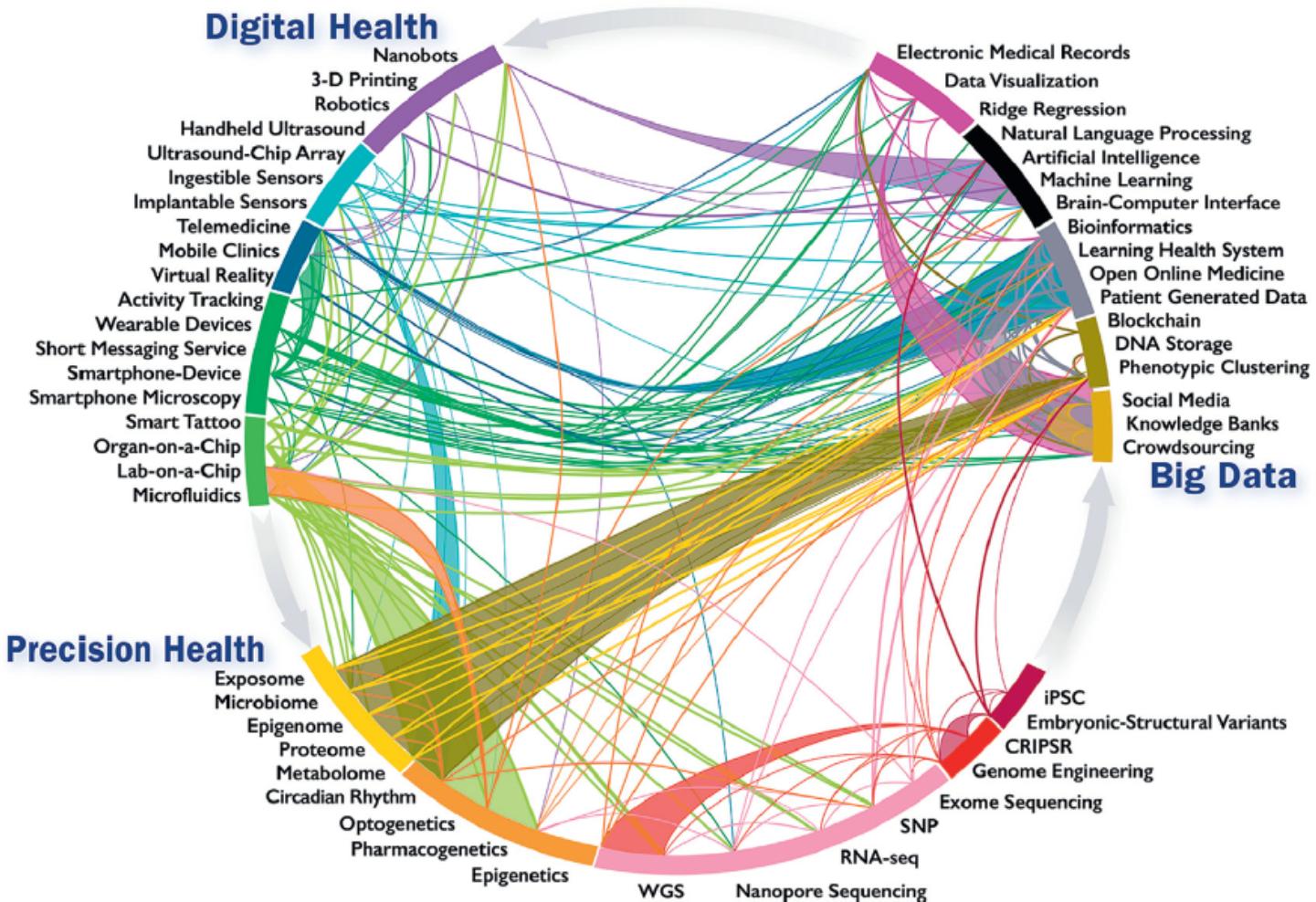
Sources of Big Data in Healthcare



Applications for Big Data in Healthcare



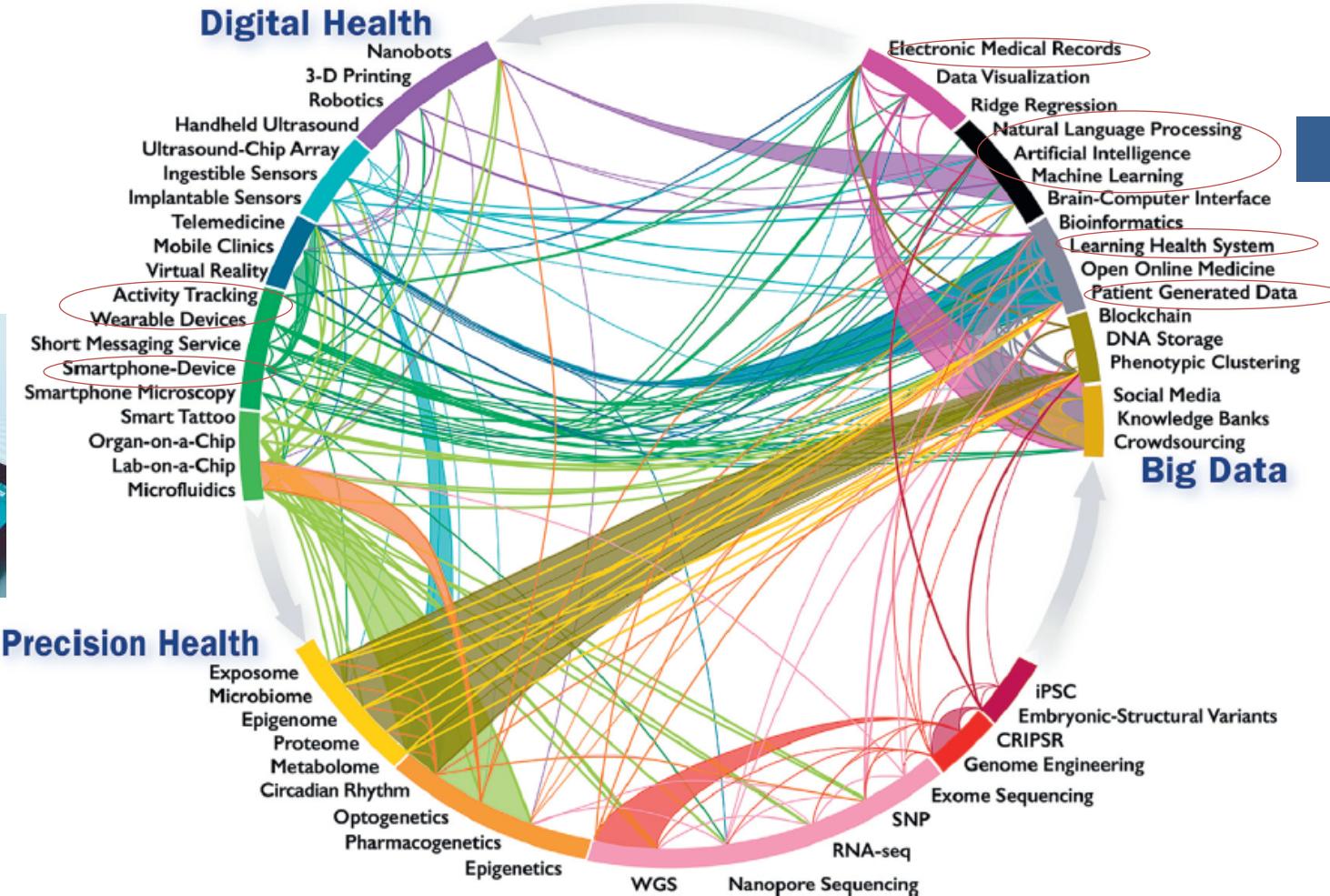
Leveraging Innovations in Healthcare to Promote the Science of Delivery for Improved Outcomes



Leveraging Innovations in Healthcare to Promote the Science of Delivery for Improved Outcomes



Patient-Centered



Despite Marked Improvements in Health, Disparities and Variation in Care Still Remain

This Issue Views 90,724 | Citations 22 | Altmetric 4322

Special Communication

November 26, 2019

Life Expectancy and Mortality Rates in the United States, 1959-2017

Steven H. Woolf, MD, MPH¹; Heidi Schoomaker, MAEd^{2,3}

» Author Affiliations

JAMA. 2019;322(20):1996-2016. doi:10.1001/jama.2019.16932

<https://jamanetwork.com/journals/jama/article-abstract/2756187>

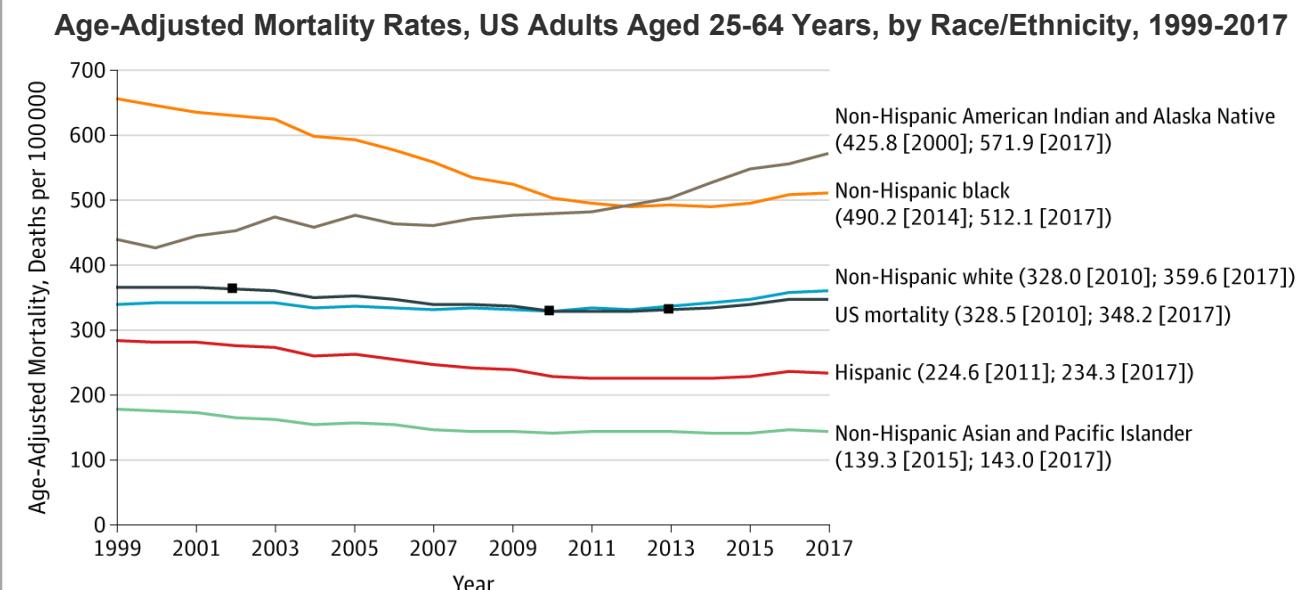
Black curve indicates age-adjusted mortality for all US adults aged 25 to 64 years; bolded data points indicate joinpoint years, when the linear trend (slope) changed significantly based on joinpoint analysis. The lowest mortality rates per 100 000 (and the years they were achieved) are listed first in parentheses; mortality rates for 2017 listed second. Source: CDC WONDER. Copyright 2019 American Medical Association. All Rights Reserved. Date of download: 4/28/20

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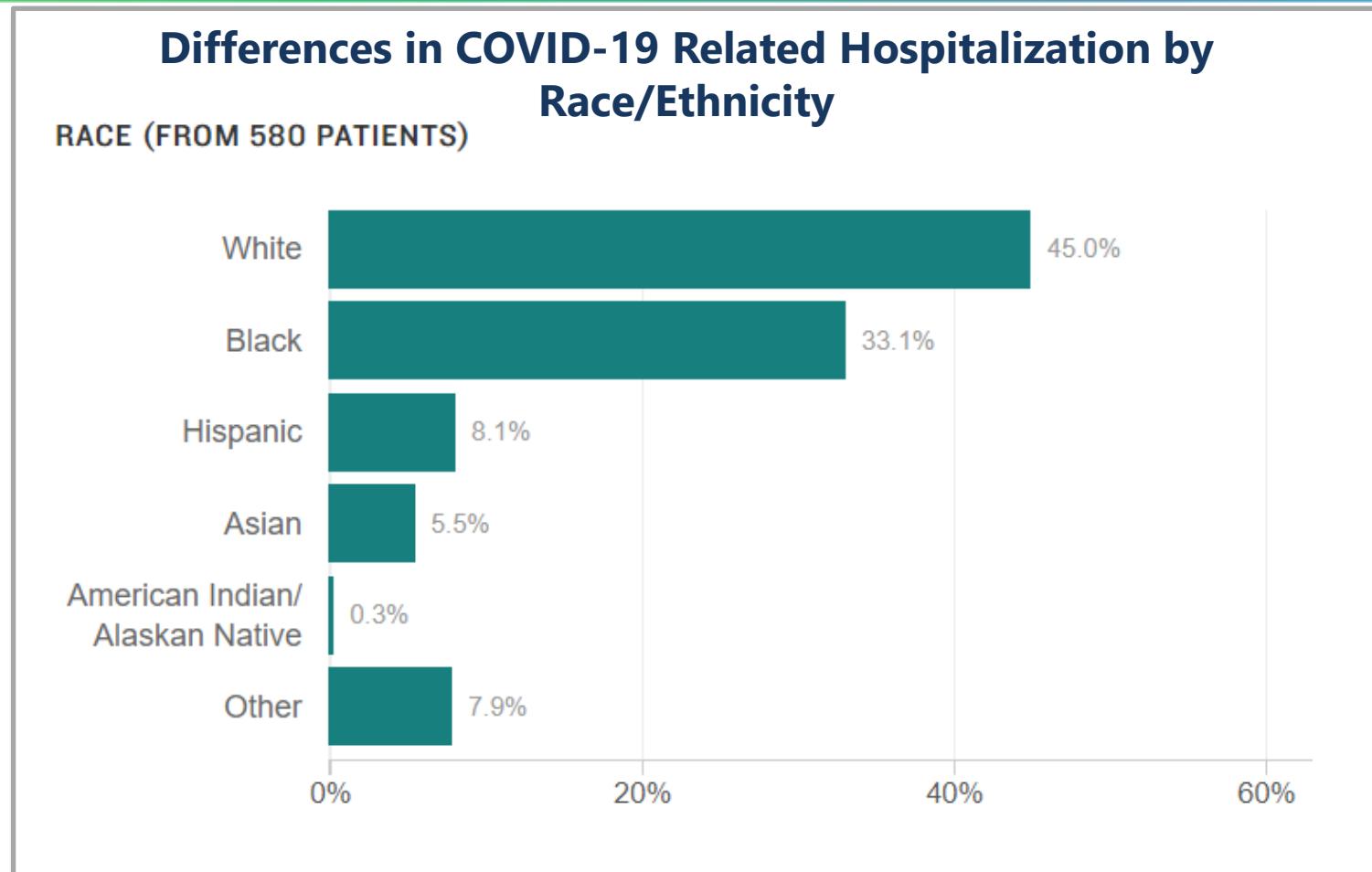
The analysis documents a host of health disparities by geography, sex, and race... The authors also consider how poverty, income inequality, unstable employment, psychological distress, and divergent state policy choices could explain these outcomes, especially for vulnerable populations.

Quote from Associated Editorial

Koh HK, et al. Confronting the Rise and Fall of US Life Expectancy. JAMA. Nov 2019. <https://jamanetwork.com/journals/jama/fullarticle/2756159>

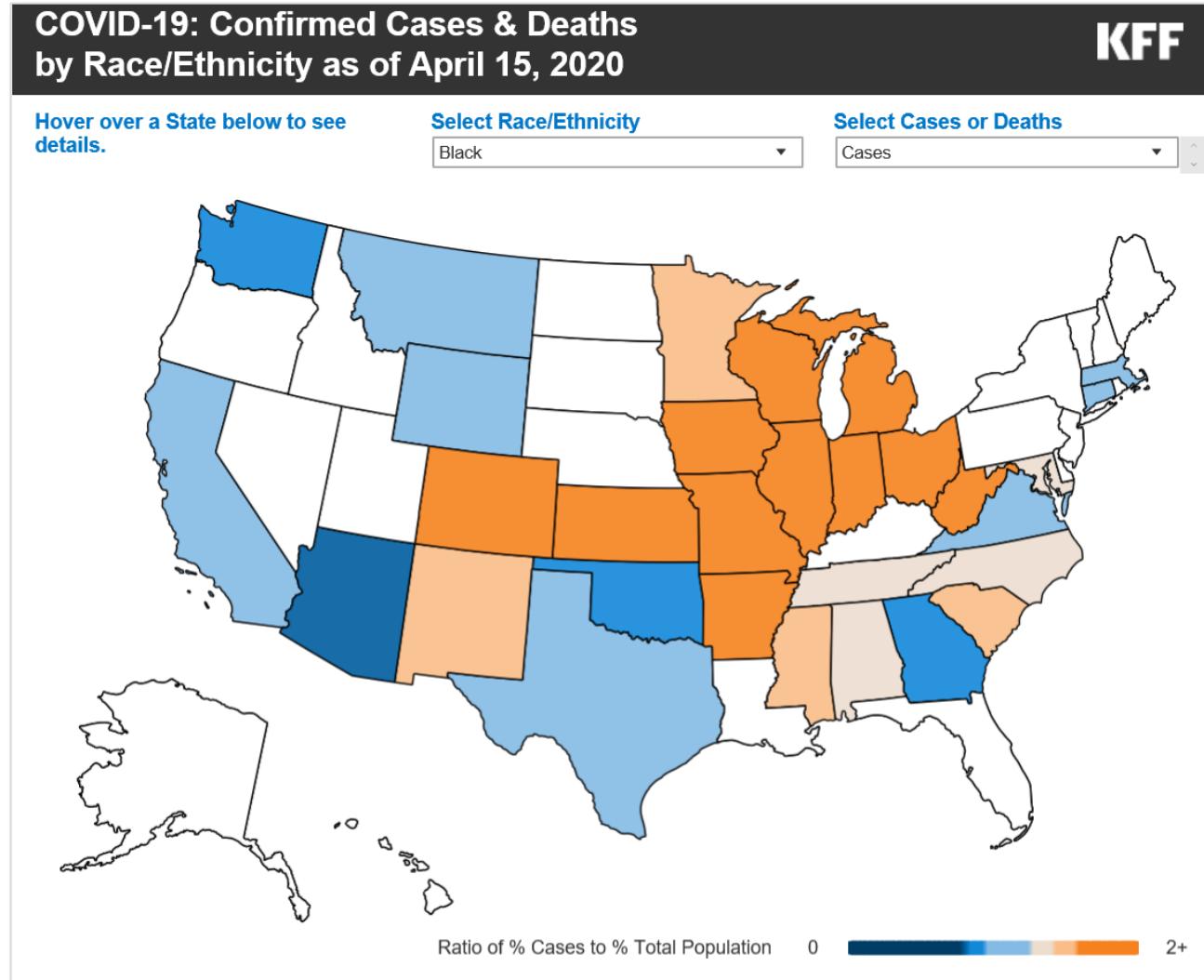


COVID-19 Outcomes Clearly Elucidate the Challenge of Health Disparities



Source: Aubrey A, Neel J. CDC Hospital Data Point To Racial Disparity In COVID-19 Cases. April 8, 2020. ([link](#))
Data from Centers for Disease Control and Prevention ([link](#)); Figure credit: Stephanie Adeline/NPR

Emerging Data: Unmasking the Interplay Between Race/Ethnicity and COVID-19

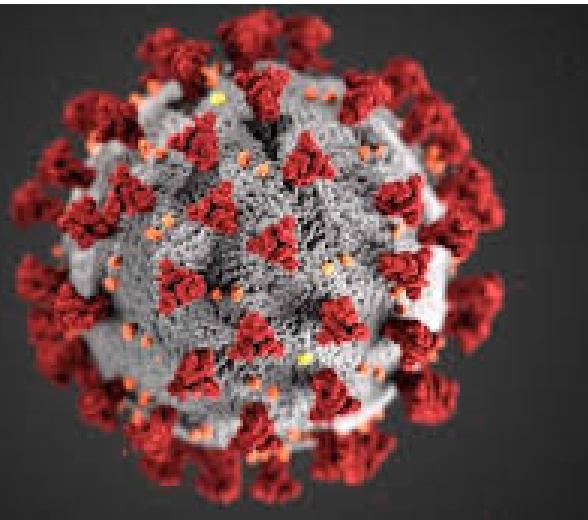


Source: Kaiser Family Foundation. [COVID-19: Confirmed Cases & Deaths by Race/Ethnicity as of April 15, 2020](#). Distribution of Cases/Deaths by Race/Ethnicity based on KFF analysis of publicly available state websites. Total State Population Distribution by Race/Ethnicity based on KFF analysis of 2018 American Community Survey. Accessed 4/28/20

A Pandemic of Unprecedented Scale and Consequences



Cumulative Confirmed Cases of COVID-19:
>6 million worldwide

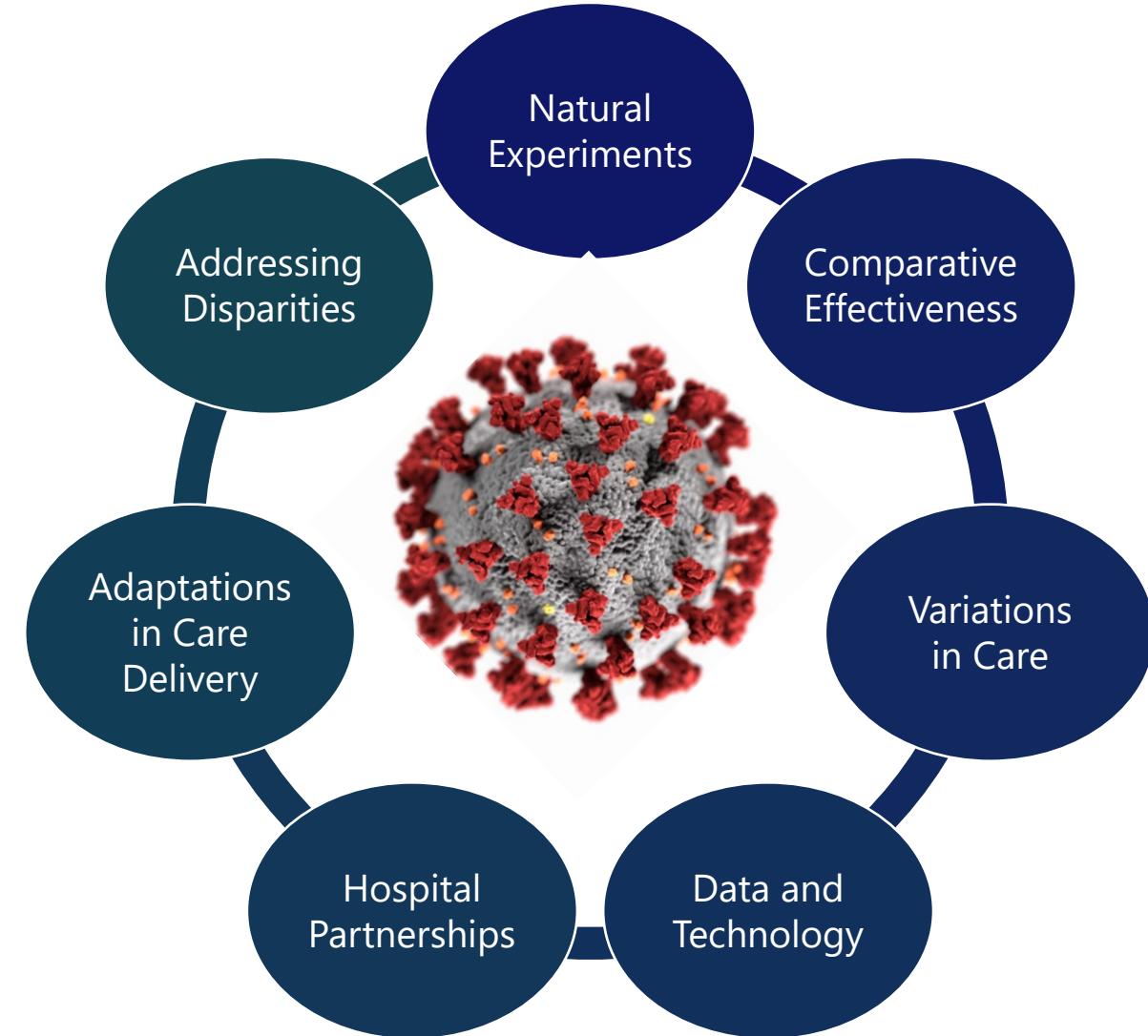


Source: COVID-19 Dashboard by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University (JHU). <https://coronavirus.jhu.edu/map.html> Accessed 4/28/20.

COVID-19 Pandemic – Not Only a Stress Test, But Also Learning Opportunity



Advancing PCORI 2.0
A Learning Organization
Nimbly Embracing
Opportunities in a Crisis for
Short and Long-term Impact



A Multi-Pronged Approach in Response to the COVID-19 Health Crisis



In our efforts to inform the current pandemic and learn for the future, PCORI has identified **three priority areas**:

Health Care Delivery

Vulnerable Populations

Health Care Workers

Many approaches to supporting critical work in these three areas and more:

Awards

- Enhancements of existing awards
- Solicitation of new awards, e.g., natural experiments
- Health care worker registry and trial

Information Sharing

- Webinars
- Collaboration with other funders

Adapting for Awardees and Applicants

- Adaptations to existing projects
- Extending application timelines

HERO

Healthcare Worker Exposure Response & Outcomes

Uniting our healthcare community to protect the health and well-being of America's frontline workers



Confronting COVID-19: Finding Hospital Capacity and Improving Patient Flow

A Webinar Series Hosted by PCORI for Hospitals and Health Systems

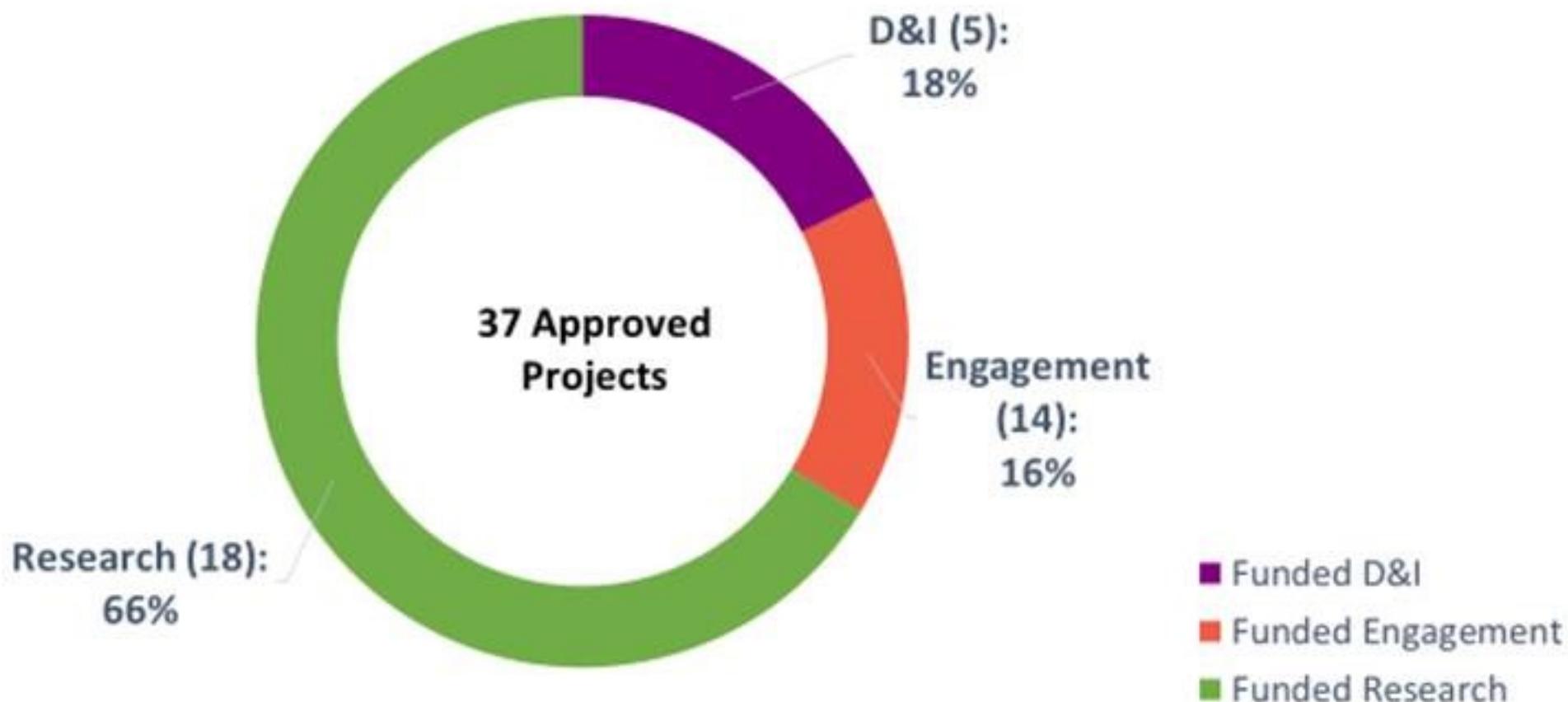
Open Opportunities

Applicant and Awardee FAQs Related to COVID-19: PCORI is working to assist applicants and awardees in finding solutions that may help address issues related to disruptions associated with COVID-19, including general guidance and information about funding application deadline extensions.

COVID-19 Enhancements – Current Funding

Funded Enhancements Data

Last updated: June 2, 2020



COVID-19 Enhancements – Current Funding

Health Condition	Research Awards & Intervention Strategy						Dissemination & Implementation Awards	Engagement Awards
	Drug	Other Clinical	Health Services	Telemedicine	Training and Education	N/A*		
<i>Cardiovascular Diseases</i>								
<i>Cancer</i>								
<i>Gastrointestinal Disorders</i>								
<i>Genetic Disorders</i>								
<i>Infectious Diseases</i>								
<i>Mental/Behavioral Health</i>								
<i>Muscular and Skeletal Disorders</i>								
<i>Neurological Disorders</i>								
<i>Nutritional and Metabolic Disorders</i>								
<i>Reproductive and Perinatal Health</i>								
<i>Respiratory Diseases</i>								
<i>Other or Non-Disease Specific</i>								

PCORI – Always Relevant

Meaningful research questions in health care delivery



Does pre-exposure prophylaxis with HCQ reduce rates of COVID-19 among healthcare workers?

What are the most effective practices for telehealth? Can this natural experiment shed light on whether telehealth can deliver similar outcomes for patient care and management?

What are the predictors of poor outcomes in COVID-19 infection and can we systematize predictive algorithms to determine who is likely to need intensive care?

What approaches are effective in eliminating health and health care disparities in COVID outcomes and how are they generalizable to disparities more broadly?

PCORI 2.0: Opportunities to Accelerate Impact on Care Delivery and Patient Health Outcomes



Engagement

- New and sustained partnerships
- Diverse stakeholder inclusion
- Bipartisan congressional support

Impact:

- *Patients, payers, systems as partners for dissemination & uptake*
- *Evidence to implementation*
- *PCORI integral in research ecosystem*

Innovation

- Patient-centered learning healthcare
- Rapid cycle of evidence to implementation
- Pragmatic approaches to ↓ disparities

Impact:

- *"Real-time" implementation of findings*
- *Uptake into guidelines & care*
- *Reduced variation in care & disparities in conditions/pops*

Operations

- Creative funding approaches
- Efficient & effective processes

Impact:

- *Nimble and adaptable methods to speed innovation to results to patients*
- *Robust pool of outstanding research (built capacity)*

PCORI 2.0: Opportunities to Accelerate Impact on Care Delivery and Patient Health Outcomes



Engagement

- New and sustained partnerships
- Diverse stakeholder inclusion
- Bipartisan congressional support

Innovation

- Patient-centered learning healthcare
- Rapid cycle of evidence to implementation
- Pragmatic approaches to ↓ disparities

Operations

- Creative funding approaches
- Efficient & effective processes

Impact in Post COVID-19 Era:

- Hospitals and healthcare systems working together
- Gaps in evidence for decision-making driving research
- PCORI essential

Impact in Post COVID-19 Era:

- "Real-time" queries, output, and implementation
- Accelerated uptake
- Acute focus on variation in care & disparities

Impact in Post COVID-19 Era:

- Nimble and adaptable processes, research
- Clearer approach to leveraging data, technology, infrastructure
- Expanded research pool

Envisioning PCORI 2.0



Advance Patient-Centered Learning Health Care

Reduce Health Disparities

Disseminate & Implement Scientific Findings

Engage Stakeholders

Crowdsource

Reflect, Discuss

Comment

**Generate Evidence:
Patient-Centered & Relevant to Patients**

Envisioning PCORI 2.0



Advance Patient-Centered Learning Health Care

Reduce Health Disparities

Disseminate & Implement Scientific Findings

Engage Stakeholders

Crowdsource

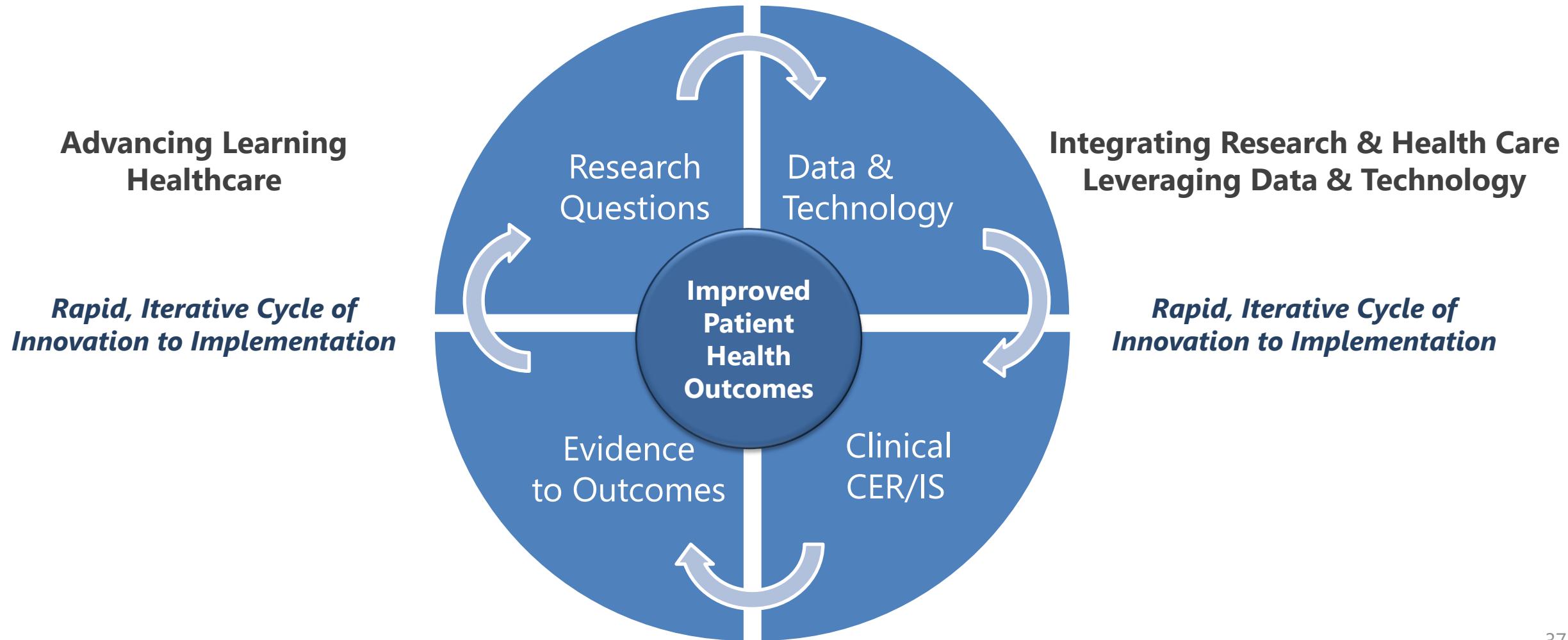
Reflect, Discuss

Comment

**Generate Evidence:
Patient-Centered & Relevant to Patients**

Pillars Underscored by Current Pandemic

PCORI 2.0: A Virtuous Cycle of Evidence to Implementation



Navigating Our Course Together



- **My First Few Months at PCORI**
 - My Personal Journey
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- **Envisioning PCORI 2.0**
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- **Our Course Together**
 - Year 1 Priorities
- **PCORI's Response to the COVID-19 Pandemic**

Navigating Our Course Together



First Year Focus

- **Onboarding and Virtual Listening Tour**
- **PCORI's Response to the COVID-19 Pandemic**
- **National Priority Setting and Development of Research Agenda and Strategic Plan**
- **Other Priorities Stemming from Legislation (e.g., Maternal Mortality, Intellectual and Developmental Disabilities, Cost Outcomes, and Methodology Committee)**



Collaborative Strategy to Advance a Vision for PCORI 2.0



Refreshing National Priorities, Research Agenda, and Strategic Plan

Garner diverse input to guide scientific directions

*Patients, Clinicians, Researchers, Purchasers, Payers, Industry,
Hospitals & Health Systems, Policy Makers, Training Institutions*

Listening Tour
Board & Staff

Conduct portfolio analyses & evaluate research programs

Refine priority research areas

Develop implementation plans

Align resources with research priorities

PEAP Advisory Panel

National Priority Setting and Research Agenda



How can PCORI better support outreach to communities that are underrepresented?

How do we better address diversity and equity issues within the scientific community?

How can we further the expansion of patient-driven research?

Questions?

Our Work: COVID-19 Pandemic

PCORI's Immediate Commitments

Jean Slutsky, Joanna Siegel, Karen Martin

Frontline Perspectives from Advisory Panelists

Crispin Goytia, Maureen Fagan, Umair Shah

Karen Martin

PCORI's New Director of Engagement Awards



- Prior to joining PCORI, she oversaw the grants program at Truth Initiative
- Brings a strong background in supporting communities disproportionately affected by tobacco

HERO Research Program

Jean Slutsky

Chief Engagement and Dissemination Officer



HERO Research Program

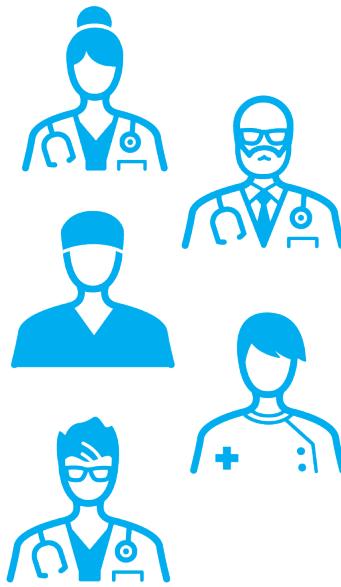


HERO Registry

- Create a community of healthcare works (HCWs) who may be at risk of COVID-19 infection
- Identify HCWs interested in engaging in upcoming clinical trials related to COVID-19 and obtain preferences and willingness regarding participation
- Create a dataset of basic clinical and environmental COVID-19 risk factors and clinical and emotional outcomes for analysis
- Recruitment goal for the HERO registry is 100,000 HCWs

HERO-HCQ Trial

- Will randomize 15,000 at-risk HCWs into a randomized clinical trial to evaluate the efficacy of hydroxychloroquine (HCQ) to prevent COVID-19 clinical infection in HCWs
- HCWs eligible for the HERO-HCQ trial will work at one of the 40 PCORnet sites participating in the trial
- Secondary aims:
 - To evaluate the efficacy of HCQ to prevent viral shedding of SARS-CoV-2 among HCWs
 - Evaluate safety and tolerability of HCQ



Join the
HERO Registry

- 1 Answer short surveys + participate in future clinical studies
- 2 Learn results from HERO research
- 3 Share ideas for problems to address and research to do

HERO Registry

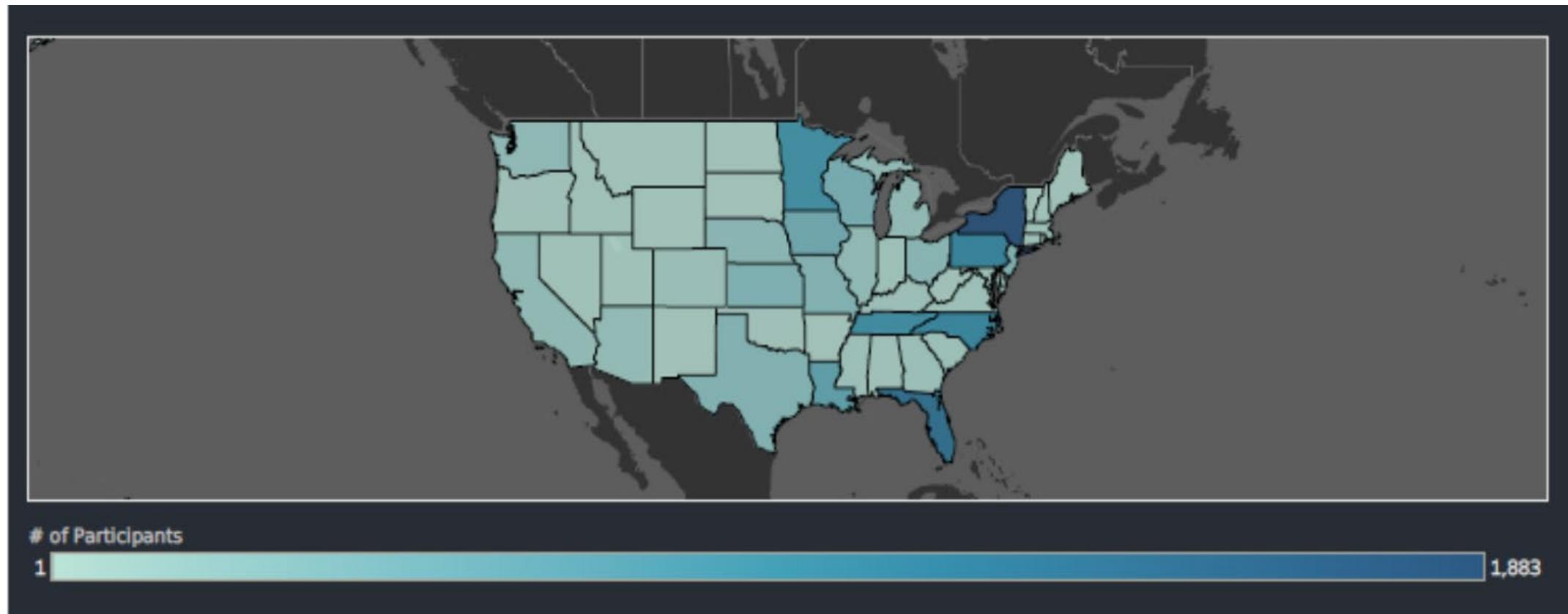


- **Community:**
 - Build a community of healthcare workers organized to better understand effects of the pandemic on them.
 - Contribute to our knowledge on the impact of the pandemic on the health and lives of HCWs
- **Research:**
 - Offer participants opportunities to participate in research that can improve their health and lives (Elicit their priorities)
 - HCWs gain access to trials, tools, and technologies that may improve their health (e.g., HERO-HCQ trial)
- **Return results:**
 - Return results to all participants as a group and personalized to each individual

HERO Registry Coverage



- 13,329 participants have signed registry consent
 - Covers all 50 states



As of May 29, 2020

HERO HCQ Trial Site Activation and Enrollment



- As of May 28, 2020
 - 28 sites activated
 - **23 sites have enrolled 708 participants**

Site Name	Total Randomized
Clinical Trials Center of Middle Tennessee, LLC (#1709)	269
Vanderbilt University Medical Center	91
University of Kansas Medical Center (#1201)	55
University of South Florida in partnership with Tampa General Hospital (#1405)	43
Ochsner Clinic Foundation (#1603)	40
Duke University (#1706)	39
Baylor Scott & White Medical Center - Temple (#1606)	31
University of Florida Jacksonville (#1406)	26
University of Missouri - Columbia (#1208)	25
Temple University	18
University of Florida (#1401)	17
Hospital for Special Surgery	11
Weill Cornell Medicine	10
University of Iowa	6
Marshfield Clinic Health System (#1204)	6
University of Texas Southwestern Medical Center (UTSW) (#1207)	5
Mayo Clinic Rochester	5
University Medical Center New Orleans (#1602)	4
University of Michigan	2
Wake Forest Baptist Health Sciences (#1705)	2
Columbia Univ Irving Med Ctr Columbia Physicians & Surgeons Div of Infectious Disease	1
AdventHealth Orlando	1
Seattle Children's Hospital	1

Oversight of the HERO-HCQ RCT



- The **HERO-HCQ** trial oversight mechanisms include the following:
 - Trial conducted under Investigational New Drug Safety FDA requirements
 - Data Safety and Monitoring Board established by DCRI, the sponsor
 - DSMB is engaged with other DSMBs of large COVID-19 related trials
 - Recommend continuation, revision or discontinuation of protocol
 - Trial subject to Institutional Review Board (IRB) review
- Monitoring processes assure safety or futility issues will be addressed promptly
- Consistent with best practices for RCT oversight, early termination is possible if indicated by either safety or futility
- PCORI Advisory Panel is advising PCORI's ED about overall funding and monitoring questions and issues
- PCORI contractual mechanism and processes reduce financial impact of early termination



Healthcare Worker Exposure
Response & Outcomes

heroesresearch.org

**Uniting our healthcare community to protect the health
and well-being of America's frontline workers**

Update: PCORI COVID-19 Commitments

Joanna Siegel

Director, Dissemination & Implementation



Update on Initiatives



Update on initiatives:

- **COVID-19 Targeted PFA**
- **COVID-19 Related Enhancements to Currently-Funded PCORI Awards**
 - Enhancements to Dissemination & Implementation Awards
 - Enhancements to Engagement Awards (Karen Martin)
- **Webinar Series**

COVID-19 Targeted PFA



New research funding announcement with accelerated timeline.

Objectives:

- Strengthen understanding of approaches to mitigate the impact of COVID-19 on individuals, communities, healthcare providers, and healthcare systems;
- Provide evidence to inform clinical and public health responses, decision making, and planning.

Three priority areas: (other topics allowable but these given preference)

- **Adaptations to healthcare delivery**
- **Impact of COVID-19 on vulnerable populations** (includes those particularly vulnerable in the COVID-19 context, e.g., those with chronic conditions and individuals with intellectual, developmental, or physical disabilities)
- **Impact of COVID-19 on healthcare workforce** well-being, management, and training

COVID-19 Targeted Funding Initiative

Key Information



Timeline:

- Preannouncement April 21, 2020
- PFA Release: May 5, 2020
- **Application Deadline:** May 26, 2020
- **Merit Review (expedited):** June 2020
- **Awards Announced:** July 2020

Small Studies: up to \$2.5M

Large Studies: up to \$5.0M

- *All projects maximum 2 years, with primary outcomes reported within 12 months*

Total Funds Available: up To \$30 million. (May be re-issued if funds are available).

COVID-19 Related Enhancements to Currently-Funded PCORI Awards



On April 1, 2020 PCORI's Board approved up to \$20M in funding to support **adaptations or enhancements to currently funded projects** in response to COVID-19. Applies to Research, D&I, and Engagement Award projects.

Announcement posted April 10, 2020

- **Adjustments:** Changes to allow projects **to meet original goals**.
- **Enhancements:** Modest additions to existing projects, **to mitigate the outcome of the pandemic.**
 - Leverage existing teams with ongoing working relationships
 - Must be feasible to initiate quickly
 - Must serve the goals of the original award
 - May modify existing aims or be adjunct project

Total Cost and Maximum Project Period

	Research/Research Infrastructure Awards	Engagement Awards	D&I Awards
Total Cost Maximum (Direct + Indirect)	\$500,000*	\$150,000	\$500,000*

Enhancement may not increase project timeline by more than 12 months

**Higher amounts considered on case-by-case basis with appropriate justification*

Enhancements to Dissemination and Implementation Awards – Scope



- May address COVID-19 directly or problems emerging in the context of COVID-19
- D&I project enhancements support implementation -- i.e., not exploratory studies, tools development.
- Eligible D&I Awardees: **29 active projects**

Priority issues for D&I awardees:

- Tremendous disruption to in-person care delivery
 - Dramatic surge in telehealth – some specific demands for training, materials, tested programs.
 - Barriers to access for vulnerable groups, including individuals with chronic illness, individuals with intellectual, developmental, or physical disabilities; and racial and ethnic minority groups.
- New challenges associated with distancing, such as new roles and challenges for caregivers
- Changes in treatment risks and trade-offs in the shared decision making equation.

Webinar Series for Hospitals and Health Systems



- Six-part series March 31 – May 5, 2020
- Featured frontline clinicians, operations management experts, and hospital and healthcare administrators sharing real-time learnings.
- **Topics:**
 - Part 1 - Report from the Field: How We Are Managing Incident Command
 - Part 2 - Dealing with the Emergency Department amid COVID-19
 - Part 3 - Elective and Urgent Surgeries amid COVID-19
 - Part 4 - Nurse Staffing amid COVID-19
 - Part 5 - Discharging Patients Recovering from COVID-19
 - Part 6 - The Changing Role of Telehealth

Webinar Response & Resources



Total Audience: 1,083

Audience Composition:

- Hospital/Health system – 31%
- Academic – 11%
- Nonprofit (profession or patient organizations) – 10%
- International – 9%

Follow-up Access on PCORI's website:

- **Video recordings** – 1798 downloads as of May 31, 2020
 - *Nurse Staffing topic (747 views)*
- **Session Summaries** – 834 downloads as of May 31, 2020
 - *Managing Incident Command, Surgery, Nursing Staffing (each 220+ views)*

Engagement Awards: COVID-19 Funding Announcements

Overview and Updates

Karen Martin

Director, Eugene Washington
PCORI Engagement Awards



COVID-19-Related Enhancements to Existing PCORI-Funded Engagement Awards



- Supports enhancements to **existing** Engagement Awards
- Enhancements must:
 - Use existing project infrastructure to build capacity to conduct engagement in CER/PCOR through alternative mechanisms;
 - Enhance a project's efforts to increase patient and stakeholder communities' understanding of CER/PCOR around COVID-19, particularly through those studies funded by PCORI; **or**
 - Leverage existing engagement infrastructure to expand upon objectives/aims/methods to more specifically be responsive to the COVID-19 pandemic
- Up to \$150,000 in total costs; cannot extend project term more than 12 months

Engagement Award Special Cycle:

Supporting Engagement in and Dissemination of PCOR/CER in the Context of COVID-19



- Opportunity for organizations and community groups to build capacity and skills for a) **PCOR/CER** and b) **active dissemination of PCORI-funded research results** during the COVID-19 pandemic (not exclusively for current Engagement Award projects)
- Projects will focus on **identifying and using effective methods of engagement** to build the knowledge, competencies, and abilities of their community to be meaningful partners in research in the context of the COVID-19 pandemic.
- Up to \$150,000 in total costs for one year
- Project start dates: July 1 or August 1

COVID-19: Reflections from Advisory Panelists

Crispin Goytia-Vasquez

Program Manager, Icahn School of Medicine at Mount Sinai

Umair Shah

Executive Director, Harris County Public Health

Maureen Fagan

Chief Experience Officer, University of Miami Health System





The Reality of COVID 19 in NYC

PCORI PEAP
Meeting
June 2020

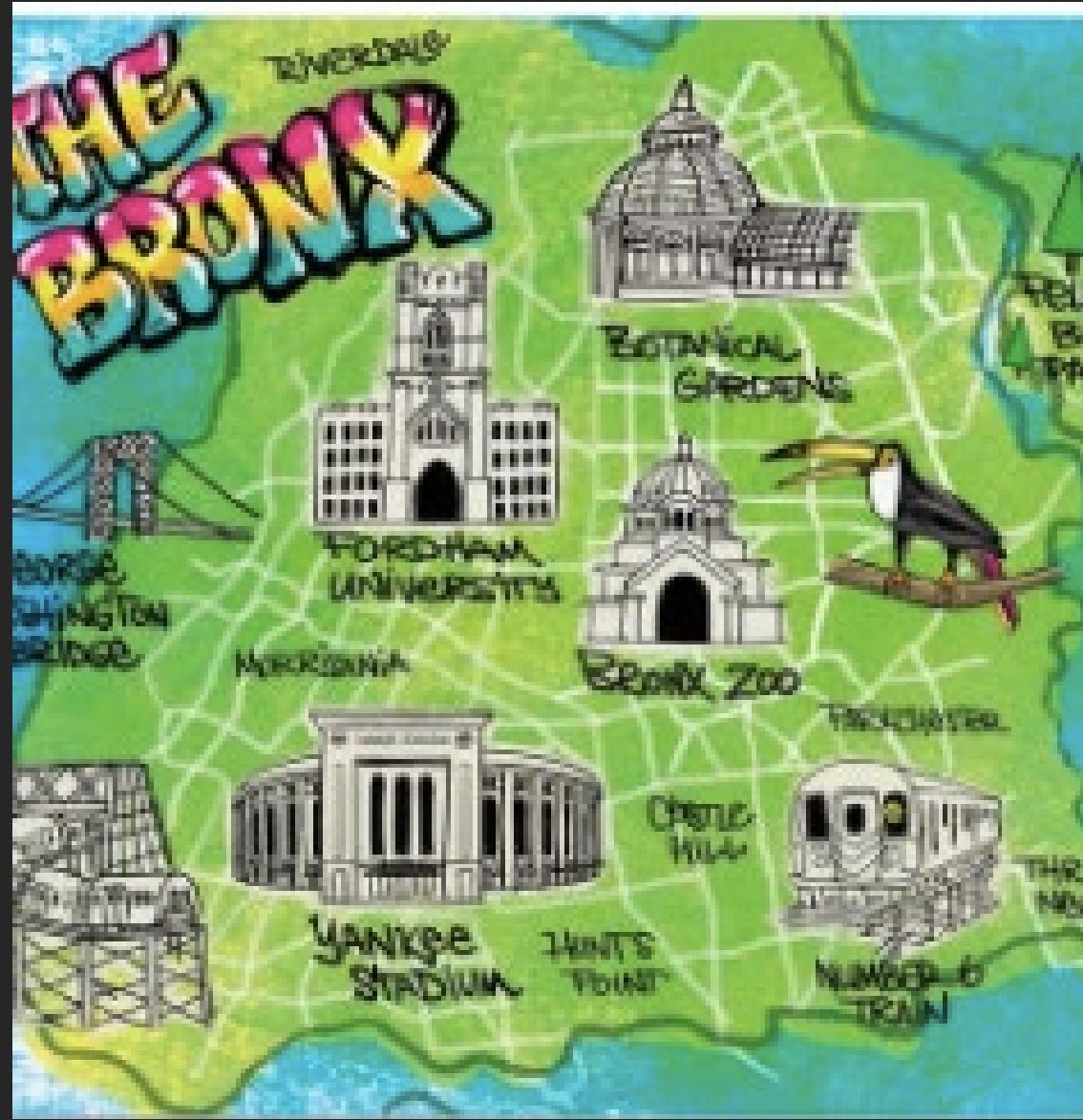
Crispin Goytia-Vasquez

My COVID 19 Timeline

- On **March 4th**, I was in an all-day meeting preparing for grant submission & the sense in the room was of concern, especially since I have elderly parents with chronic diseases.
- On **March 17th** I began to fall ill with covid19 symptoms: severe cough (like a barking dog), loss of taste and smell and extreme fatigue.
- By **March 20th**, my husband began showing symptoms and I began to experience what seemed like a mental “fog”. I couldn’t concentrate on anything.
- Around **March 23rd** my husband and I began to have respiratory issues (him more than I b/c of his asthma). Thankfully a friend who is an EMT brought us oxygen to our home. **(THANK GOD)**
- By **April 8th** we had some residual loss of taste and smell, but respiratory issues were gone.
- Simultaneously, my cousin, his wife & my best friend were also positive for covid19. My cousin had it the worst out of all of us. He is still recovering from his symptoms and it’s already **May**.
- We have had about 3 people we know die from the virus and countless others on ventilators.

NYC
5 BOROUGHS





*<https://theculturetrip.com/north-america/usa/new-york/articles/5-days-5-boroughs-a-guide-to-the-bronx/>

*https://www.wayfair.com/Trademark-Fine-Art-Bronx-Map-Graphic-Art-Print-on-Wrapped-Canvas-ALI5538C-L1318-K~HYT63299.html?refid=GX431473187492-HYT63299_21024570&device=c&ptid=897100281293&network=g&targetid=pla-897100281293&channel=GooglePLA&ireid=38490897&fdid=1817&PiID%5B%5D=21024570&gclid=Cj0KCQjwn7j2BRDrARisAHJkxmzT-pjMnAFAbkzy19sAUPzP-9bc1itRyFjqRzCP-3ohMH-cVCkxkyEaAkT_EALw_wcB

Cases, Hospitalizations and Deaths

Cases	191,650
Hospitalized	50,618
Confirmed deaths Deaths following positive COVID-19 laboratory test	16,059
Probable deaths Cause of death reported as "COVID-19" or equivalent, but no positive laboratory test	4,828
<i>Updated</i>	<i>May 19, at 2:15 p.m.</i>

[Get the data](#) • Created with [Datawrapper](#)

Deaths in NYC reported by New York State	15,293
<i>Updated:</i>	<i>May 19</i>

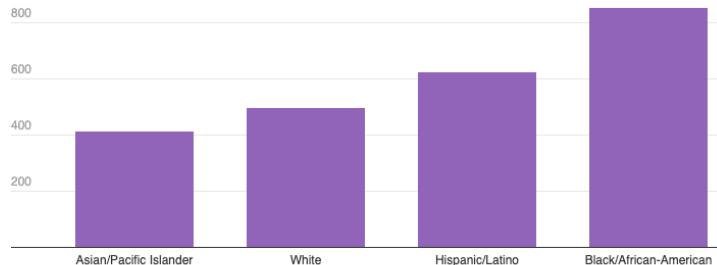
*NYC Department of Health and Mental Hygiene: <https://www1.nyc.gov/site/doh/covid/covid-19-data.page>

Bronx

View by: Age Sex Race/ethnicity

Rate per 100,000 people (age-adjusted)

Cases **Hospitalizations** Deaths



[Get the data](#) • Created with [Datawrapper](#)

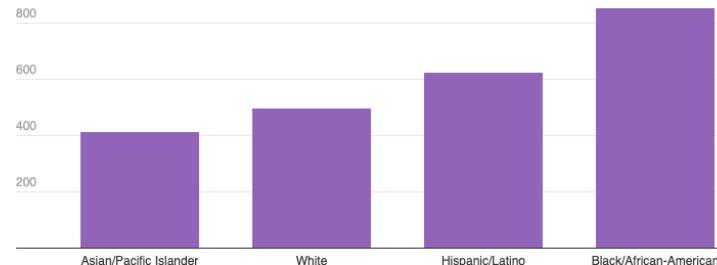
Data on people identified as other categories, including Native American/Alaska Native or multi-racial, are not provided here. The Hispanic/Latino category includes people of any race. Race and ethnicity information is most complete for people who are hospitalized or have died. There are much less demographic data currently available for non-hospitalized cases.

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[Get the data](#) • Created with [Datawrapper](#)

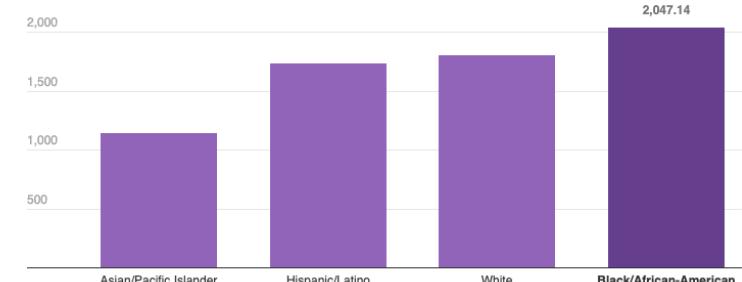
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A Tale from the Bronx

Current Work/Next Steps

- A week after NYC was under quarantine as a network of people (from CBOS, local government, academic institutions) we thought about what could we do to help those that are the most vulnerable.
- We decided to help our diverse communities of NYC especially those who are the hardest hit because of disparities in economics, healthcare, access to health foods and built environment to name a few.
- Over 150 organizations came together (in less than two weeks) to develop a COVID19 community survey in 11 languages to reflect the diversity of NYC and its residents.
- We created a video for marketing of the survey with people representing different age groups, ethnicities, boroughs and jobs.
- There are still many challenges especially for our frontline essential workers who did not receive the best guidance from their agencies or organizations at the start of the pandemic. Many lost their lives, especially in the NYC Transit System, where 91 people died from covid19. (Video of Mark Vasquez, shared with group)

A blurred background image of a stadium. In the foreground, there are spectators in the stands, and a large screen is visible on the right side of the stadium structure. The image is out of focus, creating a soft, hazy effect.

Comments, Thoughts???

Thank you!

COVID 19 Reflections from UMiami

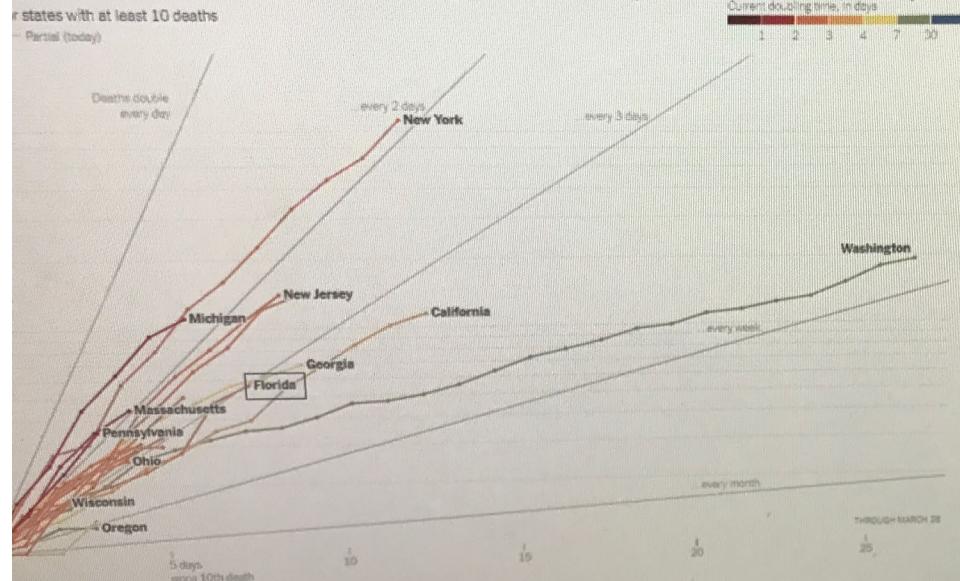
Maureen Fagan, DNP, MHA, FNP-BC, FAAN

In the beginning...

COVID-19 Progression in Florida

Florida has not been hit as hard as New York thus far - the state now experiencing a doubling of cases every 3 days (a rate exceeding California) - disease spread is expected to accelerate significantly in the coming several weeks.

COVID-19 Death Rate Progression (as of 3/29/20)

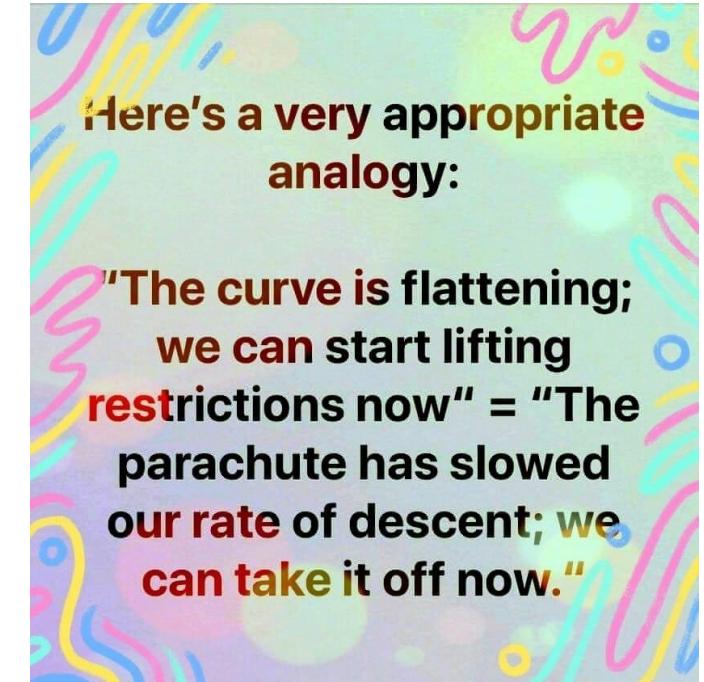


COVID-19 in Florida

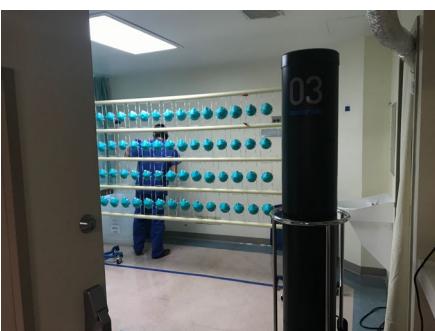
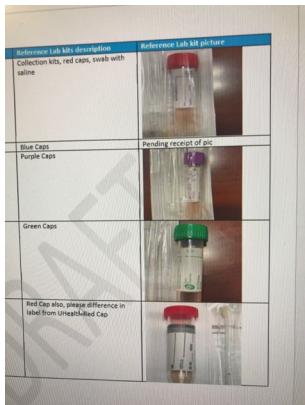
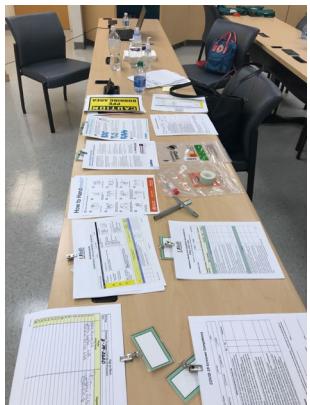
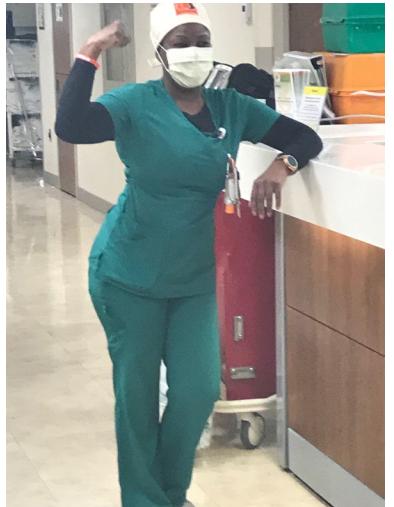
Latest numbers from Florida Department of Health

	4,246	Total number of confirmed cases
	56	Deaths reported in Florida
	594	Hospitalized
	45,045	Total tests

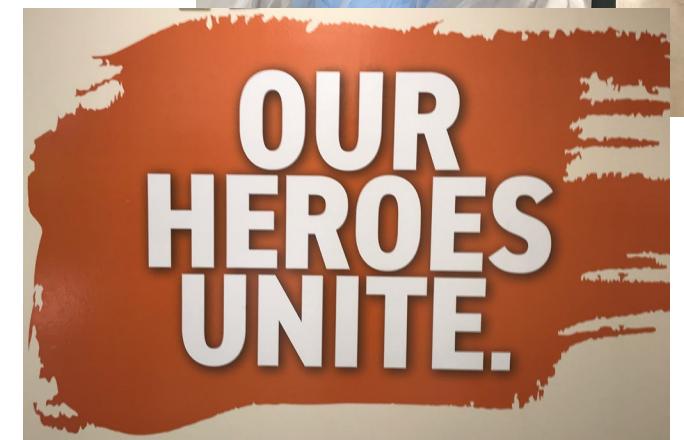
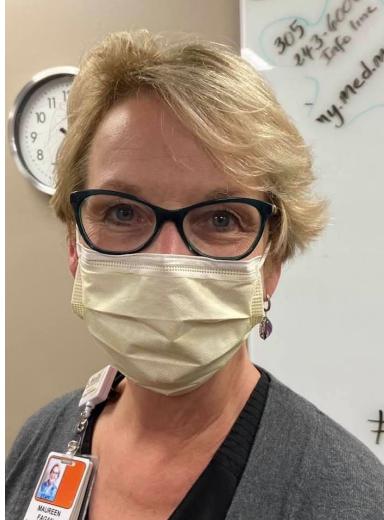
Source: New York Times and FL Department of Health



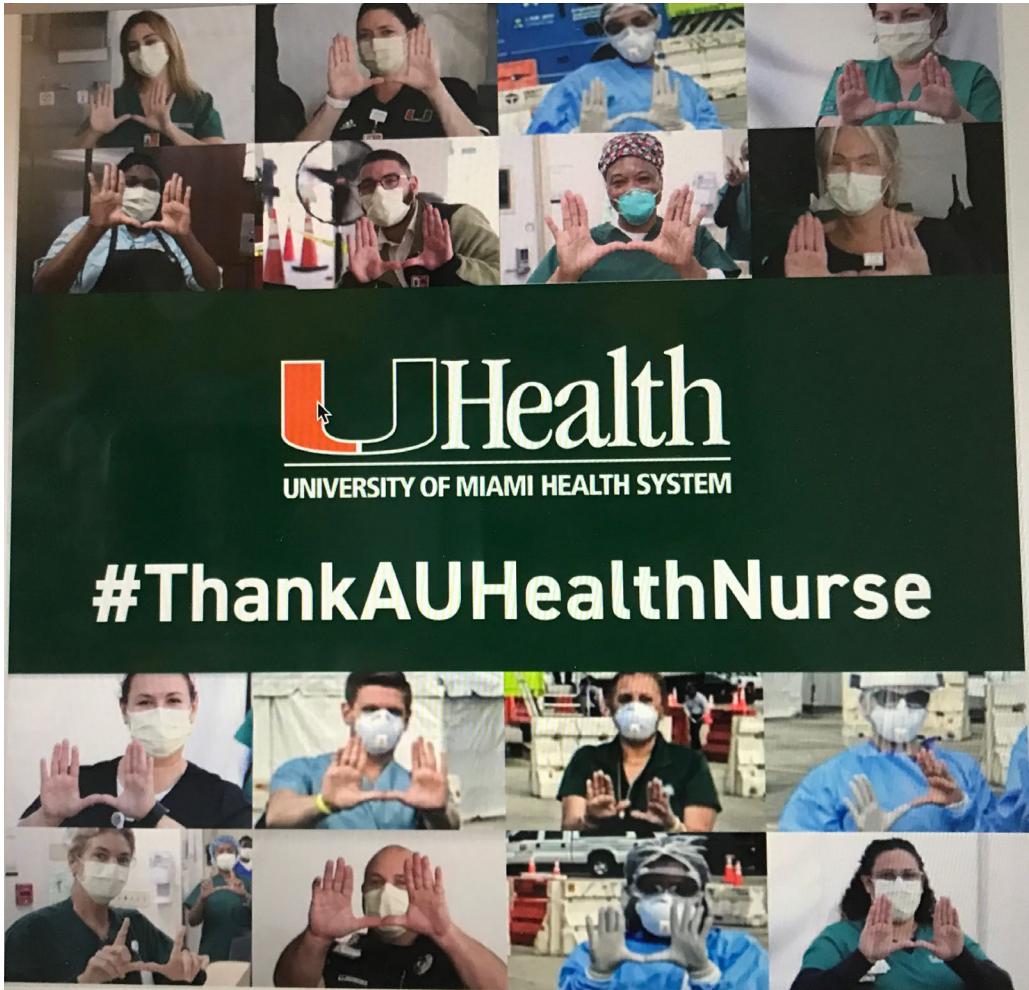
The Unintended Consequences of a Pandemic



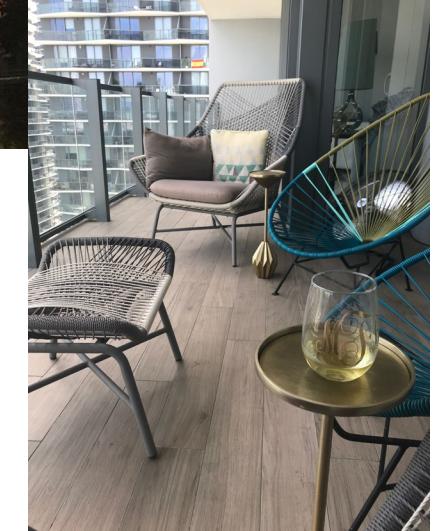
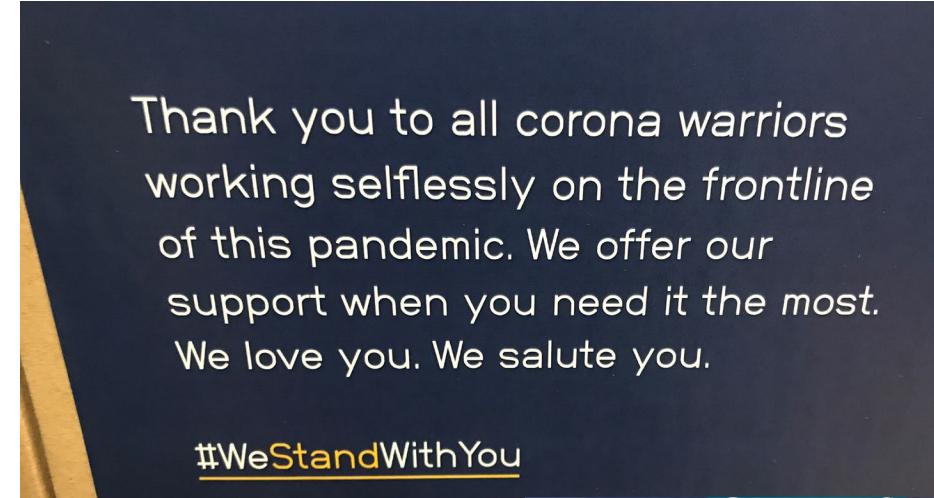
Our S/hero & Hero Journey's



A Nation's Gratitude



Coming Out of the First Wave!



COVID-19 RESPONSE

UMAIR A. SHAH MD, MPH,
EXECUTIVE DIRECTOR & LOCAL HEALTH AUTHORITY
HARRIS COUNTY PUBLIC HEALTH





Harris County
Public Health
Building a Healthy Community

HARRIS COUNTY: BIG DIVERSE & COMPLEX



Harris County is the third most populous county with over **4.7 million** people spread over **1,778 square miles**.



Harris County Public Health

Building a Healthy Community





LLWWP: HEALTH IS A COMPLEX EQUATION BASED ON A NUMBER OF INPUTS NOT LIMITED TO THE CLINIC SETTING. HEALTH TAKES PLACE:

WHERE PEOPLE **LIVE**

WHERE PEOPLE **LEARN**

WHERE PEOPLE **WORK**

WHERE PEOPLE **WORSHIP**

WHERE PEOPLE **PLAY**

OUR PREMISE: LLWWP

HARRIS CARES:

a 2020 Vision of Health in Harris County

PUBLICHEALTH.HARRISCOUNTYTX.GOV/RESOURCES/HARRIS-CARES

- 1 Harris County average life expectancy is 78.7, however some census tracts are as low as 65 years and others as high as 89 years (**24 year difference**).
- 2 Several population centers live more than 15 minutes away from a Trauma Center, including those with a high Social Vulnerability Index.
- 3 Approximately 1 in 5 adults lacks health insurance, with some communities having more than 1 in 3 adults lacking health insurance.
- 4 Local experts in health overwhelmingly agree: access is the #1 challenge facing health in Harris County, and increased funding support for prevention activities is needed.
- 5 In Harris County, 1 in 3 youth aged 12-17 are overweight or obese. For adults, some communities have over 50% of adults classified as obese.

HARRIS CARES

2020

a Vision of Health in Harris County

Harris County
Public Health
Building a Healthy Community

HCPH NEVER A DULL MOMENT

- Tropical Storm Allison (2001)
- Nation's first Biowatch hit in Houston (2003)
- Monkey Pox found in exotic pet market (2003)
- Possible Lassa Fever on cargo ship – Africa (2004)
- Crosby Well natural gas explosion (2005)
- Hurricane Katrina Response – Astrodome (2005)
- Hurricane Rita Evacuation (2005)
- Multi-State GI illness investigation – soccer (2005)
- Fake Flu Investigation (2005)
- Hydrobromic acid release – (2006)
- Rabies Response – teenager death (2006)
- Hepatitis A Response – restaurant worker (2007)
- Salmonella Saint Paul investigation (2008)
- Hurricane Ike Response (2008)
- Hepatitis B in nursing home (2009)
- nH1N1 18 month response (2009 – 2010)
- West Nile virus (WNV) response (2012)
- Cyclospora investigation (2013)
- Ebola readiness/response activities (2014 – 2015)
- Rabies in Harris County dog (2015)
- Memorial & Tax Day Floods (2015 & 2016)
- Zika Response (2016 – 2017)
- Hurricane Harvey (2017)
- Measles Resurgence (2019)
- Chemical Fire (2019)
- Tropical Storm Imelda (2019)
- **COVID-19 (2020- ongoing)**

COVID-19 BACKGROUND

Symptoms

- Fever or chills
- Cough
- Shortness of breath or difficulty breathing
- Fatigue
- Muscle or body aches
- Headache
- New loss of taste or smell
- Sore throat
- Congestion or runny nose
- Nausea or vomiting
- Diarrhea

Coronaviruses are viruses that circulate among animals but some of them are also known to affect humans. The 2019 novel coronavirus was identified in China at the end of 2019 and is a new strain that has not previously been seen in humans.

Prevention

- Clean your hands with soap and water for 20 seconds or a hand sanitizer.
- Avoid contact with sick people.
- Put distance between yourself and other people (at least 6 feet).
- Cover your mouth and nose with a cloth face cover when around others.
- Cover your cough or sneeze.
- Clean and disinfect frequently touched objects and surfaces.

Transmission

- Via respiratory droplets
- 2-14 days estimated incubation period

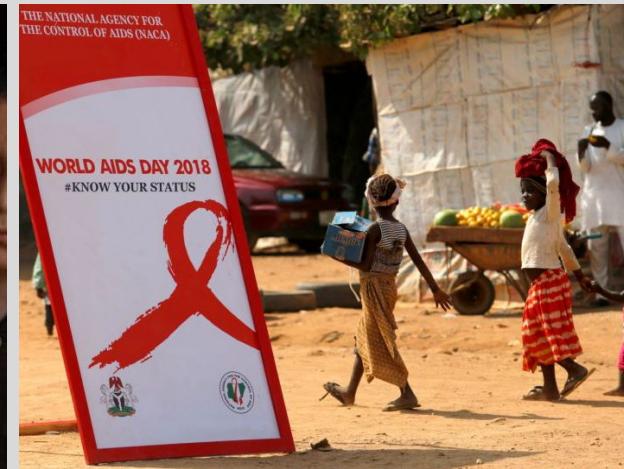
COVID-19



A GLOBAL THREAT

Public Health Challenges and Solutions

Do not Recognize Borders



HARRIS COUNTY LOCAL RESPONSE TO COVID-19



January 23, 2020
First COVID-19 in-person meeting



March 05, 2020
First 2 COVID-19 cases in Harris County



May 31, 2020
Release of guidance for reopening

4 STAGES OF COVID-19

1

MONITORING AROUND THE WORLD

2

COVID-19 IN OUR REGION

3

SLOWING THE SPREAD

4

REOPENING

OUTREACH

APARTMENT OUTREACH

FAITH-BASE OUTREACH

OVER 39 PSA'S

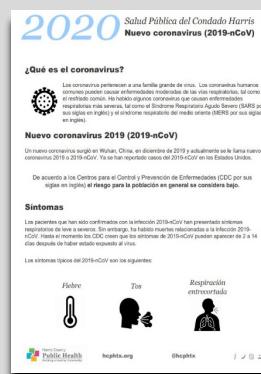
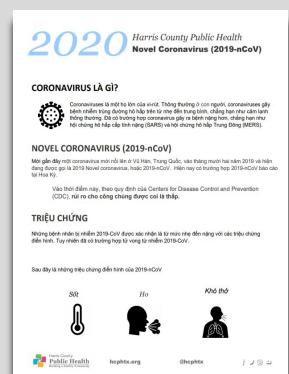
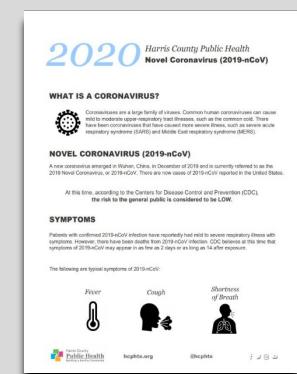
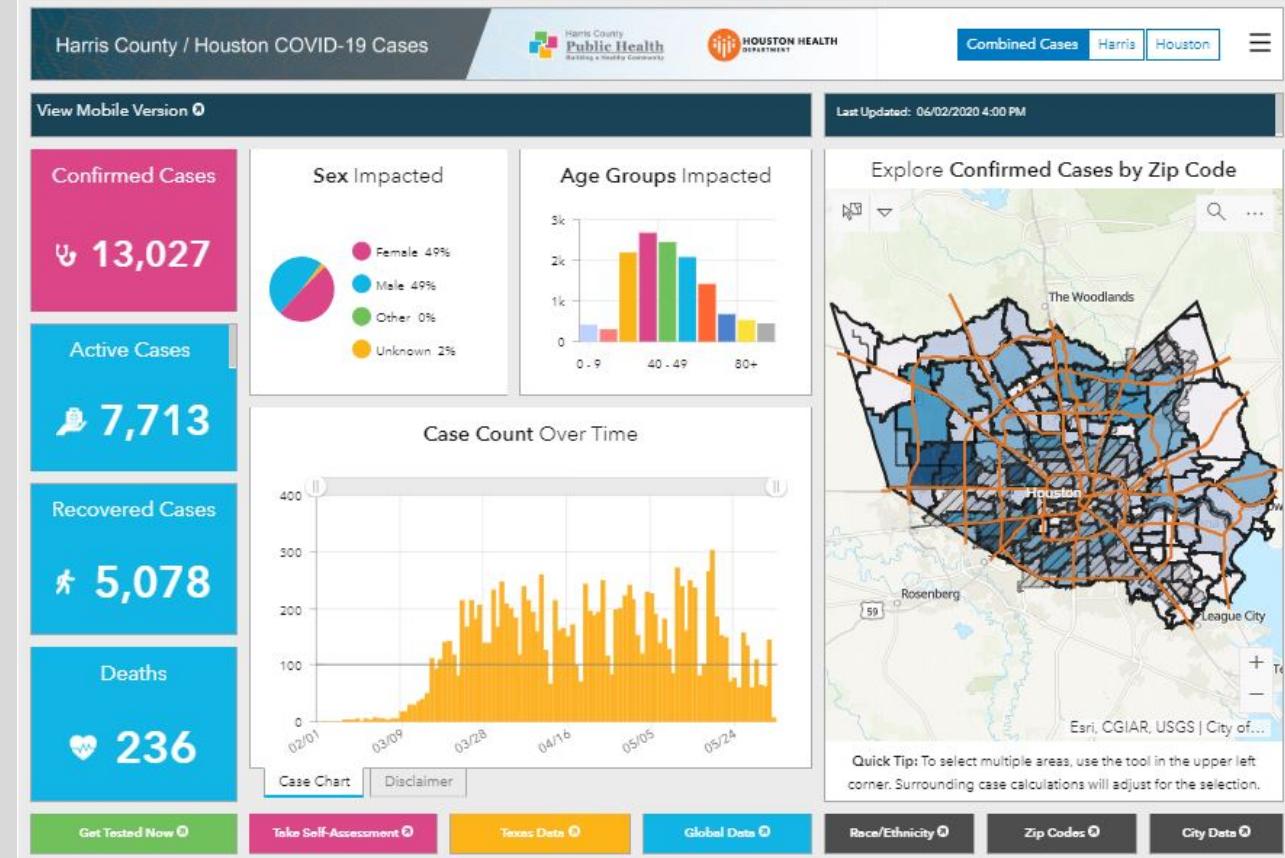
BUSINESSES

CHILD CARE

ASK HCPH CAMPAIGN

SOCIAL MEDIA POST- ONGOING

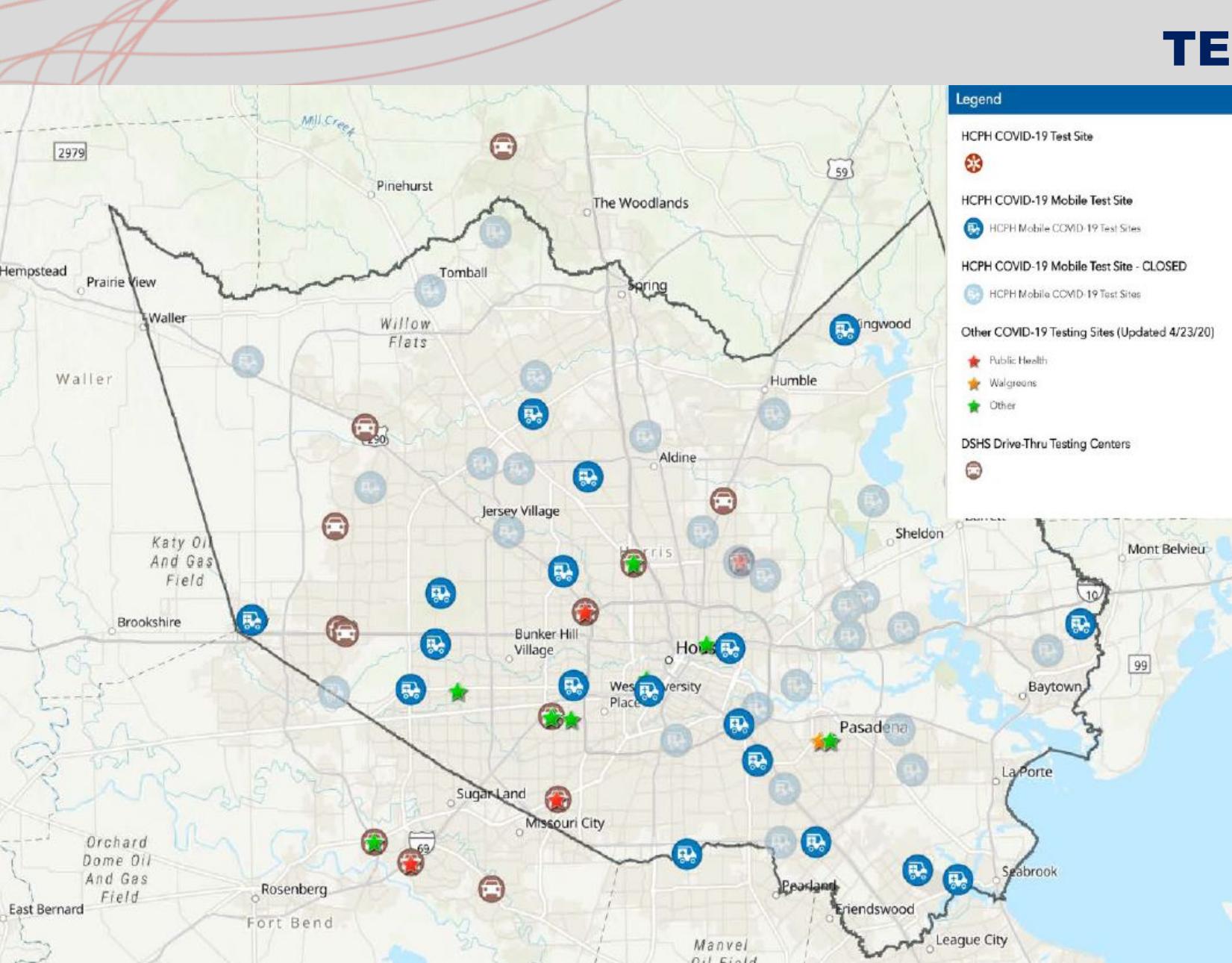
LEVERAGING KEY PARTNERSHIPS



Harris Cares: Focus Issues



TESTING SITE PLACEMENT

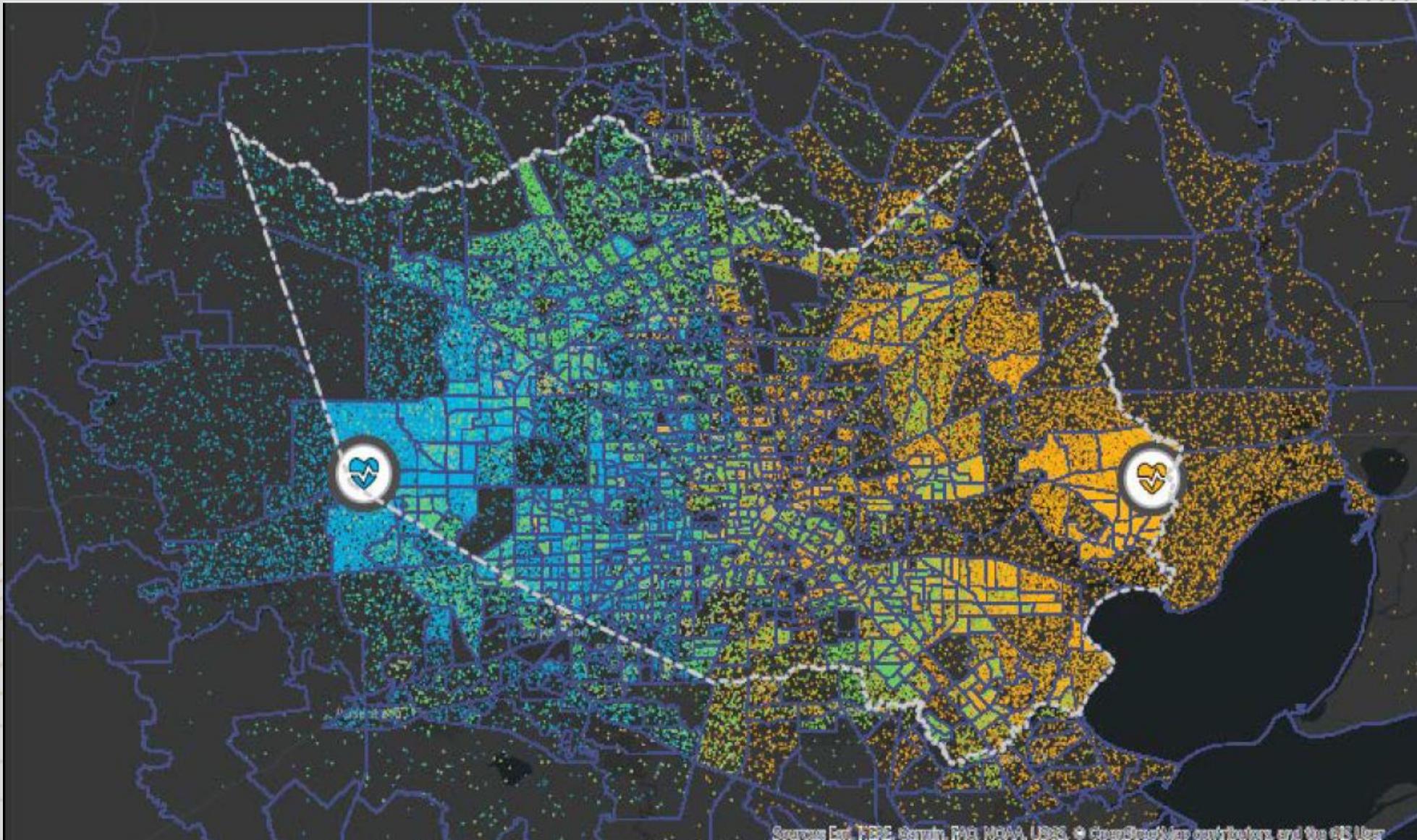


- Using SVI, SES factors, concept of testing “deserts”, etc.
- Location of Testing sites (Mobile and Federal).

WHERE ARE PEOPLE COMING FROM FOR COVID-19 TESTING

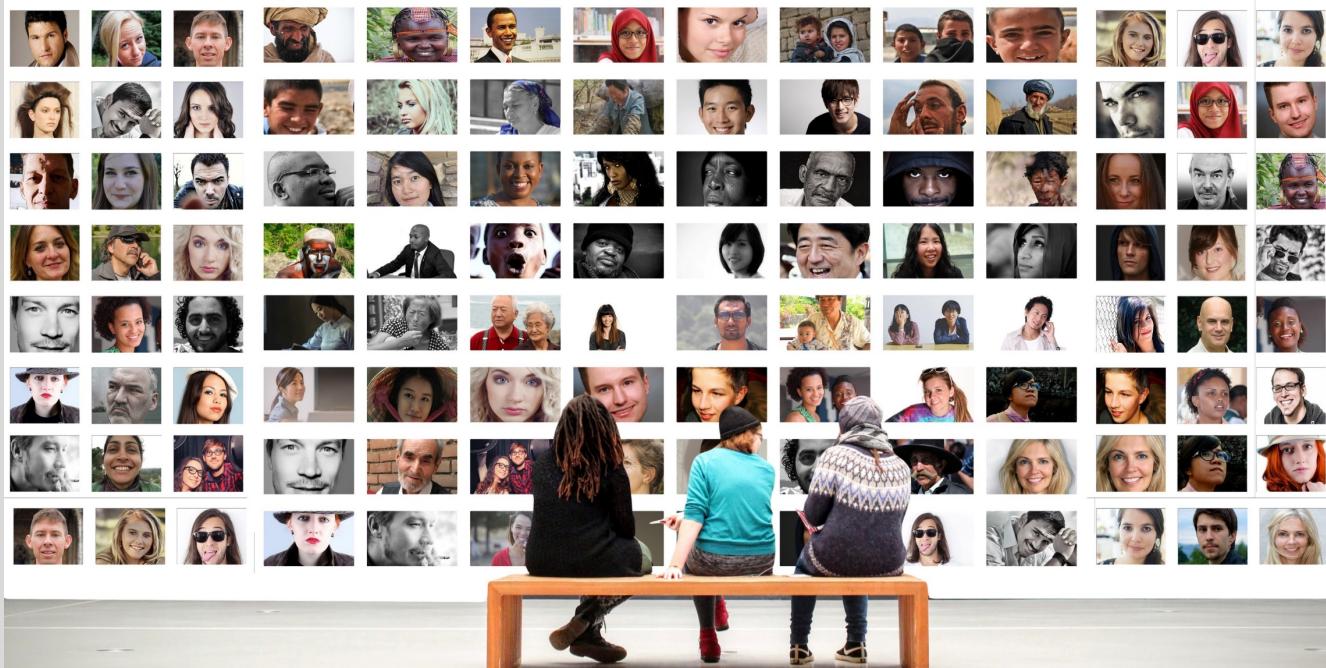
- Clusters represent people that were tested at the Baytown facility (Yellow Heart).
- Clusters represent people that were tested at the Katy facility (Blue Heart).
- Clusters represent people that were tested at the mobile sites (Green).

• All dots on this "dot-density" map are a randomized representation using data aggregate at census tract level and does not represent individual addresses.



Sources: Esri, HERE, Garmin, Mapzen, NGA, NOAA, USGS, OpenStreetMap contributors, and the GIS User

ADDRESSING INEQUITIES OF COVID-19 IN COMMUNITIES OF COLOR



The ongoing pandemic we are continually facing is racism, violence, trauma, all rooted in systemic inequities. These are all public health concerns and deserve our constant attention.

- Long-term solutions must take into consideration where communities LLWWP.
- Use data-driven decision-making to inform strategies and solutions to mitigate long-standing health inequities in midst of an overwhelming pandemic.
- Procuring, analyzing, and visualizing data by race/ethnicity/location/age/etc. helps keep health inequities a central focus of response.
- *“This is no time for politics”* though the reality is that public health is inherently political.
- Remember it is ultimately about community trust and working together to get through this pandemic.



#InvisibilityCrisis

THREE V'S OF PUBLIC HEALTH

Visibility

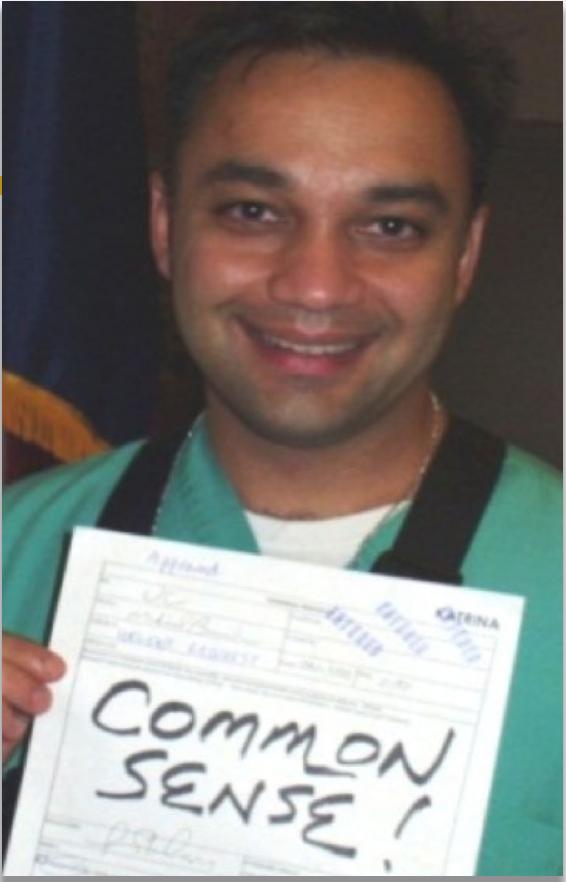


Value



Validation

PUBLIC HEALTH JUST MAKES "COMMON SENSE"



...And it takes a village...

Umair A. Shah, MD, MPH
Twitter: [@ushahmd
@HCPHTX](https://twitter.com/ushahmd)
www.hcphtx.org

Reflections



Discussion



- What do you see emerging as the greatest needs in your community during this time that PCORI could help with? With respect to the type of research that PCORI's funds and our unique support of patient and community engagement, do you feel we are currently targeting community needs correctly?
- As we think about engaging more broadly, what are quick, impactful ways to involve the populations most impacted in research during these times? What community assets should be leveraged?

THANK YOU!!



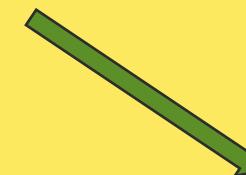
How to Use Padlet

 Meghan Berman • 1d

Advisory Panel on Patient Engagement

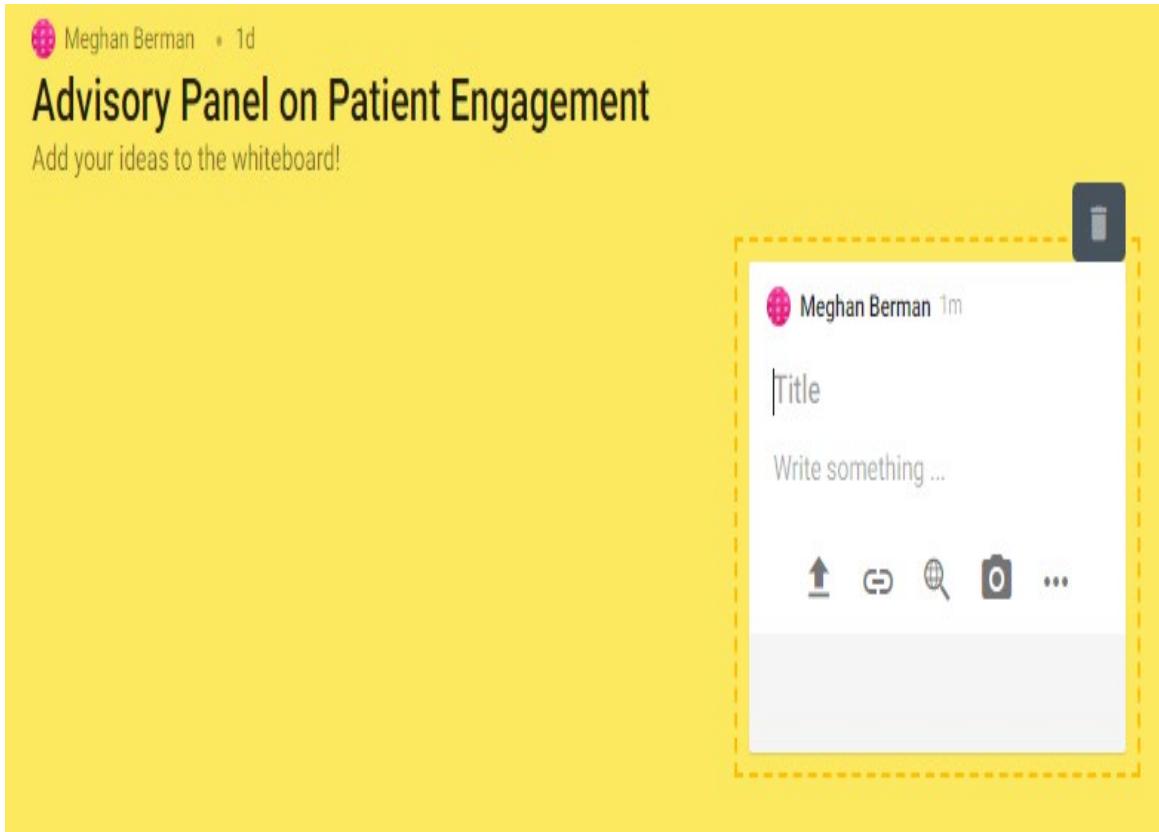
Add your ideas to the whiteboard!

**Click on the pink circle in
the bottom right corner
to start a post**



How to Use Padlet

- When writing a post, please make the title your first name, then write your comment in the space below. You can also upload files, links, and photographs.
- You can rate posts by clicking on the star next to the word “RATE” and then clicking 1-5 stars.
- Navigate here for additional support: <https://padlet.com/support>



Meghan Berman • 1d

Advisory Panel on Patient Engagement

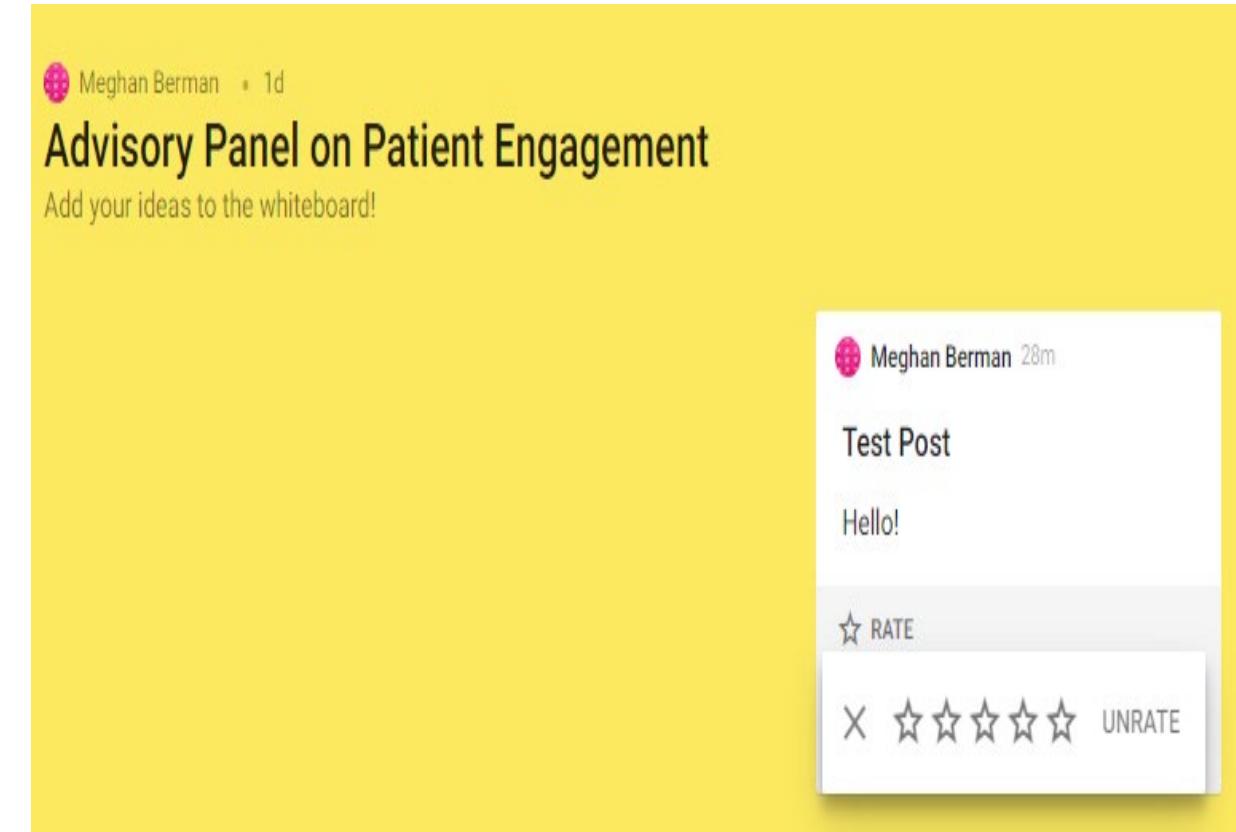
Add your ideas to the whiteboard!

Meghan Berman 1m

Title

Write something ...

Upload Link Search Options More



Meghan Berman • 1d

Advisory Panel on Patient Engagement

Add your ideas to the whiteboard!

Meghan Berman 28m

Test Post

Hello!

★ RATE

X ★★★★☆ UNRATE

Break

1:45pm EDT – 2:15pm EDT

*Feel free to share comments via Padlet
related to communities' research needs
during COVID-19*



Continued Discussion



- What do you see emerging as the greatest needs in your community during this time that PCORI could help with? With respect to the type of research that PCORI's funds and our unique support of patient and community engagement, do you feel we are currently targeting community needs correctly?
- As we think about engaging more broadly, what are quick, impactful ways to involve the populations most impacted in research during these times? What community assets should be leveraged?

Adjourn

