

# Establishing a Research Network in Primary Care Settings

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NIH Advisory Committee to the Director Meeting

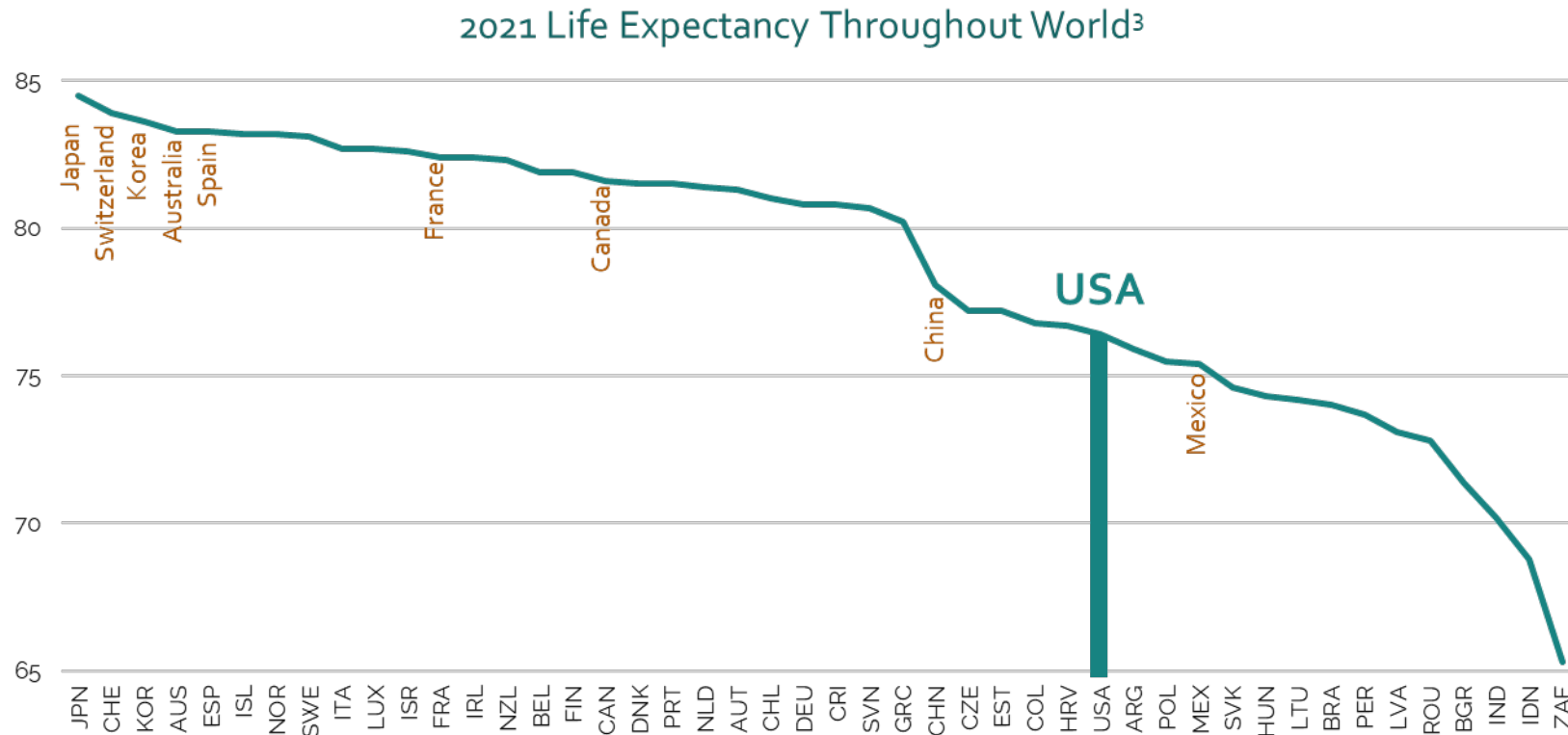
June 13, 2024

A blurred hospital hallway with a gurney in the foreground and people walking in the background. The image is overlaid with a blue tint.

**The health of the U.S.  
population is declining.**

**Decline is steepest among the  
underserved and underrepresented.**

# U.S. life expectancy ranks low among peers



## Concerning U.S. life expectancy trends:

- Declined 2014-2017<sup>1</sup>
- Dropped significantly—2.4 years—between 2019 and 2021<sup>2</sup>
- Increased in 2022 by 1.1 years; gain does not make up for pandemic losses.<sup>2</sup>

(1) National Academies of Sciences, Engineering, and Medicine. 2021. *High and Rising Mortality Rates Among Working-Age Adults*. Washington, DC: The National Academies Press.

<https://doi.org/10.17226/25976>.

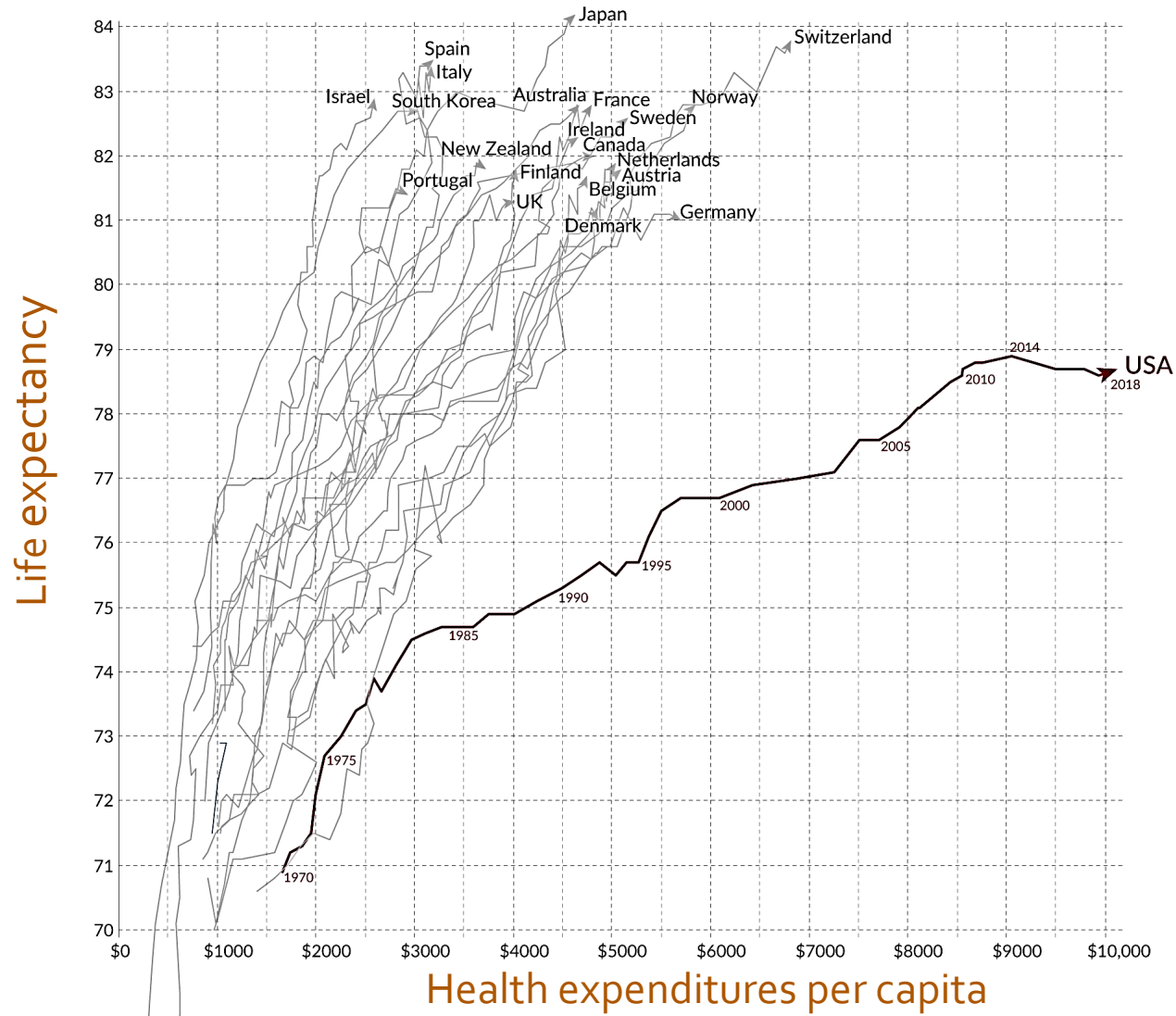
(2) Arias E, Kochanek KD, Xu JQ, Tejada-Vera B. Provisional life expectancy estimates for 2022. Vital Statistics Rapid Release; no 31. Hyattsville, MD: National Center for Health Statistics. November 2023.

<https://dx.doi.org/10.15620/cdc:133703>.

(3) Chart data: OECD (2024), Life expectancy at birth (indicator). DOI: 10.1787/27e0fc9d-en (Accessed on 10 January 2024)

# Life expectancy vs. health expenditures

## 1970-2018



Source: Max Roser (2020) - "Why is life expectancy in the US lower than in other rich countries?" Published online at [OurWorldInData.org](https://ourworldindata.org). Retrieved from: <https://ourworldindata.org/us-life-expectancy-low> Data source for table: Organization for Economic Co-operation and Development (OECD)

# Barriers to Accessing Clinical Research

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# Improving Health Outcomes and Research Equity through Integrating Research in Primary Care Settings

Facilitate and accelerate research advances for adoption and implementation into everyday clinical care

Improve health outcomes and advance health equity for all Americans





# Communities Advancing Research Equity for Health (CARE for Health)

Conduct research addressing **issues important to diverse communities**, particularly those **underrepresented** in biomedical research

**Reduce burden on providers** using innovative data collection methods

**Integrate research** into the clinical care environment

**Engender trust** in science by addressing community needs

Achieve **longitudinal collection of clinical data** to address health across the lifespan

Increase adherence to **evidence-based care**

Improve **efficiency of care delivery**



Community-based primary care practices

# Our Approach

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## What?

Expand enrollment in existing studies and eventually pilot new studies

## Who?

Work with existing research networks and identify new collaborations

Partner with primary care providers and community partners

## How?

Build trust with the communities through addressing the questions that they want asked

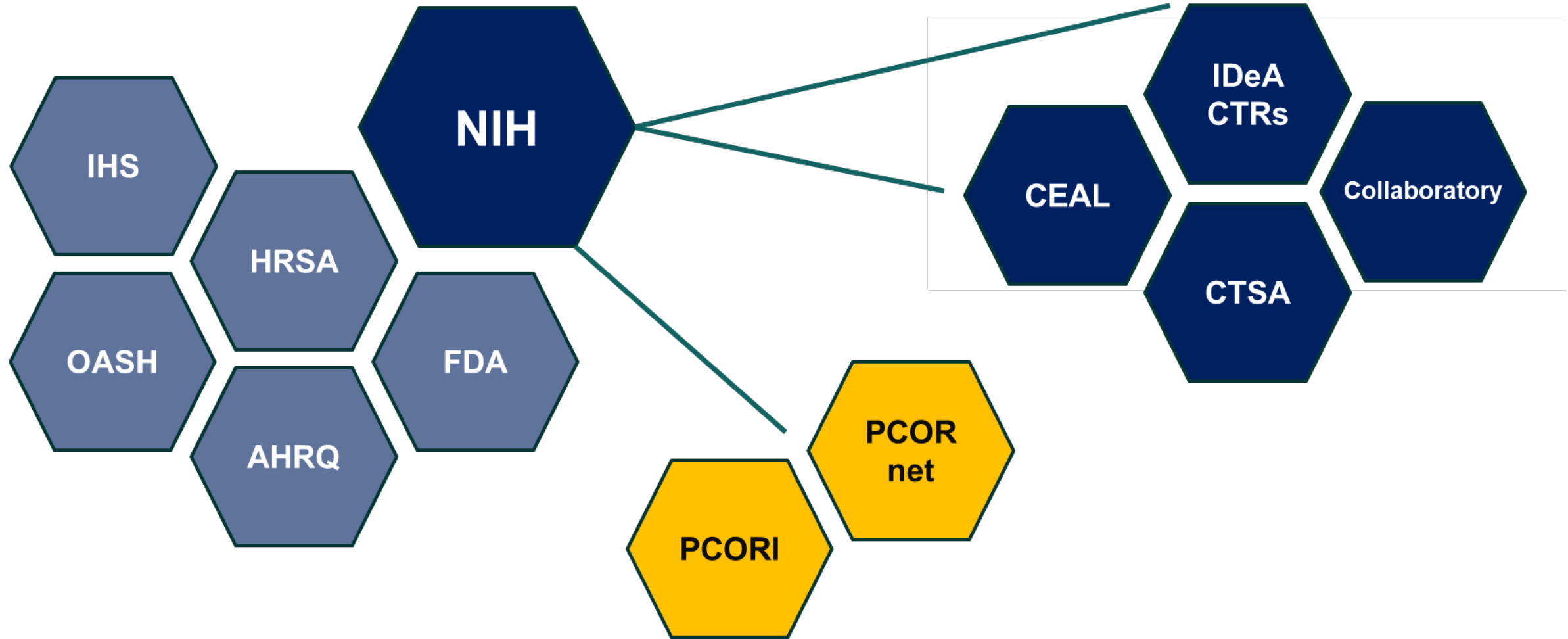
Build a sustainable and durable network to provide opportunities for longitudinal data collection and leverage innovative study designs

## When?

Starting FY24



# Coordination with Potential Partners and Resources



# CARE for Health Governance

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**Amy Patterson, MD**

**Interim Scientific and Medical Director**



**Trinidad Ajazi, MM**

**Operations Director**

# CARE for Health Governance



# CARE for Health Infrastructure 1 of 2

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Infrastructure components anticipated to be piloted and implemented



Clinical Science Center



Operations Center



Independent Review  
and Monitoring Boards



Network Research Hubs



Community Engagement



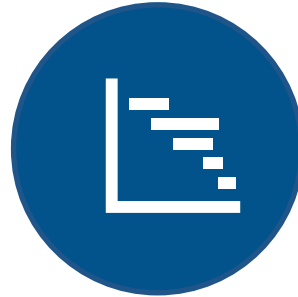
Industry Partnerships

# CARE for Health Infrastructure 2 of 2

Infrastructure components anticipated to be piloted and implemented



Clinical Science Center



Operations Center



Independent Review  
and Monitoring Boards



**Network Research  
Hubs**



Community Engagement



Industry Partnerships

# Network Research Hubs: Objectives

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Research in Primary Care Settings in collaboration with Clinical Sites on Select Existing NIH-Funded Studies and New Studies



Participant and Community Engagement



Innovations in Clinical Study Design



Participation in Coordinated Infrastructure Supporting Research in Primary Care Settings



# Integrating Clinical Research into Primary Care Settings through Network Research Hubs– Pilot (OT2): OTA-24-016

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**Purpose:** Invite applications for organizations to serve as “Network Research Hubs” and establish infrastructure to conduct clinical research in primary care settings as a two-year pilot

**Eligibility:** limited to organizations that

- 1) Focus on **servicing rural communities**, located in states / jurisdictions with at least 25% of census tracts defined as rural in the [Revised 2010 RUCA Codes](#) (codes 4-10)
- 2) Are part of or funded by one or more of the following
  - NIH Institutional Development Award Clinical and Translational Research (**IDeA-CTR**) awards
  - NIH Clinical and Translational Science Award (**CTSA**) Program
  - Patient-Centered Outcomes Research Institute’s (PCORI) Patient-Centered Clinical Research Network (**PCORnet**)

**Submission Deadline: TOMORROW,  
June 14, 2024 at 5:00pm EDT**

**Number of Awards:** Between 2 to 5  
Awards Issued in FY24

# Phased Approach to Launching Studies and Building Infrastructure

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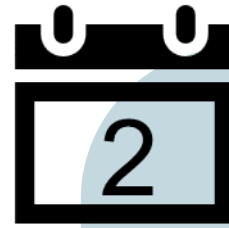
This effort is expected to be a **two-year pilot**



## Year 1

### Fund Network Research Hubs

These selected *existing* studies may be interventional or observational and are expected to be suitable for primary care settings.



## Year 2

### New Research

In coordination with the other components of the infrastructure.

### Program Evaluation

Programs will be evaluated to assess which approaches and efforts are working.

# Listening Sessions and Public Workshop

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**Goal:** Obtain perspectives from external partners to inform planning for the network

## **Participants:**

- Patients and community organizations
- Primary care providers/organizations
- Community health partners
- Hospital systems
- Research networks
- Federal agencies

## **Listening Session Topics, April – May 2024:**

- Early, sustained engagement of patients and community organizations
- Clinical research network capabilities and gaps
- Needs of providers and health care systems for research participation
- Clinical research innovations to reduce site and provider burden

## **Public Workshop, June 7, 2024:**

- NIH vision for CARE for Health
- Visions of success from external partners
- Opportunity for broad public feedback

# Timeline & Budget

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**Spring 2024:** Obtain perspectives from external partners to inform planning for the network

- Listening sessions and public workshop



**Quick Launch in 2024:** Expand existing studies to increase engagement with underrepresented populations and to enhance accrual and collaboration

- Anticipated Budget: OD funds \$5M in FY24 ROA



**Expand in 2025 and Beyond:** Launch new studies across the network and further establish and solidify the network infrastructure

- Anticipated Budget: OD funds \$25M in FY25; anticipate ramp up of ~\$50-100M/year after assessing feasibility and budget requirements

# Questions?