ANNUAL REPORT

2024

NATIONAL MINORITY QUALITY FORUM

TABLE OF CONTENTS

MESSAGE FROM THE CEO

> The question is no longer *Do we have the data?* The question is *What will we do with it?* *"We Have the Data. Now What?!?"*—is more than a slogan. It is our call to action. The data is the foundation, but solutions are the structure we must build on top of it.
>
> **Gary A. Puckrein, PhD**
>
> President & Chief Executive Officer

When I founded the National Minority Quality Forum in 1998, our mission was clear: collect the data we need to protect the most vulnerable. For more than 25 years, we have done exactly that—gathering, analyzing, and publishing data that has illuminated health disparities in almost every area of our nation's healthcare system. From chronic disease to maternal health, from cancer outcomes to access to preventive care, the numbers have told a sobering story.

But now, the question is no longer *Do we have the data*? The question is *What will we do with it*?

That is why the theme of this year's Annual Summit—"*We Have the Data. Now What?!?*"—is more than a slogan. It is our call to action. The data is the foundation, but solutions are the structure we must build on top of it.

At NMQF, we have aligned our work through six specialized centers, each charged with using our unparalleled data resources to tackle our nation's biggest health challenges. Whether it's advancing clinical research equity, improving cancer outcomes, addressing maternal mortality, building community-based health solutions, shaping public policy, or enhancing our national response to public health crises—each center transforms knowledge into action.

This year's report shows how those centers are not only identifying problems but driving measurable change. They are partnering with communities, informing policymakers, guiding industry leaders, and pushing forward the innovations that will redefine health equity in this country.

Over the decades, we have seen the power of information. Now, we are demonstrating the power of application. The work ahead will be challenging, but the opportunity is unprecedented. We have the insights. We have the experience. And now, we have a model that ensures those insights lead to healthier, more equitable futures for every community we serve.

For us, the "Now What?" is not a question—it is our mandate.

Sincerely,

Gary A. Puckrein, PhD

LEADERSHIP: EXECUTIVE TEAM

Gary A. Puckrein, PhD

President & Chief Executive Officer

Brandon Garrett

Chief Operating Officer & Chief of Staff

Adjoa Kyerematen, MS

Vice President,
Center for Communications & Public Affairs (COMMS)

Akeia Blue, MPH, MS

President,
Center for Sustainable Health Care Quality & Equity (SHC)

Ernest Smiley, MS, MBA, CISM, CGEIT, CRISC, CDPSE

Chief Information Security Officer

Senior Vice President,
Center for Health Information Strategy & Services (HISS)

Gretchen Wartman

Vice President,
Center for Public Policy (CPP)

Director, Institute for Equity in Health Policy & Practice

Director, National Alliance for Brain Health and Awareness

Jenine Caulkins

Senior Vice President,
Center for Clinical & Social Research (CCSR)

Kelelaye Emiru, MBA

Vice President,
Center for Professional & Strategic Alliances (CPSA)

Laura Lee Hall, PhD

President Emeritus,
Center for Sustainable Health Care Quality & Equity (SHC)

LEADERSHIP: ADVISORY BOARD (1/2)

Chijioke Asomugha, MBA

Founder and Managing Director,
The Inkwell Group

Ulysses Burley III, MD

Founder,
UBtheCURE LLC

Michael R. Crawford, MBA, MHL

AVP for Strategy and Innovation at
Howard University

Kafui Dzirasa, MD, PhD

Professor,
Duke University Medical Center

Brian T. Fisher, Sr., MD

Physician Lead,
Vascular Services at HCA Healthcare
(TriStar Division)

Donney John, PharmD

Executive Director,
NOVA ScriptsCentral

Mia Keeys, MA, DrPH(c)

Director,
Federal Affairs, Hologic, Inc

Rosalyn Kumar

Senior Director,
Federal Government Affairs, Abbott

Javier Martinez

Director,
Federal Government Affairs, Davita

Michelle Mathey

Principal,
Capitol Counsel

LEADERSHIP: ADVISORY BOARD (2/2)

Kameron Matthews MD, JD, FAAFP

Chief Health Officer, Cityblock Health

Winta Menghis

Senior Manager,
Government Affairs and
Health Equity, Amgen

Suzanne Miyamoto, PhD, RN, FAAN

CEO of American Academy
of Nursing

Ravyn Miller

Vice President,
Portfolio Strategy and Business
Development, Medtronic

LaTasha Seliby Perkins, MD

Georgetown University,
School of Medicine

Jirair Rateovosian, MPH

Candidate for Congress,
CA-30

Loren Robinson, MD

Chief Medical Officer and Vice
President of Medical Affairs,
CHRISTUS Health

Shyrea Thompson

Founder and Principal,
IRS

Brandon Webb

Senior Manager of Public Policy,
Amazon

Victor Yang

Chief Government Affairs Officer,
NAPCA – National Asian Pacific
Center on Aging

CORPORATE ROUNDTABLE

The National Minority Quality Forum (NMQF) convenes a Corporate Roundtable to address critical challenges in the era of health care reform. NMQF's Corporate Roundtable works to advise NMQF with federal, state, and local government through partnerships on events and activities.

In addition to the Annual Summit on Health Disparities, NMQF works with Corporate Roundtable members on a variety of events, including the Annual Legislative Conference Fall Health Braintrust, Community Health Clinics and Festivals, as well as various policy reports and research.

MEMBERS

- abbvie
- amazon
- AMGEN
- ardelyx
- Baxter
- Biogen
- BlueCross BlueShield
- Bristol Myers Squibb
- CHA Catholic Health Association of the United States
- CENTENE Corporation
- DaVita.
- dexcom CONTINUOUS GLUCOSE MONITORING
- MERCK
- Genentech A Member of the Roche Group
- GILEAD
- gsk GlaxoSmithKline
- HCSC Health Care Service Corporation
- HOLOGIC
- IES INTEGRATIVE EMERGENCY SERVICES
- Jazz Pharmaceuticals
- IPSEN Innovation for patient care
- novo nordisk
- Pfizer
- PhRMA RESEARCH • PROGRESS • HOPE
- REGENERON
- sanofi
- Takeda
- VERTEX

NATIONAL ANNUAL SUMMIT ON HEALTH DISPARITIES

Award Winners

The Honorable Lisa Blunt Rochester

Congressional Award

Dr. Bernard Harris

Lifetime Achievement Award

Martha Cramer

Congressional Award for Congressional Staff Leadership

Fund II Foundation

Booker T. Washington Award

Blue Cross Blue Shield Association

Booker T. Washington Award

NATIONAL ANNUAL SUMMIT ON HEALTH DISPARITIES

We Have The Data, Now What? A Look Back at Over 25 Years

April 29-30, 2024
The Watergate Hotel
Washington, DC

The 2024 National Annual Summit on Health Disparities, “We Have The Data, Now What?" saw roughly 700 clinicians, policy makers, patient advocates, researchers and community members discuss **our health during and after a pandemic.**

We heard from experts from across the healthcare space discuss everything from **mental health and COVID-19 to maternal mortality and obesity.** We welcomed our 10th Class of 40 Under 40 Honorees and were able to highlight and recognize the work of Dr. Bernard Harris.

40 UNDER 40

Leaders in Minority Health

Since 2016, NMQF has selected 40 minority health leaders under the age of 40 who have been leading the charge to better patient outcomes and build sustainable healthy communities.

These leaders are clinicians, patient advocates, researchers and policymakers. Despite the unexpected healthcare trials during the past couple of years, these 40 leaders persevered in strengthening their communities and reducing health disparities.

> These young leaders are working to eliminate health inequities and improve outcomes across the country. Their dedication is inspiring, and I know that their intelligence, care and determination will contribute to a healthcare system that works to heal everyone.
>
> **The Honorable Robin Kelly, PhD**
> Congressional Black Caucus Health Braintrust Chair

40 UNDER 40

Leaders in Minority Health (1/4)

Benjamín Aceves, PhD, MPH, MA

School of Public Health
San Diego State University

Chidiebere Akusobi, MD, PhD

Massachusetts General Hospital

Simar Bajaj

Massachusetts General Hospital

Lawrence B. Brown, MD, MPH, MHS

Johns Hopkins University

Taneal D. Carter, MS, MPA

National Comprehensive Cancer Network

Aariel Dees, MD

Medical University of South Carolina

Ashley Ford, MD

Mount Sinai Health System

Aaron Douglas Dotson, MD

The University of Iowa

Guilmate Pierre Fuller, MPH, MCHES, CQIA

UT MD Anderson Cancer Center

Rochelle Garza, JD

United States Commission on
Civil Rights

40 UNDER 40

Leaders in Minority Health (2/4)

Juan Carlos Gonzalez, MBA, PMP

Meharry School of Global Health

Henry J. Henderson III, PhD

Foundation Medicine, Inc.

Domonic Hopson, MPH, FACHE

Neighborhood Family Practice

Irogue Igbinosa, MD

Stanford University School of Medicine

LTC Milissa U. Jones, MD, MPH, FAAP

Uniformed Services University

Nathaniel K. Jones, MD, MA, FAAP

Perelman School of Medicine, University of Pennsylvania

Kamara Jones

U.S. Department of Health and Human Services

Ariel Jordan, MD

University of Michigan

Sandy Juste, MD MSc

Meharry Medical College

William J. Lee, JD, MS, MACE

Kershaw Talley Barlow, P.C.

40 UNDER 40

Leaders in Minority Health (3/4)

Minghui Sam Li, PhD, MS

University of Tennessee Health Science Center

Alister Martin F., MD, MPP

A Healthier Democracy

Bianca Mayes, MPH, CHES

Planned Parenthood Federation of America

Adam J. Milam, MD, PhD, FASE

Mayo Clinic

Randy C. Miles, MD, MPH

Denver Health

Antonio Moya, MD, MPH

Los Angeles Department of Health Services

Kimberly Nettles, PharmD, RPh

Johnson & Johnson Innovative Medicine

Robin Ortiz, MD, MSHP, FAAP, DipABLM

NYU Grossman School of Medicine

David Ramirez, MD

Lurie Children's Hospital, Northwestern University

Emilie Rodriguez, BA, CD, LC

The Bridge Directory

40 UNDER 40

Leaders in Minority Health (4/4)

Brittani Saafir-Callaway, PhD, MPH

DC Health

Evan Michael Shannon, MD, MPH

UCLA David Geffen School of Medicine

Nilay S. Shah, MD, MPH

Northwestern University Feinberg School of Medicine

Bethany Strong, MD, MS, FACS

University of Maryland School of Medicine

Subhan Tabba, MD, MBA

Texas Health Presbyterian Hospital Dallas

Nadine Tavares

Rhode Island Department of Health

Ijeoma Uche, MPH

Birth By Us/University of California, Davis School of Medicine

Jordee Wells, MD, MPH

The Ohio State University College of Medicine

Elshaddai White, PhD

Black in Cancer/Elevar Therapeutics

Gabriela Ziccarelli, PharmD, BCACP

Walgreens, Co.

NMQF EXPANDS TO ELEVATE OUR MULTI-GENERATIONAL FIGHT FOR HEALTH EQUITY

Since our inception in 1998, the National Minority Quality Forum (NMQF) has grown to become the nation's largest minority-led healthcare research and education organization. From data to action, NMQF is now organized around a robust managing team and six interconnected centers:

NMQF Offices of the President

The National Minority Quality Forum’s (NMQF) Offices of the President serve as a linchpin in the effective management of the organization, providing vital support to ensure the fulfillment of its mission and the success of its Centers.

Center for Clinical & Social Research and Development (CCSR)

Advances equitable healthcare through rigorous scientific exploration, enabling data-driven generation of deep insights on the intersection between clinical and social determinants of health.

Center for Communications and Public Affairs (COMMS)

Promotes health equity through patient education, health communication, health advocacy, stakeholder partnerships, coalition building, and community events that educate on a variety of health topics.

PRIVATE CLOUD

Center for Health Information Strategy and Services (HISS)

Advances health equity through evidence-based, data-driven insights to reduce patient risk, eliminate disparities, and improve the quality of care & outcomes for vulnerable communities via our data warehouse and private cloud.

NATIONAL MINORITY QUALITY FORUM

Center for Professional and Strategic Alliances (CPSA)

Promotes healthy communities by working with health systems, faith leaders, barbers/stylists and pharmacists to deliver community interventions.

NATIONAL MINORITY QUALITY FORUM | CENTER FOR PUBLIC POLICY

Center for Public Policy (CPP)

Provides leadership to advance changes to policies that impact the health of minoritized populations.

Center for Sustainable Health Care Quality and Equity

Center for Sustainable Health Care Quality and Equity (SHC)

Promotes healthy communities by working with health systems, faith leaders, barbers/stylists and pharmacists to deliver community interventions.

Why This Matters

Our expansion allows us to work with and support different types of healthcare organizations and leaders — in the delivery of appropriate healthcare to minoritized communities — including historically marginalized, low-income, and rural communities. More broadly, NMQF utilizes science and research to reduce patient risk in our healthcare system.

How We're Making a Difference

- Our mission is to reduce patient risk for hospitalizations, emergency room visits, disabilities, and death while conserving long lives, by assuring every individual has access to optimal care.
- NMQF partners with other healthcare-related organizations to work across a variety of healthcare issues such as public policy, diabetes, cancer, vaccination, heart disease, chronic disease, neuroscience, women's health, and clinical trial inclusivity.

NMQF OFFICES OF THE PRESIDENT

The National Minority Quality Forum's (NMQF) Offices of the President serve as the linchpin in the effective management and strategic direction of the organization, ensuring that NMQF remains mission-driven, resilient, and impactful across all its Centers and programs.

The Offices of the President empower NMQF's Centers to function seamlessly and effectively as "one NMQF" to reduce patient risk and advance health equity in historically underserved communities across the nation. Through a commitment to excellence and operational efficiency, the Offices of the President provide the leadership, infrastructure, and collaborative environment necessary for NMQF to fulfill its mission.

Our Offices of the President include:

Operations: Manages NMQF's internal infrastructure, including human resources, key advisory and sponsor relationships, administrative processes, and day-to-day organizational efficiency, enabling staff and programs to thrive.

Finance & Business Management: Secures, manages, and optimizes NMQF's funding streams through diligent financial stewardship, grants management, and financial alignment with business operations—ensuring both sustainability and accountability across all Centers.

Special Projects: Leads innovative, cross-cutting initiatives and strategic partnerships that fall outside traditional Center-specific workstreams, positioning NMQF as an agile leader capable of responding to emerging health equity challenges.

Why This Matters

A robust operational backbone enables the Offices of the President to secure and diversify funding through strategic, mission-aligned partnerships. By streamlining processes and upholding lean efficiency, the Office ensures that every dollar, every partnership, and every initiative directly aligned with NMQF's mission and is optimized for maximum impact. Prioritizing targeted, project-based opportunities in underserved communities—gaps too often bypassed by broader grants—allows NMQF to leverage its specialized expertise and stand out in a competitive nonprofit environment.

NMQF OFFICES OF THE PRESIDENT

Uniting Our Centers as “One NMQF”: Key Projects & Collaborations Index

CANCER		OOP	CCSR	COMMS	HISS	CPSA	CPP	SHC	
Flint Cancer Feasibility Assessment: Overview	p. 22	●							MDHHS
Nationwide Cancer Care Equity Study	p. 26		MYCLINICAL						Carolina Biooncology Institute BioCytics
NMQF Community Health Biobank	p. 27		CANCER SHIFTING / STAGE INITIATIVE						Carolina Biooncology Institute BioCytics
Cancer Care Equity Summit: Overview	p. 28		CANCER SHIFTING / STAGE INITIATIVE						CEO ROUNDTABLE ON CANCER
Community Mini Clinics: Cancer Education	p. 32			NMQF connect					Genentech LEUKEMIA & LYMPHOMA SOCIETY
Cancer Care Equity Summit: FYHN Vodcast interview series	p. 34			FOR YOUR HEALTH NEWS POWERED BY NATIONAL MINORITY QUALITY FORUM					Hessian Labs JOHNS HOPKINS UNIVERSITY PAHO PhRMA EXACT SCIENCES
Alliance for Cancer Care Equity	p. 53						CENTER FOR PUBLIC POLICY		American Cancer Society Cancer Action Network NCCN
Breast and Colorectal Cancer Index	p. 40				●				EXACT SCIENCES
ICD-10-CM Code Development for Triple-Negative Breast Cancer	p. 52						CENTER FOR PUBLIC POLICY		CDC
DRIVing Equity in Colorectal Cancer Screening	p. 62							DRIVE	CDC

GASTROINTESTINAL & AUTOIMMUNE		OOP	CCSR	COMMS	HISS	CPSA	CPP	SHC	
Celiac Health Equity Index	p. 40				●				BEYOND CELIAC Together for a Cure
HIV Patient Value Task Force	p. 54						CENTER FOR PUBLIC POLICY		

WOMEN’S HEALTH & MATERNAL EQUITY		OOP	CCSR	COMMS	HISS	CPSA	CPP	SHC	
Improving Maternal Immunizations Task Force	p. 54						CENTER FOR PUBLIC POLICY		ACOG AAFP AMERICAN COLLEGE of NURSE-MIDWIVES

NMQF OFFICES OF THE PRESIDENT

Uniting Our Centers as "One NMQF": Key Projects & Collaborations

CARDIO- KIDNEY- METABOLIC		OOP	CCSR	COMMS	HISS	CPSA	CPP	SHC	
CKM Health Collaborative	p. 43					CKM Health Collaborative			dexcom ABC
NEKC: Kidney Care Equity Leadership & Policy Education	p. 44					NEKC			ardelyx NMA American Kidney Fund
Community Mini Clinic: Diabetes Education	p. 32			NMQF connect					novo nordisk
Kidney PATIENT Act: Advocacy Network In-District Fly-Ins	p. 35			●					ardelyx
The New ERA Coalition for Rare Kidney Disease	p. 54						CENTER FOR PUBLIC POLICY		NephCure
Unknown Cause Kidney Disease Coalition	p. 54						CENTER FOR PUBLIC POLICY		American Kidney Fund
Anti-Obesity Medication Education: Advocacy Network In-District	p. 35			●					novo nordisk
Diabetes Working Group and Equity Task Force	p. 55							DIABETES WORKING GROUP AND EQUITY TASK FORCE	dexcom novo nordisk sanofi Lilly Boehringer Ingelheim Abbott MERCK
DRIVE Oakland	p. 58							DRIVE	novo nordisk
T1D in Communities of Color Report	p. 58							DRIVE	sanofi
Cardiology Physician Workforce Equity Study	p. 30		CCSR						ABC
Pulmonary Hypertension Burden Study	p. 30		CCSR						MERCK

NMQF OFFICES OF THE PRESIDENT

Uniting Our Centers as “One NMQF”: Key Projects & Collaborations

RESPIRATORY & INFECTIOUS DISEASE		OoP	CCSR	COMMS	HISS	CPSA	CPP	SHC	
RSV Health Equity Report	p. 35			●					sanofi
DRIVing RSV Protection Among Minoritized Children	p. 60							DRIVE	sanofi
Minority and Rural Coronavirus Insights Study (MRCIS)	p. 29		CCSR						MERCK OMH U.S. Department of Health and Human Services Office of Minority Health EXACT SCIENCES FDA
COVID-19 & Influenza Vaccination Communications, Education, Training: Black & Hispanic Equity	p. 60							Center for Sustainable Health Care Quality and Equity	CDC U.S. Centers for Disease Control and Prevention
Influenza Vaccine Index	p. 40				●				sanofi
Influenza Healthcare Disparity Study	p. 30		CCSR						Opella.
Community Flu Education & Vaccination Events	p. 60							Center for Sustainable Health Care Quality and Equity	Walgreens
DRIVE FLU	p. 60							DRIVE	sanofi
DRIVE SHINGLES	p. 61							DRIVE	gsk GlaxoSmithKline

BRAIN & COGNITIVE HEALTH		OoP	CCSR	COMMS	HISS	CPSA	CPP	SHC	
Project PAUSE	p. 52						CENTER FOR PUBLIC POLICY		Alliance for Aging Research ascp
National Alzheimer’s Data Index (NADEX)	p. 40				●				UsAgainst Alzheimer’s
Clinical Trial Learning Community (CTLC): Alzheimer’s Advisory Board Blueprint Report	p. 45					●			Biogen
L.E.A.D. Coalition — CPP	p. 54						CENTER FOR PUBLIC POLICY		UsAgainst Alzheimer’s Volunteers of America

NMQF OFFICES OF THE PRESIDENT

Uniting Our Centers as “One NMQF”: Key Projects & Collaborations

LUPUS		OoP	CCSR	COMMS	HISS	CPSA	CPP	SHC	
National Lupus Outreach & Clinical Trial Education: Overview	p. 22	●							OMH U.S. Department of Health and Human Services Office of Minority Health
National Lupus Outreach & Clinical Trial Education: Lupus Patient Empowerment Guides	p. 33			LIFT EVERY VOICE					OMH U.S. Department of Health and Human Services Office of Minority Health
Lupus Health Equity Index	p. 40				●				LUPUS RESEARCH ALLIANCE
Clinical Trial Learning Community (CTLC): Overview	p. 45					●			Biogen
Clinical Trial Learning Community (CTLC): Lupus Patient Network	p. 33			LIFT EVERY VOICE					Biogen
DRIVE Lupus	p. 61							DRIVE	NIH

HEALTH DATA & POLICY EQUITY		OoP	CCSR	COMMS	HISS	CPSA	CPP	SHC	
Data Equity Coalition	p. 50						CENTER FOR PUBLIC POLICY		BlueCross BlueShield Association
Centering Equity Initiative and Annual Survey	p. 50						CENTER FOR PUBLIC POLICY		
NMQF Private Cloud	p. 39				PRIVATE CLOUD				
SDOH Data Library	p. 46					●			
Health Equity & Accountability Act (HEAA): Title IX Lead	p. 51						CENTER FOR PUBLIC POLICY		United States Congress

COMMUNITY ACCESS & NAVIGATION EQUITY		OoP	CCSR	COMMS	HISS	CPSA	CPP	SHC	
Exact Sciences Patient Assistance Fund	p. 32			NMQF connect					EXACT SCIENCES
ARC: Inclusive Clinical Trials Infrastructure Development	p. 25		ARC						
All of Us Research Program & Policy Roundtables	p. 54						CENTER FOR PUBLIC POLICY		NIH

NMQF OFFICES OF THE PRESIDENT

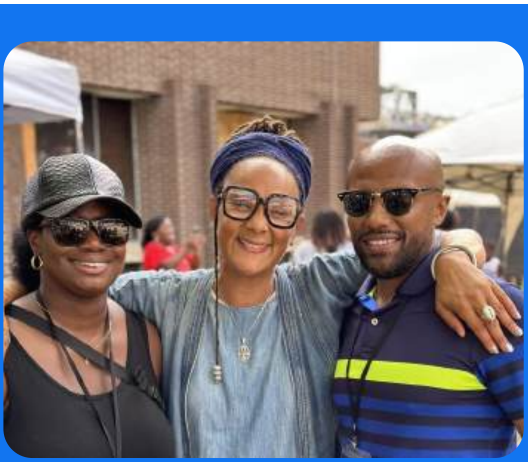
Special Projects: Advancing Health Equity through Innovation

Flint Cancer Feasibility Assessment

Laying the Groundwork for Environmental Justice

In Collaboration with MDHHS

The Flint Cancer Feasibility Assessment Project is a community-driven initiative designed to evaluate the potential for an epidemiological cancer study in Flint, Michigan. With deep roots in community engagement and trust-building, this project ensures that research priorities reflect the lived experiences of residents impacted by environmental injustice.



2024 Highlights:

- Launched FlintCancerFeasibility.org, attracting 544 unique users and 750 page views within six months.
- Collected public input from over 165 residents through town halls, events, and digital platforms.
- Reached more than 220,000 individuals through targeted radio, print, and outreach campaigns.
- Issued a Request for Grant Applications (RGA) to fund the next phase of the cancer feasibility assessment.

Why It Matters

By centering community voices and creating a replicable framework for environmental cancer research, this project is a model for restoring trust and addressing health disparities born from environmental harm.

National Lupus Outreach and Clinical Trial Education Program

Trusted Messengers in Action

With Support from OMH U.S. Department of Health and Human Services Office of Minority Health

NMQF's lupus education initiative is bridging the gap between clinical trials and communities of color by engaging trusted community leaders to deliver culturally responsive education about lupus and clinical research.

2024 Highlights:

- Recruited 6 churches and 12 barbers/stylists across the DMV area as Health Champions to raise lupus awareness and encourage trial participation.
- Trained the first lupus Principal Investigator (PI) from a minority-serving clinician pool; outreach continues to reach the target of seven PIs.
- Conducted focus groups and community events reaching hundreds of individuals with tailored lupus education.
- Partnered with MyClinical and Lupus Therapeutics to strengthen clinical trial referral pathways.

Why It Matters

By placing education and empowerment in the hands of trusted messengers, this program is breaking down barriers to research participation and care for Black individuals living with lupus.

NMQF OFFICES OF THE PRESIDENT

Transforming Health: Our Journey Forward

In Fiscal Year 2024, the National Minority Quality Forum (NMQF) set a new benchmark for transformative health equity initiatives. Through strategic focus and operational excellence, we achieved a remarkable **77% grant win rate**—securing **80 awards** totaling **$7.2 million from 148 submissions.** This represents a **53% increase** over FY23's $4.7 million, underscoring our growing capacity to attract diverse funding and accelerate minority health advancements.

Our success reflects a deep commitment to expanding our reach and impact. With rigorous grant research, we explored **459 funding opportunities**, strategically engaging both new and repeat funders. Leading partners such as HHS (CDC & OMH), MDHHS, Sanofi Pasteur, Bayer, Gilead Sciences, and others have entrusted us with critical resources to scale programs across the nation.

CENTER FOR CLINICAL AND SOCIAL RESEARCH (CCSR)

The Center for Clinical and Social Research (CCSR) is a multidisciplinary team that promotes equitable healthcare by leading observational and interventional clinical and social research that directly affects minoritized populations. CCSR's primary activities in 2024 centered on four key programs:

ARC: The Alliance for Representative Clinical Trials (ARC) is a national network of community-based clinicians—many from Federally Qualified Health Centers (FQHCs)—being trained as principal investigators through ARC's PI Institute, to increase racial and ethnic minority participation in clinical trials and address healthcare disparities.

MyClinical: MyClinical, a for-profit affiliate of the ARC program, is an investigative research network of PI Institute graduates, empowering trusted independent community clinicians and FQHCs to simplify trial recruitment and operations, helping sponsors select research sites that include historically underserved patients.

CSSI: The Cancer Stage Shifting Initiative (CSSI) embeds early-detection screening and community-driven biobanking within medically underserved areas to shift cancer diagnoses to earlier, more treatable stages—built on a national registry and precision research framework.

MRCIS: The Minority and Rural Coronavirus Insights Study (MRCIS) cohort conducts longitudinal research into COVID-19 disparities among medically underserved and rural communities, integrating biobanked specimens, EHR data, and participant surveys.

HDEPs: The Healthcare Data Equity Projects (HDEPs) portfolio applies Medicare and Medicaid claims analysis to uncover and address systemic inequities in care delivery across multiple disease areas.

Why This Matters

Approximately 80% of clinical trial participants are white, despite non-white populations accounting for a significant portion of patients with various medical conditions. This underrepresentation not only hinders the development of effective treatments for these populations, but also perpetuates inequalities in healthcare outcomes.

CENTER FOR CLINICAL AND SOCIAL RESEARCH (CCSR)

NATIONAL MINORITY QUALITY FORUM | CCSR CENTER FOR CLINICAL AND SOCIAL RESEARCH

ARC: Equity through Leadership for Diverse Clinical Trials

What ARC Does

Equipping minority-serving clinicians to lead clinical trials and expand research access where it's needed most.

ARC empowers community-based clinicians—including those at Federally Qualified Health Centers (FQHCs)—to become Principal Investigators (PIs) and hosts for clinical trials.

By equipping trusted care providers with research training, resources, and infrastructure, ARC brings high-quality research opportunities into historically excluded communities.

How ARC Advances Equity

Principal Investigator Institute:

13-hour certified training for clinicians and staff, delivered by a global CRO. Includes CME/CNE credit and site readiness assessment.

Capacity Building:

Feasibility assessment issued to gauge research readiness. Technical and financial support for clinics to meet infrastructure and personnel needs to conduct research.

Good Clinical Practice Certification:

Training delivered via the CITI Program for research compliance and ethics.

2024 Impact at a Glance

- 17 total ARC network sites in underserved communities
- 51+ research personnel trained to date
- 4 new ARC sites added in 2024
- 20+ newly trained clinicians and staff in 2024 through the PI Institute
- 10 minority-serving clinicians trained via FDA OMH grant, all completed site feasibility assessments
- Peer-reviewed manuscript submitted to Journal of Clinical and Translational Science

Therapeutic Areas Represented

ARC clinicians served across high-burden health areas in 2024:

Oncology, Rheumatology, Women's Health, Cardiovascular Disease, Respiratory, Internal Medicine, Gynecology, and more.

Key Supporters

MERCK
EXACT SCIENCES
FDA U.S. FOOD & DRUG ADMINISTRATION
OMH

CENTER FOR CLINICAL AND SOCIAL RESEARCH (CCSR)

MyClinical: Equity through Inclusive Research Infrastructure

What MyClinical Does

A national research network to expand inclusive clinical trial access and streamline trial operations for community-based clinicians.

MyClinical, a for-profit affiliate of the ARC program, connects independent, community-based trial sites through a unified operating model.

By simplifying trial administration— central IRB, single contracting, and budgeting— MyClinical removes structural barriers that have historically kept underserved communities from participating in research.

How MyClinical Drives Equity

Single Coordinating Center:

Streamlined contracting, budgeting, and centralized IRB oversight reduces activation delays.

Inclusive Trial Sites:

Partners with clinics embedded in underserved communities to increase participation from historically excluded populations.

Sponsor Collaboration Model:

Industry partners work directly with the network to ensure representation in real-world trial settings.

2024 Impact at a Glance

- An industry-sponsored clinical trial activated at 2 sites through MyClinical
- 1 American Indian/Alaska Native participant enrolled in industry sponsored study—the only one in the entire study
- Central infrastructure launched for site activation, budgeting, and IRB coordination
- Network-ready model for scaling to trial-ready communities

Impact Spotlight

CANCER SHIFTING STAGE INITIATIVE

Nationwide Cancer Care Equity Study

In 2024, MyClinical laid the groundwork to expand NMQF's Cancer Stage Shifting Initiative (CSSI) to **20 medically underserved cancer care communities** nationwide.

Modeled after MRCIS, CSSI focuses on **early detection, screening, and genomics** to reduce disparities in cancer outcomes by embedding research directly within community care settings.

Leveraging MyClinical's centralized infrastructure, CSSI enables the collection of **biospecimens, genetic data, electronic health records, and survey responses** to investigate cancer's onset, distribution, and burden in underrepresented populations.

CENTER FOR CLINICAL AND SOCIAL RESEARCH (CCSR)

CSSI: Equity through Early Detection and Community-Driven Cancer Research

What CSSI Does

Shifting cancer detection to earlier stages by embedding screening and biobanking within underserved communities.

The Cancer Stage Shifting Initiative (CSSI) partners with community-based cancer centers and biotech innovators to build a comprehensive data infrastructure — combining a national cancer registry, community health biobank, and embedded screening protocols — to drive actionable insights and equitable access to care.

2024 Impact at a Glance

- **2 pilot sites readied:** Houston & Flint for 2025 cancer study launch
- **500+ biospecimens collected:** Blood, tissue, and EHR data
- **100K enrollment goal:** Cancer study target set
- **Community screening workflow integration**: Clinics, leaders & advocates mobilized
- **150+ stakeholders engaged:** Resulting in Summit endorsements and intervention commitments secured

NMQF Community Health Biobank & Nationwide Cancer Study

In collaboration with

The nation's first cancer disparities biobank, the **NMQF Community Health Biobank** — launched with Carolina BioOncology, BioCytics, and local health systems — serves as the data engine for **CSSI's upcoming 2025 national cancer equity study**.

Achievements include:

Biospecimen Collection: Amassed 500+ blood and tissue samples from Houston's Fifth Ward and Flint, integrating genomic sequencing, EHR records, and social determinant data.

Data Integration: Integrated genomic sequencing pipelines, enabling high-resolution mapping of cancer biomarkers across diverse cohorts.

Multi-disease capacity: Supporting studies in diabetes, cardiovascular, and renal health.

Scale Strategy: Operational readiness to enroll 100K participants, with community-based protocols refined for noninvasive early detection in local clinics.

Research Framework: Scalable framework adapted from MRCIS and led under MyClinical — replicable in 20 communities to study cancer onset, progression, and treatment equity in historically excluded populations.

CENTER FOR CLINICAL AND SOCIAL RESEARCH (CCSR)

CSSI: Equity through Early Detection and Community-Driven Cancer Research

NMQF Cancer Care Equity Summit

In partnership with CEO Roundtable on Cancer

In 2024, the first NMQF Cancer Care Equity Summit was convened to confront persistent disparities in cancer outcomes and access to care.

The Summit brought together clinicians, policymakers, researchers, advocates, and patients to share data-driven insights and community perspectives. Conversations focused on advancing equity across the cancer care continuum—from prevention and early detection to treatment and survivorship.

By centering patient voices and strengthening cross-sector collaboration, the Summit reinforced NMQF's commitment to ensuring that all communities, particularly those historically underserved, have access to high-quality, equitable cancer care.

Cancer Environmental Risk Report

Cancer Moonshot, Public Policy, and Medically Underserved Cancer Care Communities

National Minority Quality Forum

Cancer Shifting Stage Initiative

CEO Roundtable on Cancer

Report to the White House Office of Science and Technology Policy

The Cancer Moonshot, Public Policy, and Medically Underserved Cancer Care Communities

January 24, 2024

Gary Puckrein

MaryLisabeth Rich

Scan for full report

At the first NMQF Cancer Care Equity Summit, CSSI's inaugural report, ***Cancer Moonshot, Public Policy, and Medically Underserved Cancer Care Communities,*** connected rigorous environmental risk analysis with stakeholder insights to accelerate action.

Key takeaways and outcomes include:

Environmental Disparities: 7–13% higher carcinogenic exposure among Black communities, with 54% of people of color living in high-risk zones.

Policy Blueprint: Five strategic reforms proposed, including mobile screening units deployed to pilot sites and fast-tracked IRB review processes.

Stakeholder Engagement: Engagement of 20+ federal and state agencies, securing commitments to pilot reforms within underserved regions.

Summit Activation: 150+ attendees endorsed 10 community-led interventions aimed at streamlining care pathways and expanding screening access.

CENTER FOR CLINICAL AND SOCIAL RESEARCH (CCSR)

MRCIS: Equity through Inclusive Longitudinal Pandemic Insight

What MRCIS Does

A longitudinal research platform illuminating the pandemic's unequal impact on minority and rural communities.

The Minority and Rural Coronavirus Insights Study (MRCIS) is a national, prospective study launched to investigate how COVID-19 affects racially and ethnically diverse populations.

Conducted over five years (2020–2026), MRCIS integrates biobank data, electronic health records (EHR), and biannual participant surveys to study disparities in infection, severity, and outcomes.

How MRCIS Advances Equity

Focused Cohort Enrollment:

Prioritizes racial and ethnic minorities, rural residents, and medically underserved communities often underrepresented in pandemic research.

Biospecimen & Data Integration:

Links biospecimen, EHR, and survey data to offer a multidimensional understanding of social and biological risk factors.

Evidence-Based Publications:

2024 study revealed **increased COVID-19 risk** among Hispanic/Latino and Black non-Hispanic populations, even after adjusting for confounders.

2024 Impact at a Glance

- 3 states enrolled (California, Louisiana, Florida)
- Biannual survey administered across study sites

COVID-19 Disparities Research: Published peer-reviewed research in Journal of Personalized Medicine.

Scan for report

- Multiple data types integrated: EHRs, biospecimens, and self-reported health data
- Second biospecimen collection round planned to expand biobank capacity

Study Focus Areas

COVID-19 infection susceptibility in minority populations

Risk of severe COVID-19 illness and death

Impact of biomarkers on infection outcomes, including vitamin D levels

Long-term post-COVID conditions resulting from racial and ethnic disparities

Sponsors & Collaborators

CENTENE Corporation Roche Quest Diagnostics Pfizer

CENTER FOR CLINICAL AND SOCIAL RESEARCH (CCSR)

NATIONAL MINORITY QUALITY FORUM | CCSR CENTER FOR CLINICAL AND SOCIAL RESEARCH

HDEPs: Equity through Claims-Based Disparities Evidence

What HDEPs Does

Turning Medicare and Medicaid data into action for health equity.

The Healthcare Data Equity Projects (HDEPs) are single-sponsor, data-driven research collaborations that analyze Medicare and Medicaid claims to identify disparities in disease burden, health outcomes, and workforce equity.

These projects help policymakers, providers, and partners understand where systemic gaps persist—and how to close them.

How HDEPs Advances Equity

Policy-Relevant Data Insights:

Equips stakeholders with timely, population-scale data on where disparities persist—and how to target interventions.

Workforce Representation Analysis:

Highlights demographic gaps in key specialties like cardiology, driving conversations around training, recruitment, and support for underrepresented providers.

Evidence for Investment:

Quantifies the impact and economic potential of minority-serving clinicians to inform more equitable funding and policy approaches.

2024 Impact at a Glance

In 2024, CCSR advanced three major health equity studies through collaborations with Merck, the Association of Black Cardiologists (ABC), and Opella:

Pulmonary Hypertension Burden Study

Explored racial/ethnic and access-driven disparities in hospitalizations, emergency visits, and mortality among **Medicare and Medicaid enrollees** using 2016–2017 claims data to guide equity-focused care strategies.

Cardiology Physician Workforce Equity Study

Assessed the racial, ethnic, and gender composition of the **U.S. cardiology workforce** relative to population needs—highlighting underrepresentation in key specialties and informing investment in minority-serving providers.

Influenza Healthcare Disparity Study

Explored influenza healthcare utilization and disparities between **Medicaid and commercial populations** using retrospective claims data (2015–2019); *submitted for publication in PLOS ONE in September 2024.*

Key Sponsors

MERCK ABC Opella.

CENTER FOR COMMUNICATIONS AND PUBLIC AFFAIRS (COMMS)

The Center for Communications and Public Affairs (COMMS) is the voice of the National Minority Quality Forum, advancing health equity through targeted communications, community engagement, public education, and policy advocacy. The multidisciplinary team specializes in culturally competent messaging and storytelling that meets the moment—empowering communities of color to make informed health decisions and influencing national conversations around health disparities.

COMMS works across NMQF programs and platforms to connect with historically underserved communities, amplify patient voices, shape public narratives, and mobilize change. In 2024, COMMS focused on four core platforms that together form the foundation of NMQF's communications and engagement ecosystem:

NMQF Connect: NMQF Connect is a hyper-local patient and community engagement program that brings health education, screenings, and resources directly to underserved neighborhoods via Equity Fairs, Wellness Hubs, Traveling Mini Clinics, and the Connect Guardians patient navigation initiative.

Lift Every Voice (LEV) Patient Network: LEV Patient Network is A national community of empowered patients who contribute their stories, insights, and lived experiences to shape peer-to-peer education campaigns, advocacy initiatives, and patient-centered communication tools.

For Your Health News (FYHN): FYHN is a digital media platform and podcast delivering culturally relevant health news, expert perspectives, and practical wellness content to over 120 million Americans of color. FYHN bridges information gaps often ignored by mainstream outlets.

Public Affairs: The advocacy and strategic policy voice of NMQF, focused on mobilizing stakeholders, activating grassroots and grasstops coalitions, and driving action on critical equity issues through media campaigns, issue messaging, and in-district engagement.

Why This Matters

Marginalized communities encounter substantial obstacles to healthcare, including systemic racism, language barriers, socioeconomic disparities, and limited access to quality services. It is imperative to foster dialogue and implement changes that dismantle these barriers by advocating and engaging with cultural sensitivity, ensuring equitable healthcare access for everyone.

CENTER FOR COMMUNICATIONS AND PUBLIC AFFAIRS (COMMS)

NMQF Connect: Expanding Community Access and Engagement in Underserved Cities

What NMQF Connect Does

Access that Reaches You! — Delivering health equity through hyper-local screenings, education, and navigation.

NMQF Connect brings health education, screenings, and patient navigation services directly into underserved neighborhoods via Mobile Mini Clinics, Community Health Equity Fairs, and Patient Navigation Workshops.

By meeting people "where they are," Connect uses a scalable model to build trust, deliver vital preventive services, and guide residents toward ongoing care.

2024 Impact at a Glance

- **3 cities** piloted in 2024
- **365+** individuals reached through on-site services
- **Multi-regional** navigation connections established
- **$67,859** invested in local community partners
- **Collected event feedback** and demographic/SDOH data via surveys and REDCap to tailor outreach.

Patient Experience Insights

- **Collected feedback** from participants via event surveys, patient listening sessions, and digital channels.
- **Captured demographic and social determinants data** (via REDCap) at community events to tailor future outreach.

Geographic Expansion

- **New Mini Clinic partnerships launched** in:
  - Flint, MI – Cancer education with Genentech
  - Houston, TX – Blood cancer with LEUKEMIA & LYMPHOMA SOCIETY
  - Oakland, CA – Diabetes education with novo nordisk
- **2025 expansion planned** for Atlanta, Birmingham, Chicago, DMV, Lumberton, New Orleans, New York, and Phoenix Metro.

Patient Assistance Launch with EXACT SCIENCES

- **Exact Sciences Patient Assistance Fund activated**, facilitating Cologuard distributions and financial support for follow-up care.
- **Navigation contacts** made in 3 key cities, guiding residents to screenings, providers, and clinical trials.
- **Partner workshops** in Houston and Flint (with ACS, Sanofi, Cancer Moonshot) trained local clinicians and advocates in navigation protocols.

Local Investment & Partnerships

- Invested **$14,462** (Flint), **$32,444** (Oakland), and **$20,953** (Houston) in local vendors.
- Shifted over **40%** of budget to minority- and women-owned local businesses.

CENTER FOR COMMUNICATIONS AND PUBLIC AFFAIRS (COMMS)

LEV: Empowering Patients Through Education, Storytelling, and Research Access

What LEV Does

Sharing Stories. Driving Change. — Harnessing patient voice to transform education, advocacy, and research equity.

The Lift Every Voice (LEV) Patient Network leverages the lived experience and voices of patients—especially Black women—to co-create culturally tailored education materials, amplify peer stories on social media, and improve clinical research diversity.

By partnering with community leaders, health agencies, and sponsors, LEV builds trust, informs care decisions, and drives actionable change in lupus treatment and beyond.

Lupus Patient Network Launch

Clinical Trials Learning Community

In partnership with Biogen

- **Collaborative Framework:** Partnered with Biogen, NMQF's CPSA, and SHC to convene a Lupus Clinical Trial Learning Community—advisory meetings, social listening, and a microsite prototype—to guide culturally competent campaign development.
- **Challenge Addressed:** Address stark disparities—women of color face 2–3× higher lupus prevalence, and average 5-year diagnostic delays—by forging a dedicated patient network to inform education and research.
- **Network Launch:** Convened a collaborative of **50** Black and Hispanic women living with lupus as the inaugural LEV Patient Network cohort.
- **Data-Driven Outreach:** Identified that 1 in 537 young Black women has lupus, with 55% seeing ≥4 providers before accurate diagnosis. These insights shaped network priorities for symptom awareness and care navigation.
- **Materials Development:** Audited existing resources to produce culturally resonant language and imagery for brochures, infographics, discussion guides, a landing page/toolkit — and a **PSA** (English/Spanish) reaching **1.2M** primarily in the target audience with ~**1.5% CTR** to Biogen Trial Link.

2024 Impact at a Glance

- **9** patient education guides produced
- **800+** direct patient engagements through digital engagement and peer-led education sessions
- **1.2 M** digital impressions via PSA with ~**1.5% CTR** driving to Biogen Trial Link
- **50** active patient ambassadors

Lupus Patient Empowerment Guides

National Lupus Outreach and Clinical Trial Education Program

In partnership with OMH U.S. Department of Health and Human Services Office of Minority Health

- Developed and released **9** "Empower and Thrive" guides covering symptom tracking, genetics, clinical trials, and post-diagnosis navigation.
- Distributed guides through print, digital downloads, and community workshops, supporting peer-to-peer education sessions.
- Peer testimonials activated in **20+** social media PSAs, normalizing lupus conversations and promoting self-advocacy.
- Launched a comprehensive toolkit guiding newly diagnosed patients through appointments, medication management, and lifestyle changes.
- Toolkit resources downloaded or distributed to clinical and community settings, boosting patient confidence in self-management.

CENTER FOR COMMUNICATIONS AND PUBLIC AFFAIRS (COMMS)

FYHN: Delivering Culturally Resonant Health News & Expert Voices

What FYHN Does

Your Health. Your News. Your Power. — Elevating trusted health stories and expert voices for communities of color.

For Your Health News (FYHN) operates as both a digital news platform (fyh.news) and a podcast/vodcast series, curating culturally relevant health content—top stories, expert insights, and wellness guidance—to empower communities of color.

By spotlighting research, policy, and patient perspectives, FYHN fills critical information gaps and drives health literacy.

2024 Impact at a Glance

- **120 million** Americans of color represent FYHN's total addressable audience.
- **25%** of site users are aged 25–34, with **70%** identifying as women.
- **12** podcast episodes produced; **5,000+** total downloads.
- **6** vodcast episodes at launch; **2,500+** streaming hours.
- **1,200+** live summit viewers; **150+** news outlets covering FYHN content.

Podcast Launch & Cancer Care Equity Series

Launched the "For Your Health News" podcast in February 2024 (formerly "Reducing Patient Risk"), now available on Spotify, Google Podcasts, and Apple Podcasts.

Produced 12 podcast episodes in 2024—featuring Cancer Care Equity Summit interviews with AI, policy, and community health leaders—which garnered **5,000+** downloads and a **4.8/5** average rating.

Launched with a vodcast series of **6 video episodes** from the 2024 Cancer Care Equity Summit, collectively streaming **2,500+** hours on YouTube.

Cancer Care Equity Summit: Coverage & Engagement

Scan for video

Promoted 2024 Cancer Care Equity Summit livestream, attracting **1,200+ live views** and **3,000+ recorded views** post-event.

Generated **150+** earned media mentions—including Politico, MedPage Today, The Hill, and MLive—amplifying FYHN's visibility among policymakers and healthcare professionals.

Website Redesign & Audience Growth

fyh.news was relaunched with a modern interface and streamlined navigation.

Expanded content partnerships with community organizations and influencers, amplifying reach into **8 new metropolitan markets**.

CENTER FOR COMMUNICATIONS AND PUBLIC AFFAIRS (COMMS)

Public Affairs: Mobilizing Policy and Advocacy for Health Equity

How Public Affairs Drive Equity

Mobilizing Policy and Advocacy for Health Equity — Advancing legislation, coalitions, and campaigns that close care gaps.

Public Affairs drives NMQF's policy and advocacy efforts by shaping health equity agendas, fostering coalitions, and engaging lawmakers and influencers.

Through strategic issue messaging, digital advocacy, in-district meetings, and grassroots/grasstops social campaigns, public affairs efforts advance legislation and reports that address disparities in respiratory health, kidney disease, obesity treatment, and beyond.

Sanofi RSV Health Equity Report

Circulated our comprehensive RSV Health Equity Report in partnership with Sanofi, highlighting hospitalization risks and vaccination gaps among infants in minority communities.

Distributed executive summaries and briefed **25** congressional offices and state health departments.

Secured **four** media features in leading outlets to elevate RSV equity recommendations.

Scan for report

2024 Impact at a Glance

- **25** RSV congressional and state health briefings
- **50+** Advocacy Network members engaged
- **15** in-district meetings conducted
- **30** advocates in Kidney Patient Act fly-in; **20** offices met
- **2,500+** providers reached via AOM toolkit distribution

Advocacy Network Established: In-District Fly-Ins

Established a bipartisan Advocacy Network of 50+ patient advocates, clinicians, and community leaders.

Coordinated **15** in-district meetings with members of Congress and their staff, including:

- **Kidney Patient Act**

  In collaboration with ardelyx

  Supported legislation to expand Medicare coverage for renal therapies—resulting in the Act's inclusion in the **Nov 2024** federal appropriations package.

- **Treat and Reduce Obesity Act (TROA)**

  In collaboration with novo nordisk®

  Concluded a multi-stakeholder education campaign on anti-obesity medication (AOM) coverage and best practices, with **10** in-district briefings and **5** statehouse roundtables.

CENTER FOR HEALTH INFORMATION STRATEGY AND SERVICES (HISS)

The Center for Health Information Strategy and Services (HISS) provides data-driven insights to reduce patient risk, eliminate disparities, and improve care quality and outcomes for vulnerable populations. HISS supports NMQF's mission by managing secure infrastructure, overseeing high-impact data partnerships, and enabling actionable health equity analytics. Key activities in 2024 focused on the following programs:

NMQF Private Cloud: A secure research and analytics environment offering advanced tools and protected access to over 5 billion anonymized health records. The Private Cloud empowers researchers, advocates, and partner organizations to conduct large-scale data analysis, guiding targeted interventions and evidence-based policy decisions.

NMQF Health Equity Indices: HISS maintains disease-specific equity indices using CMS claims and population-level data to uncover disparities in access, cost, and outcomes. These indices help organizations develop targeted programming and publish actionable insights. Some of our notable index partnerships include:

- **Breast and Colorectal Cancer Index:** In partnership with Exact Sciences, this index maps cancer prevalence and outcomes by geography and demographics to support equitable research and care strategies.
- **Lupus Health Equity Index:** In collaboration with the Lupus Research Alliance, this index supports shared data exploration and identifies health disparities in lupus diagnosis and treatment.
- **National Alzheimer's Data Index (NADEX):** A partnership with UsAgainstAlzheimer's leverages claims data to better understand prevalence, cost, and hospitalization among Alzheimer's patients.
- **Celiac Health Equity Index:** Developed with Beyond Celiac to examine misdiagnosis trends and disease burden, supporting research publications and community insights.
- **Influenza Vaccine Index:** Maintained with Sanofi to track flu vaccine uptake and associated outcomes across at-risk populations using aggregated CMS data.

CENTER FOR HEALTH INFORMATION STRATEGY AND SERVICES (HISS)

Establishing Best Practices for Protecting, Accessing, and Using Health Data to Advance Equity

The Center for Health Information Strategy and Services (HISS) exists at the intersection of data science, public policy, and health equity. HISS has rapidly evolved into a vital hub within NMQF, offering data-driven insights that are both actionable and ethical—especially for the benefit of vulnerable and medically underserved populations.

In 2024, HISS led enterprise-wide efforts to:

Develop comprehensive data management and security strategies that ensure the integrity and privacy of health data across NMQF platforms.

Oversee security architecture for the community data lake, GIS systems, and web-based repositories, reinforcing protections against unauthorized access.

Drive forward data-informed research projects addressing health disparities, with a focus on real-world impact.

Serve as an innovation partner across all NMQF centers, enhancing the Private Cloud to support secure, cross-functional collaboration.

Champion patient representation in data systems and tools, empowering advocacy groups through digital access and analytics.

The Center is grounded in a vision of a healthcare landscape where data insights inform more equitable outcomes—and a mission to reduce risk, eliminate disparities, and improve care through the ethical use of data.

Why This Matters

Aggregating data from historically underserved communities and minoritized populations reveals previously-unseen patterns, addressing gaps in health data monitoring. Highlighting disease patterns by factors like zip code can inform evidence-based policymaking, fostering meaningful change and equity in healthcare access and outcomes.

CENTER FOR HEALTH INFORMATION STRATEGY AND SERVICES (HISS)

Protecting Data and Vulnerable Populations

Data Security & Governance

Safeguarding Sensitive Health Information Through Ethical, Secure Infrastructure

In an era where data powers decision-making at every level of the healthcare system, the protection of sensitive health information—particularly for historically underserved communities—remains a central priority.

In 2024, the Center for Health Information Strategy and Services (HISS) implemented rigorous security architecture to safeguard over 5 billion patient records managed within NMQF's systems. This included maintaining privacy and data integrity across the community data lake, geographic information systems, and web-based data portals.

2024 Impact at a Glance

- **Enterprise-Grade Cybersecurity:** Advanced intrusion detection systems, role-based access controls, and continuous monitoring were deployed to secure both structured and unstructured health data.
- **Data Governance:** HISS maintained strict adherence to HIPAA and other regulatory frameworks, ensuring secure handling of personally identifiable and protected health information.
- **Privacy by Design:** Security protocols were embedded into every stage of the data lifecycle—from acquisition and storage to analysis and reporting.
- **Ethical Safeguards:** Emphasis was placed on protecting populations often subject to data exploitation, with measures to ensure that equity-driven data use does not increase vulnerability or risk.

Protecting data is not merely a compliance exercise—it is a moral and operational imperative for any institution aiming to build trust and drive systemic change in healthcare.

CENTER FOR HEALTH INFORMATION STRATEGY AND SERVICES (HISS)

NMQF Private Cloud: Advancing Data Use and Access

NMQF Private Cloud Overview

Expanding Secure Infrastructure for Health Equity Research

In 2024, the HISS significantly advanced the NMQF Private Cloud—an enhanced, secure research and analytics environment designed to support the ethical use of large-scale U.S. health data for researchers, advocates, and healthcare organizations.

How NMQF Private Cloud Advances Equity

Disparities Identification:

Enables precise analysis of disease burden and care gaps across diverse populations, empowering advocates with data to direct resources where they're needed most.

Predictive Modeling for Health Equity:

Supports the development of models that anticipate risk, inform early intervention, and guide patient-centered strategies.

Clinical Research Enablement:

Facilitates evidence generation for inclusive trial design, eligibility criteria, and site selection that reflect underrepresented communities.

Policy and Pricing Evaluation:

Equips advocates with real-world evidence to assess drug pricing, value-based care initiatives, and the broader financial impact of treatment access.

Digital Advocacy Tools:

Strengthens policy and public engagement efforts by translating big data insights into compelling narratives for legislative, clinical, and community action.

2024 Key Developments

Infrastructure Expansion:

- Upgraded hardware at NMQF's data center; enhanced storage systems; new virtualization layers to support dynamic workloads.

Analytical Flexibility:

- Users are now able to run advanced tools—including Python, SAS, and ChatGPT—in a secure environment, supporting everything from basic visualization to complex modeling.

Improved Data Access:

- Updated Medicare and Medicaid data were integrated into the warehouse, alongside SDOH data, claims, prescription fill data, and diagnostic codes.

Security and Compliance:

- Compliance with federal data privacy laws and implementation of layered access control ensured continued trust from both internal users and external collaborators.

Partnership Capabilities:

- The Private Cloud enables advocacy organizations, through secure virtual machines, to conduct their own analysis, manage proprietary datasets, and collaborate across institutions.

CENTER FOR HEALTH INFORMATION STRATEGY AND SERVICES (HISS)

Health Equity Indices: Advancing Data Use and Access

What Health Equity Indices Offer

Measuring Disparities to Guide Targeted Action

Data indices are central to the ability to translate complex datasets into clear, actionable insights. In 2024, HISS supported the ongoing development and application of **27 disease-focused health equity indices** to help partners, policymakers, and researchers understand disparities across clinical, demographic, and geographic dimensions.

These tools enable the identification of communities facing disproportionate burdens of disease, low access to care, or higher-than-average risk of adverse outcomes. They also guide the allocation of resources and the design of equity-focused interventions.

Notable Index Partnerships

EXACT SCIENCES

Breast and Colorectal Cancer Index

Maps cancer prevalence and outcomes by geography and demographics to support equitable research and care strategies.

LUPUS RESEARCH ALLIANCE

Lupus Health Equity Index

Supports shared data exploration and identifies health disparities in lupus diagnosis and treatment.

UsAgainst Alzheimer's

National Alzheimer's Data Index (NADEX)

Leverages claims data to better understand prevalence, cost, and hospitalization among Alzheimer's patients.

BEYOND CELIAC Together for a Cure

Celiac Health Equity Index

Examines misdiagnosis trends and disease burden, supporting research publications and community insights.

sanofi

Influenza Vaccine Index

Tracks flu vaccine uptake and associated outcomes across at-risk populations using aggregated CMS data.

Key Components of the NMQF Health Equity Indices

- **Disease Prevalence and Burden:** Analysis of disease occurrence by race, gender, age, and location—down to the ZIP code and congressional district level.
- **Access and Utilization:** Measures of healthcare access, service utilization, provider density, and care gaps.
- **Cost and Outcome Trends:** Comparative analysis of healthcare spending, out-of-pocket costs, and health outcomes for subpopulations.
- **Social Drivers of Health:** Integration of environmental data, income and education levels, and access to community resources such as hospitals and pharmacies.

These indices are critical for shaping equitable public policy, informing value-based care efforts, and empowering communities with data tailored to their unique contexts.

CENTER FOR PROFESSIONAL AND STRATEGIC ALLIANCES (CPSA)

The Center for Professional and Strategic Alliances (CPSA) is a multidisciplinary hub committed to uniting healthcare professionals, researchers, and community stakeholders to develop collaborative solutions that address health disparities. Established in 2024, CPSA houses a portfolio of high-impact programs targeting chronic disease disparities driving research, innovation, advocacy, and education to improve health outcomes among medically underserved communities.

CKM Health Collaborative: The Cardio-Kidney Metabolic (CKM) Health Collaborative is a joint initiative of NMQF and the Association of Black Cardiologists (ABC). The CKM Health Collaborative is a national network focused on reducing disparities in cardio-kidney-metabolic (CKM) conditions through clinical guidance, community engagement, policy/advocacy, and data utilization.

NEKC: The Nephrologists for Equitable Kidney Care (NEKC) is a national alliance of nephrologists and kidney health professionals advancing equitable access to optimal kidney care, advocating for patient-centered policy change, and building a professional community grounded in health equity.

Clinical Trial Learning Community (CTLC): The Clinical Trial Learning Community (CTLC), In partnership with Biogen, is designed to increase clinical trial access and participation among communities historically excluded from research. CTLC identifies and addresses barriers to access in chronic diseases such as lupus and Alzheimer’s.

SDOH Data Library: The Social Drivers of Health (SDOH) Data Library is a centralized repository of social drivers of health (SDOH) data, that enables customized geographic reports and dashboards, empowering initiatives to identify and address barriers to healthcare access in underserved communities.

CENTER FOR PROFESSIONAL AND STRATEGIC ALLIANCES (CPSA)

Introducing NMQF's Newest Center

In 2024, the National Minority Quality Forum (NMQF) launched the Center for Professional and Strategic Alliances (CPSA) to serve as a dedicated hub for collaboration among professional groups and health equity champions. Recognizing the growing need to coordinate alliances, manage cross-sector initiatives, and harness data to drive systemic change, CPSA was formed under the leadership of Kelelaye Emiru, MBA, Vice President, and Michael DeSalvo Solarte, MSW, Program Manager.

CPSA centralizes professional alliance management, health data resources, and strategy alignment—ensuring greater cohesion and impact across NMQF's equity-focused initiatives. From standing up new alliances to coordinating national advisory boards and leading community-based clinical research outreach, CPSA enables rapid deployment of high-impact programming that spans from advocacy to practice.

CPSA's Mission

To serve as a central hub for professional groups, fostering collaboration, knowledge sharing, and joint initiatives that leverage data-driven insights and innovative strategies to tackle health disparities.

Professional Alliances Coordination: Support and manage professional alliances and working groups committed to advancing equitable care.

Research and Innovation: Catalyze research and develop real-world solutions in areas of unmet need in collaboration with communities.

Data-Driven Decision Making: Leverage the NMQF Community Data Lake and Social Drivers of Health (SDOH) Data Library and clinical datasets to inform policy and programming.

Community Engagement: Ensure communities' lived experiences and perspectives inform research, advocacy, and care delivery.

Why This Matters

CPSA's integrated approach—linking professional collaboration with powerful datasets and on-the-ground insights—helps uncover patterns and gaps in care that traditional health systems often overlook. By equipping healthcare leaders with social and clinical intelligence at the community level, CPSA advances systemic solutions that are equitable, scalable, and measurable.

CENTER FOR PROFESSIONAL AND STRATEGIC ALLIANCES (CPSA)

CKM Health Collaborative: Equity through Holistic Care

What CKM Health Collaborative Does

CKM Health Collaborative

Uniting to reduce cardio- kidney-metabolic disease burden for underserved communities.

Launched in partnership with the Association of Black Cardiologists (ABC), the CKM Health Collaborative is a national alliance addressing the interconnected nature of cardiovascular, kidney, and metabolic conditions—disproportionately affecting Black, Hispanic, and Native American populations.

This initiative brings together clinicians, researchers, policymakers, and patient advocates to reduce the burden of CKM disease through a data-informed, community-engaged, and policy-aligned approach.

How the CKM Health Collaborative Advances Equity

Real-World Implementation Framework

Developing the CKM Care Framework — a real-world, data-driven roadmap advancing care in cardio-kidney-metabolic care across five domains: community engagement, policy/advocacy, clinical guidance, research, and data.

Trusted Voices & Education

Engaging FQHCs, physicians, community leaders, and faith-based organizations to deliver culturally relevant education on CKM prevention and care.

Data-Driven & Policy-Aligned

Leveraging NMQF's Community Data Lake and SDOH Data Library and ABC's advocacy expertise to drive evidence-based interventions and policy recommendations focused on access and outcomes.

2024 Impact at a Glance

- **Program Launch:** CKM Health Collaborative launched in Q4 of 2024 with support from Dexcom.
- **Framework in Progress:** Workstreams will be initiated in Q4 to develop the CKM Health Equity Framework, with full release expected in 2026.
- **Multi-Stakeholder Buy-In:** Actively engaged over 30 experts across cardiovascular, kidney, and metabolic health fields in collaborative subgroup development.
- **Community Insight Channels:** Began coordination with NMQF's Health Champions and the Faith Health Alliance to inform culturally tailored patient education efforts.

Founding Sponsor

Dexcom

CENTER FOR PROFESSIONAL AND STRATEGIC ALLIANCES (CPSA)

NEKC: Equity through Kidney Care Policy, Patient Voices, and Data

What NEKC Does

Allied nephrologists driving policy, research, and community outreach for underserved kidney patients.

The Nephrologists for Equitable Kidney Care (NEKC) is a multidisciplinary coalition of kidney care professionals—including nephrologists, social workers, researchers, and patient advocates—working to eliminate disparities in kidney disease diagnosis, treatment, and outcomes.

Launched under CPSA in 2024, NEKC provides a platform for clinical leadership, public policy advocacy, and professional development rooted in equity.

How NEKC Advances Equity

Data-Driven Policy Advocacy

Leverage NMQF's Community Data Lake and SDOH data library to lead national efforts urging Congress and CMS to support patient-centered kidney policies and prevent dangerous cost-cutting policies that limit access to patients.

Community-Engaged Education

Hosted public-facing events—health fairs, webinars, and LinkedIn Lives—to equip patients and caregivers with the knowledge and tools to advocate for optimal kidney care.

Professional Empowerment

Creates networking and leadership opportunities for kidney health professionals of color, with a focus on equitable workforce development and mentorship.

2024 Impact at a Glance

- **Program Launch:** Officially launched in August 2024 with support from Ardelyx.
- **Hill Engagement:** Participated in Hill meetings with NMQF Action Network to educate on Kidney PATIENT Act.
- **Professional Mobilization:** 50+ nephrologists and kidney health professionals engaged across NEKC's network.
- **Policy Leadership:** Coordinated sign-on letters to CMS and Congress with partners including the National Medical Association (NMA), the American Society of Nephrology (ASN), and the Renal Physicians Association.
- **Public Education on Kidney Care:** Hosted a high-impact webinar and LinkedIn Live event viewed by +2,000 people nationwide.

Scan for webinar

- **National Recognition:** Featured at major conferences including the NMA Annual Meeting and ASN Kidney Week.
- **Community Outreach:** Attended Brooklyn health fair hosted by Congressman Hakeem Jeffries to provide kidney health resources.
- **Thought Leadership:** NEKC member Dr. Frita Fisher published a widely shared op-ed in BlackDoctor.org on ESRD bundle impacts.

Key Collaborators

ardelyx

National Medical Association

American Kidney Fund® FIGHTING ON ALL FRONTS

CENTER FOR PROFESSIONAL AND STRATEGIC ALLIANCES (CPSA)

CTLC: Closing Gaps in Clinical Research Participation

What CTLC Does

Expanding awareness and access to clinical trials for underserved patients with chronic diseases.

The Clinical Trial Learning Community (CTLC) is a collaboration between NMQF and Biogen designed to overcome barriers to clinical trial participation among minoritized populations—especially in diseases like lupus and Alzheimer's.

Through education, community outreach, and advisory board guidance, CTLC supports informed decision-making for patients and caregivers while building trust in research.

How CTLC Advances Equity

Community-Rooted Engagement

Delivers culturally relevant education through outreach campaigns, patient workshops, and community forums in high-burden regions like the DMV and New York City.

Trains clinicians and build community trust to support patient entry into research pathways as a care option, not a last resort.

Advisory Board Model

Informs model by collecting both lived experiences and expert insight from patients, caregivers, neurologists, and researchers. The board created a national blueprint for inclusive clinical trial outreach.

Culturally Responsive Materials

Develops and distributes digital toolkits, video content, and social media campaigns tailored to Communities of Color—populations disproportionately affected by lupus and Alzheimer's.

2024 Impact at a Glance

Advisory Board Blueprint: Released a landmark report on improving Alzheimer's clinical trial inclusion.

Scan for report

- **Expanded Funding:** Secured an additional $233,000 from Biogen to expand to NYC and continue in the DMV area.
- **Clinician Training:** Provided quality improvement training to 150+ clinicians.
- **Community Reach:**
    - Directly engaged 800+ individuals through events and forums.
    - Reached 1.2 million+ Black and Hispanic women online with resources on lupus and clinical trials.
    - Achieved a **1.5% click-through rate** to Biogen Trial Link—well above the 0.83% industry average.
- **Grassroots Network Building:** Created a core network of ~50 women living with lupus in key cities to share trusted messaging.
- **Recognition & Leadership:** CTLC leaders presented at the Patients as Partners Conference in Boston, sharing their model for community-led research engagement.

CENTER FOR PROFESSIONAL AND STRATEGIC ALLIANCES (CPSA)

SDOH Data Library: Unlocking Zip-Code Level Equity Insights

What the SDOH Library Offers

Mapping social drivers of health to illuminate the root causes of health disparities—down to the ZIP code.

NMQF's Social Drivers of Health (SDOH) Data Library is a robust tool that compiles geospatial and population-level data to reveal how social, economic, and environmental factors shape health outcomes.

It enables custom reports, dashboards, and insights for internal teams, partners, and policymakers to drive data-informed decision-making and resource allocation.

Sample Report

Clinical & Environmental Health in Houston, Texas

Key Indicators of Healthcare Access and Outcomes in Your Community

The Drivers of Health

How the SDOH Library Advances Equity

Precision Health Equity

By integrating SDOH indicators like income, education, food access, and environmental quality, the library helps stakeholders identify underserved areas most in need of intervention.

Complement to Clinical Data

When used alongside claims data from NMQF, the SDOH Library paints a fuller picture of disparities in care, informing both research and program design.

Location-Based Customization

Supports local-level initiatives by providing community-specific insights that go beyond disease prevalence—enabling targeted outreach, resource deployment, and advocacy.

Cross-Program Utility

Used across CPSA initiatives and by NMQF researchers to support clinical trial site selection, policy proposals, health education targeting, and equity dashboards.

2024 Impact at a Glance

- **Integrated Across CPSA Programs:** Used by NEKC, CTLC, and CKM Health Collaborative to align disease burden with social need, aiding in site selection, policy recommendations, and outreach planning.
- **Enhanced Trial Site Planning:** Helped identify locations where underserved populations face both high disease burden and systemic barriers to care.
- **Custom Equity Dashboards:** Delivered tailored dashboards to support ongoing efforts to visualize SDOH barriers alongside patient data.
- **Community Insights for External Partners:** Supported strategic planning for funders and collaborators seeking to expand health equity efforts.
- **Operationalized in Research:** Leveraged by NMQF researchers to supplement Medicare and Medicaid claims analysis with socioeconomic context.

CENTER FOR PUBLIC POLICY (CPP)

The NMQF Center for Public Policy (CPP) articulates and aligns the NMQF policy construct with the knowledge and evidence that are grounded in the physical laws and the American social contract. CPP is proactive in seeking opportunities for policy engagements that support the missions and business models of our partners and stakeholders, including federal and state government, the pharmaceutical research and manufacturing industry, patient advocacy, organized medicine, payers and insurers, and group purchasers of healthcare.

Accordingly, CPP seeks and responds to opportunities to create a policy scaffolding that has the potential to mitigate polarizing positioning that is fueled far too often by an imbalance between patient risk mitigation and financial risk mitigation.

The CPP team operationalizes the NMQF policy vision through three interrelated portals of engagement:

The Institute for Equity in Health Policy and Practice: IEHPP is a sponsored partnership that supports members' efforts to advance their corporate imperatives in a manner that is responsive to the health concerns of all population cohorts and therapeutic areas. The Institute facilitates the exchange of information, supports educational efforts, and launches consensus-building initiatives that focus on forward-looking, population-centric policy.

The National Alliance for Brain Health and Awareness: NABHA is a sponsored initiative in recognition of the need for collaboration across the domains of brain health to design and implement initiatives regarding the prevalence of brain diseases and the assurance of quality health services for individuals with brain disease.

External Alliances & Collaborations: Partnerships with national and local patient and provider advocacy groups to develop consensus regarding structural challenges and solutions, and to educate and inform collectively regarding shared policy interests at the federal level, such as improvements in chronic disease prevalence and treatment initiatives, long-term care reimbursement, Medicare and Medicaid coverage policy, health technology/value assessment approaches, and other issues of national import.

CENTER FOR PUBLIC POLICY (CPP)

Pillars of Systemic Quality, Human Value, and Structural Order

The CPP team assesses the potential impact of public policy engagement opportunities through the lens of a foundational social contract made manifest as tangible, measurable **Pillars of Systemic Quality, Human Value, and Structural Order:**

Pillar 1

A system of care that assigns the highest priority to **patient risk mitigation** rather than financial risk mitigation.

Pillar 2

Diagnosis, treatment and payment paradigms that provide the health services delivery system with maximum flexibility in responding to **patient needs**.

Pillar 3

Research designs that assure the statistically significant and robust **inclusion of all** population and patient cohorts.

Pillar 4

Enhanced data collection, monitoring and evaluation of the outcomes associated with promulgated policy and regulation.

Why This Matters

Policy change is essential in addressing health equity for minoritized communities due to persistent systemic barriers and disparities they face. Without policy interventions, these communities continue to encounter obstacles in accessing quality healthcare, leading to worsened health outcomes and perpetuating existing inequalities.

CENTER FOR PUBLIC POLICY (CPP)

Overview of CPP Activity: 2024

Completed	Ongoing
The 117th Congress - Tri-Caucus Health Equity and Accountability Act: Title IX Lead (Accountability & Evaluation)	340B Realignment Initiative
The 118th Congress - Tri-Caucus Health Equity and Accountability Act: Title IX Lead (Accountability & Evaluation)	The 119th Congress - Tri-Caucus Health Equity and Accountability Act: Title IX Lead (Accountability & Evaluation)
ICD-10-CM Coding for Neuropsychiatric Symptoms of Dementia and Stages of Severity of Alzheimer's Disease	BCBSA/NMQF Data Equity Coalition: Co-Leadership. OMB SPD #15 focus
ICD-10-CM Coding for Triple Negative Breast Cancer	Medicaid State Prescription Drug Affordability Board Policy Engagement
Thought Leaders in Equity Policy Roundtables: All of Us Research Program Engagement -2018, 2019, 2024)	Alliance for Cancer Care Equity (Partnership among NCCN, ACS CAN, NMQF)
Medicaid State Non-Federal Share and Directed Payment Policies -State and Federal Engagement	NephCure New ERA Coalition for Rare Kidney Disease
The 2025 Centering Equity Annual Survey	The 2026 Centering Equity Annual Survey

CENTER FOR PUBLIC POLICY (CPP)

Spotlight on Selected CPP Accomplishments: 2023-2025

The Centering Equity Initiative and Annual Survey

The NMQF Centering Equity Initiative (CEI) was launched in 2020 under the umbrella of CPP's Institute for Equity in Health Policy and Practice.

CEI was established in response to concerns that the extant system of knowledge and intervention development, financing and insurance, and health care services delivery was not designed – was never intended – to create and sustain health for all population and patient cohorts in the United States.

The three components of CEI are a literature review which was completed in February 2022. The Thought Leaders in Equity Roundtable and the concurrent inaugural fielding of the Centering Equity Survey followed closely in Spring 2022.

Design and Impact of CEI

The Centering Equity Survey was designed by CPP staff to collect information that provides insights into structural processes that increase patient risk by creating, perpetuating or exacerbating inequities in health services care and outcomes.

More than 600 individuals from various racial and ethnic backgrounds, health-related companies, organizations and educational entities responded to the 2024 Centering Equity Survey.

Each survey has a core set of questions, as well as questions that are unique to that instrument. CPP is currently undertaking a multi-year analysis and is exploring options for publication. The 2026 survey is in the design phase.

Blue Cross Blue Shield Association/NMQF Data Equity Coalition

The mission of this partnership with one of the largest payers in the country is to develop and recommend policy solutions that advocate for race, ethnicity, language, sexual orientation and gender identification standards in support of health outcomes.

In 2024, the Data Equity Coalition was a highly visible component of a successful multi-year advocacy effort to update Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (OMB Statistical Policy Directive (SPD)15 for the first time since 1997.

Scan for webinar

The revised SPD-15 went into effect on March 28, 2024 for all new data collection. It revised the structure of the race and ethnicity question in a manner that allows multiple responses; adds Middle Eastern or North African (MENA) as a minimum reporting category, separate and distinct from the White category; requires the collection of more detail beyond the minimum race and ethnicity reporting categories (unless an exemption is granted) and requires agency Action Plans on Race and Ethnicity Data to assure timely compliance.

The Data Equity Coalition convenes quarterly meetings with its membership of the more than 25 patient and policy advocacy organizations and is managed by a joint Core Team and LangCo Partners. Efforts will continue to protect the progress that was made, and to expand the authority of SPD beyond race and ethnicity to include more inclusive data mandates.

CENTER FOR PUBLIC POLICY (CPP)

Spotlight on Selected CPP Accomplishments: 2023-2025

The Health Equity and Accountability Act of 2024 (HR 9161/S4773)

During the 118th Congress (January 2023 – January 2025), CPP played a pivotal role in the development of the Health Equity and Accountability Act (HEAA) of 2024.

This bill was introduced by Congresswoman Barbara Lee in the U.S. House of Representatives and Senator Mazie Hirono in the U.S. Senate in July 2024.

HEAA has represented the consensus of the Congressional Tri-Caucus since the 108th Congress in 2003.

Role of CPP in HEAA

CPP was the Lead on Title IX for the 118th and 117th Congresses and will serve in that role for the 119th Congress.

As Title Lead, CPP collaborated with hundreds of partner organizations and led the effort to expand civil rights protections for anyone operating with Federal financial assistance, ensures populations in correctional facilities receive care, and ensures that there is transparency in how protections are enforced.

Further, Title IX enforces accountability by requiring reports on how the government is addressing health disparities and inequities.

Ten Titles of HEAA

HEAA is organized into ten titles:

Title I: Data Collection and Reporting

Title II: Culturally and Linguistically Appropriate Care

Title III: Health Workforce Diversity

Title IV: Improvement of Healthcare Services

Title V: Improving Health Outcomes for Women, Children, and Families:

Title VI: Mental Health

Title VII: Addressing High-Impact Minority Diseases.

Title VIII: Health Information Technology.

Title IX: Accountability and Evaluation

Title X: Addressing Social Determinants and Improving Environmental Justice

Scan for webinar

CENTER FOR PUBLIC POLICY (CPP)

Spotlight on Selected CPP Accomplishments: 2023-2025

ICD-10-CM Coding for Triple-Negative Breast Cancer, and for Neuro-Psychiatric Symptoms of Dementia and Stages of Severity of Alzheimer's Disease

An essential component of policy to support more precision in research, diagnosis and payment is the availability of coding based upon the International Classification of Diseases (ICD) which is published by the World Health Organization (WHO).

The United States expands upon the periodic, numbered releases of the WHO ICD by creating a clinical modification (CM) that is used in the United States, currently the ICD-10-CM. The process to create and maintain this coding system is managed by the National Center for Health Statistics, Centers for Disease Control and Prevention.

The Center for Public Policy led successful collaborative efforts to establish ICD-10-CM codes for Neuro-Psychiatric Symptoms of Dementia and Stages of Severity of Alzheimer's Disease, which became effective in October 2023, and for Triple-Negative Breast Cancer, which became effective in October 2024.

The collaborations included representatives of organized clinical specialists (psychiatry, neurology), and coding specialists.

Project PAUSE (Psychoactive Appropriate Use for Safety and Effectiveness)

CPP is a member of Project PAUSE, a coalition of national patient and professional organizations collectively advocating on clinical regulatory and legislative issues in long-term care.

Project PAUSE aims to educate policymakers and the public on effective solutions for improving clinical care in long-term care settings by advocating for streamlined, clinical surveyor training, improved quality measures to appropriately determine antipsychotic drug use in long-term care settings, and other solutions aimed at improving the diagnosis and management of neuropsychiatric symptoms (NPS) in dementia.

Project PAUSE is convened by the Alliance for Aging Research and the American Society of Consultant Pharmacists (ASCP).

CENTER FOR PUBLIC POLICY (CPP)

Spotlight on Selected CPP Accomplishments: 2023-2025

The Alliance for Cancer Care Equity (ACCE)

American Cancer Society Cancer Action Network

NCCN National Comprehensive Cancer Network

There is a dearth of coordinated efforts and strategic partnerships that focus on the disproportionate impact of racial and ethnic disparities and inequities, as well as their root causes, across all cancers in the United States today.

The National Minority Quality Forum (NMQF), the American Cancer Society Cancer Action Network (ACS CAN), and the National Comprehensive Cancer Network (NCCN) jointly launched the Alliance for Cancer Care Equity (ACCE) — a coalition patient advocacy organizations, and medical, legal and public health working to support policies, promote practices and create systems that prioritize the elimination of racial and ethnic disparities and inequities across all cancers.

Role of CPP in ACCE

The membership meets quarterly, and the founding partners meet bi-weekly. The founding partners have assigned responsibilities based upon the partners' organizational strengths.

Accordingly, CPP informs and advances ACCE forward-looking positioning on federal legislative proposals, executive branch rules and guidance, and commercial sector perspectives on cancer care equity; and provides leadership on policy-related educational engagements for ACCE sponsors and members.

ACCE Focus Areas

ACCE focuses on the following policy issues:

1. Enhancing advocacy efforts to eliminate racial and ethnic disparities and inequities in prevention, screenings, incidence, early detection, and outcomes of care.
2. Expanding access to quality, timely cancer care through patient navigation.
3. Bolstering efforts to expand access to and significantly increase the diversity in cancer clinical trials.

Activity Spotlight

During 2024, ACCE sponsored a congressional briefing on the topic *Advancing Access and Addressing Representation in Clinical Trials*, hosted quarterly meetings of the alliance with guest speakers from the public and private sectors.

CENTER FOR PUBLIC POLICY (CPP)

External Alliances and Collaborations

Partnerships with national and local patient and provider advocacy groups to develop consensus regarding structural challenges and solutions, and to educate and inform collectively regarding shared policy interests at the federal level.

Such partnerships involve improvements in chronic disease prevalence and treatment initiatives, long-term care reimbursement, Medicare and Medicaid coverage policy, health technology/value assessment approaches, and other issues of national import.

Key External Partnerships

CMS Coverage Policy Task Force (Alliance for Aging Research)

HIV Patient Value Task Force

L.E.A.D. (Leaders Engaged on Alzheimer's Disease) Coalition

National Health Council

NephCure New Era Coalition

Mallinckrodt Patient Advocacy Advisory Board

NIH All of Us Research Program

Project PAUSE (Psychoactive Appropriate Use for Safety and Effectiveness)

Unknown Cause Kidney Disease Coalition (American Kidney Fund)

Improving Maternal Immunizations Task Force

CENTER FOR SUSTAINABLE HEALTH CARE QUALITY AND EQUITY (SHC)

Since its founding in 2017, the Center for Sustainable Health Care Quality and Equity (SHC) has focused on health care in underserved and vulnerable communities, identified through NMQF's state-of-the-art health geographic information system. Applying the rapid cycle improvement and collective impact model, SHC promotes patient-centered, team-based care that respects clinicians, patients, and caregivers in achieving high-quality and equitable health outcomes for underrepresented communities, with outreach in both English and Spanish. SHC currently promotes its work through:

Community Pharmacists Ambassadors (CPA): CPAs serve as health educators outside of the pharmacy, provide sound health information, and showcase the vital role pharmacists can play in health promotion. The program promotes healthy outcomes to diverse populations, both in-person and virtually, and includes over 200 pharmacists as of 2024.

Diabetes Working Group and Equity Task Force (DWG): DWG is a private-public partnership to promote equity in diabetes treatment and outcomes. It includes research experts, clinicians, patient representatives, community leaders, and corporate partners who guide efforts and the continued expansion in diabetes outreach through an evidence-based and expanded effort to improve health outcomes.

Demonstrating Real Improvement in Value and Equity (DRIVE): DRIVE is a free online toolkit series to support quality improvement, education, and community engagement. It is utilized by more than 150 clinical teams across the country to help identify gaps in healthcare and implement evidence-based QI education, in addition to patient and community engagement.

Faith Health Alliance (FHA) and Advocacy Council: FHA is a network of pastors with the common goal of increasing awareness on and services for a variety of health topics in underserved communities throughout the United States. In 2024, the network included over 25 churches and 3 regional networks. The FHA Advocacy Council is composed of health care industry leaders and offers opportunities to support and participate in community-based events.

Health Advocates In-Reach and Research (HAIR) Wellness Warriors: The HAIR Wellness Warriors provide education and outreach through barbershops and salons. This community-level approach encourages a better understanding of people's beliefs and concerns, encourages conversations, and sparks healthy outcomes. In 2024, HAIR Wellness Warriors hosted several events across multiple disease states.

In 2024, SHC focused much of its efforts in four key areas:

Diabetes

Fostering community-driven education, support, and culturally-rooted care for **Type 1 Diabetes** and **Type 2 Diabetes.**

Respiratory Diseases

Building community trust to reduce preventable illness and deaths from **COVID-19, RSV, and Influenza.**

Immunology

Bridging education gaps between underserved communities and local providers via **Shingles** vaccine education and cultural-competency guidance to recruit for **Lupus** clinical trials diversity.

Cancer

Advancing equitable access to education, early detection tools, and well-equipped local providers for **colorectal cancer (CRC)** prevention.

Why This Matters

Engaging minoritized communities on health topics like vaccination and cancer screenings is challenging without trusted community voices. Lack of representation risks perpetuating mistrust and misinformation, hindering access to vital healthcare. Collaboration with authentic community leaders is essential to bridge the gap, address concerns, and promote preventative care within cultural contexts.

CENTER FOR SUSTAINABLE HEALTH CARE QUALITY AND EQUITY (SHC)

Diabetes: Making a Difference

Culturally-Relevant Diabetes Care through Community Ownership

Through innovative, community-led campaigns, SHC continues to address diabetes disparities in minoritized communities by elevating patient voices, building trust, and delivering culturally relevant care.

Working in deep collaboration with local partners—including clinics, churches, stylists, and advocacy organizations—SHC has empowered individuals with the knowledge, support, and resources needed to better manage their health and reshape care systems from the ground up.

2024 Impact at a Glance

- **1.0% average HbA1c reduction** among participants in DRIVE Oakland
- **255 individuals** tracked in DRIVE Oakland, majority identifying as Black or Hispanic/Latino
- **500+ community members** reached through food distribution and education outreach
- **100+ attendees** engaged in DSMES-centered community sessions
- **T1D Focus Group Report:** "T1D in Communities of Color – An Initiative to Learn About Insights on Screening, Access, and Bias"
- **Webinar convened** featuring patient voices, clinicians, and advocacy leaders to amplify findings and drive equity-focused action

Voices from the Community

> Our partnership with Faith Health Alliance made me more aware of our congregation—I didn't know we had many so many diabetics. One of the ways we're helping is by bringing doctors directly to our church. People don't like to go to the doctor, so we do all we can to make it easy for them, and get our community healthy.
>
> *—Pastor Erik Nation, Hope Center Church (CA)*

Notable Campaigns

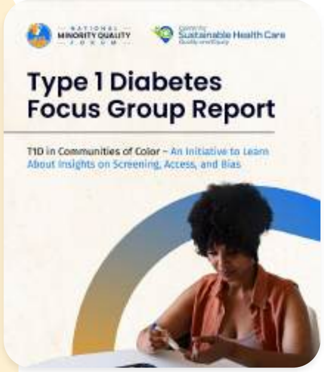
T1D in Communities of Color: An Initiative to Learn About Insights on Screening, Access, and Bias

In collaboration with sanofi

This initiative gathered deep insights from Black and Hispanic individuals living with Type 1 Diabetes (T1D) to uncover the emotional, financial, and systemic challenges they face in accessing culturally responsive care.

Through focused community conversations, participants called for greater access to DSMES, mental health support, and diabetes technology, while emphasizing the urgent need to address bias in care.

The findings were shared in a public report and national webinar, spotlighting the voices of patients, clinicians, and advocates to guide more equitable, patient-centered solutions in diabetes care.

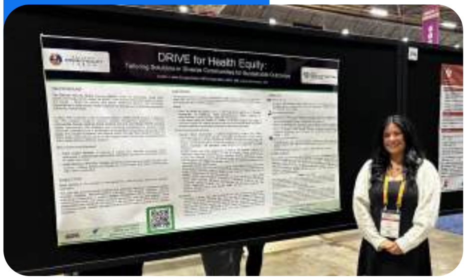


Type 1 Diabetes Focus Group Report

T1D in Communities of Color – An Initiative to Learn About Insights on Screening, Access, and Bias

Scan the QR Code to read the full report

Scan for report



DRIVE Oakland

Powered by novo nordisk

DRIVE Oakland targeted Type 2 Diabetes (T2D) disparities among minoritized populations by combining culturally tailored education, trusted community partnerships, and DSMES. The program achieved a notable HbA1c reduction—from 10.3 to 9.4—across 255 participants, most of whom identified as Black or Hispanic/Latino/a.

With outreach reaching over 500 individuals, and education sessions drawing over 100 attendees, the initiative reinforced the power of culturally grounded care. Collaborative efforts with local health centers, stylists, churches, and academic partners helped build long-term trust and deliver measurable impact on health outcomes.

Findings published in European Society of Medicine: *DRIVE for Health Equity: Tailoring Quality Improvement, Clinical Education, and Community Engagement to Improve Type 2 Diabetes (T2DM) Outcomes for Minoritized Communities in Oakland, California* (2024)

CENTER FOR SUSTAINABLE HEALTH CARE QUALITY AND EQUITY (SHC)

Respiratory Diseases: Making a Difference

Building Community Trust for Targeted Vaccine Equity

Through a range of targeted campaigns, SHC has worked alongside trusted community partners to increase awareness, build trust, and drive vaccine uptake among Black, Hispanic, and other minoritized populations.

By collaborating with churches, stylists, barbers, community pharmacies, and clinics, SHC has made significant strides toward equitable protection against serious infectious diseases.

2024 Impact at a Glance

- 175,102 flu vaccines and over 10,000 COVID-19 vaccines administered across more than 150 community events
- 326,221 views on social media posts and 291 posts shared to increase vaccine awareness
- 408 participants in webinars focused on vaccine education and equity
- Engagement with 43 churches, 15 stylists and barbers, 155 clinics, and 215 pharmacists to facilitate vaccine access in hard-to-reach communities

Community Pharmacist Ambassadors

Voices from the Community

> I am so incredibly grateful for the opportunity to receive my flu shot at no cost from this clinic. As someone with no insurance, I've always been worried about the cost of getting vaccinated. It's a huge relief to know that I don't have to choose between my health and my finances.
>
> *— Berenice P., Shifa Clinic (SC)*

Notable Campaigns

COVID-19 and Influenza Vaccination Communications, Education, and Training to Promote Equity in Black and Hispanic Communities

In collaboration with the CDC

This campaign focused on promoting vaccine equity in Black and Hispanic communities through targeted communication, education, and outreach. With a specific focus on COVID-19 and influenza, it aimed to reduce illness and death in historically underserved populations.

Findings published in: Springer Journal of Racial and Ethnic Health Disparities: “Building and Sustaining Flu Vaccine Acceptance and Trust in the Black Community through Partnerships with Churches, Salons, and Barbershops”

DRIVE FLU

Powered by sanofi

The DRIVE FLU campaign was designed to combat flu-related disparities by increasing vaccine access and education in underserved areas. It reached a broad audience, significantly improving flu vaccination rates and building trust in the healthcare system.

DRIVE

> Dr. Latressa Gordon, DRIVE Flu leader in Flint, was honored with city, state, and congressional awards for her impactful public health leadership. Her work is transforming access and equity across Michigan.
>
> *— Honoring Dr. Latressa Gordon*

New Campaign Launch

DRIVing RSV Protection Among Minoritized Children

Powered by sanofi

This initiative follows the success of the DRIVE FLU program, with additional funding from Sanofi to expand RSV education.

Goal: To raise awareness about RSV among pregnant and new mothers in underserved communities.

Early Outcomes: The campaign has reached 3,000 community members through 27 local FHA churches hosting educational sessions.

CENTER FOR SUSTAINABLE HEALTH CARE QUALITY AND EQUITY (SHC)

Immunology: Making a Difference

Bridging Lupus and Shingles Education Gaps between Communities and Local Providers

The Center for Sustainable Health Care Quality and Equity (SHC) is driving progress in chronic disease prevention and care by addressing long-standing disparities in access, awareness, and treatment. Two recent initiatives—targeting shingles prevention and lupus clinical trial equity—are examples of how SHC partners with communities and providers to deliver tailored solutions that improve health outcomes for underserved populations.

These efforts focus on education, trust-building, and provider engagement to empower patients and strengthen healthcare systems. Whether by increasing vaccination rates or enhancing access to clinical research, SHC continues to work toward a future where quality care and innovation are equitably distributed.

Campaign Spotlight

DRIVE Lupus

In collaboration with NIH

SHC launched the lupus DRIVE Toolkit to equip primary lupus-treating physicians with the knowledge and tools to promote clinical trials as a treatment option, particularly for patients from historically underrepresented backgrounds.

The campaign hosted a series of “lunch and learn” events with NIH experts, providing education on the importance of clinical trial diversity and equipping clinicians to hold informed conversations with their patients about equity in research participation.

New Campaign Launch

DRIVE SHINGLES

Powered by gsk GlaxoSmithKline

Goal: To significantly enhance shingles vaccination rates, particularly in underserved communities, and contribute to improved health outcomes for all.

Early Outcomes: One pilot site achieved a 63% increase in patients completing the full shingles vaccine series. This campaign builds on SHC’s growing portfolio of vaccine equity initiatives, targeting preventable diseases through trusted community and clinical partnerships.

CENTER FOR SUSTAINABLE HEALTH CARE QUALITY AND EQUITY (SHC)

Colorectal Cancer: Making a Difference

Advancing Equity Through Early Detection and Community Trust

SHC is driving measurable change in colorectal cancer (CRC) prevention by closing gaps in awareness, screening, and access to care among historically underserved populations.

Through trusted community partnerships, education, and clinic-level engagement, SHC's CRC initiatives are improving early detection and advancing health equity in high-burden regions across the country.

2024 Impact at a Glance

- 127,013 individuals screened for colorectal cancer
- 64% of those screened were from historically underrepresented communities
- 500+ educational resources distributed, including Cologuard demo kits
- 25 Faith Health Alliance churches and 10 HAIR Wellness Warriors engaged
- 18+ community events reaching ~2,220 attendees
- 1 community partner training on CRC disparities and screening guidelines
- 1 public webinar with ~100 attendees

Campaign Spotlight

DRIVing Equity in Colorectal Cancer Screening

In collaboration with the CDC

SHC focused on reducing health disparities in five high-burden regions through education, clinical engagement, and culturally responsive outreach. The campaign activated 35 trusted community partners—including faith-based leaders and barbershop stylists—to increase awareness and normalize conversations around CRC prevention.

A clinical expert-led training prepared partners to deliver accurate, equity-centered messages about screening, while the distribution of over 500 resources, including Cologuard demonstration kits, helped demystify the process. This model of community-rooted health promotion made CRC screening more accessible, trusted, and actionable for thousands.

WELLNESS WARRIORS

NATIONAL MINORITY QUALITY FORUM