



Creating an Optimal  
Environment for Quality  
Healthcare for Individuals,  
Families, and Communities

## Project PIVOT (Patients Involved in deVeloping Outcomes Together)

A Patient-Led Approach to Identifying and Prioritizing Patient Reported Experiences and Outcomes Related to Safety, Diagnosis, Transparency and Bias



# Project PIVOT Funding



PFPS US is extremely thankful to the following organizations:



The  
**John A. Hartford**  
Foundation



# AGENDA

---

- Landscape and status of patient safety
- Origin and rationale for Project PIVOT
- Building the community and next steps

**CMS 2024**  
**Quality**  
**Conference**  
Resilient and Ready Together

Creating an Optimal  
Environment for Quality  
Healthcare for Individuals,  
Families, and Communities



**Martin**

Martin J. Hatlie, Co-  
Founder, PFPSUS



**Sue**

Sue Sherdian, Co-  
Founder, PFPSUS



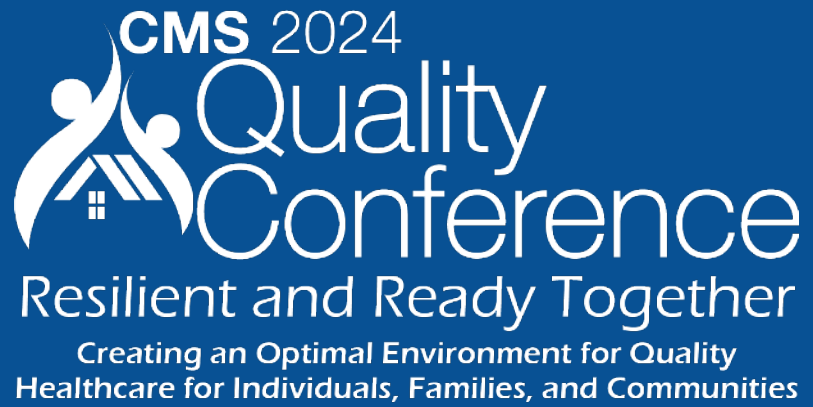
**Armando**

Armando Nahum, Co-  
Founder, PFPSUS



**Suz**

Suz Schrandt, Founder  
& CEO, ExPPect



# Landscape and Status of Patient Safety



# President's Council of Advisors on Science and Technology Report: A Transformational Report on Patient Safety (1 of 2)

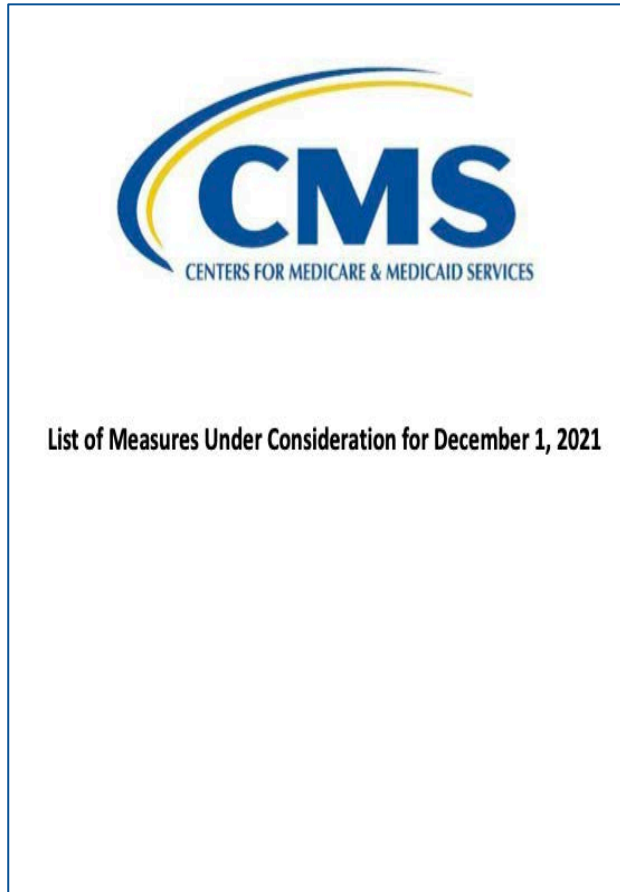


“...partnering and collaborating with the patients, families, and communities most impacted by unsafe care...and give special attention...to those communities that have experienced long-standing disparities.”

# President's Council of Advisors on Science and Technology Report: A Transformational Report on Patient Safety (2 of 2)

“To improve data and transparency to reduce disparities, the President should direct the Secretary of HHS to require AHRQ to lead the development and validation of new questions focused on racial/ethnic bias and patient safety in the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) Survey...”

# CMS Patient Safety Structural Measure 2023 Measures Under Consideration (MUC) List

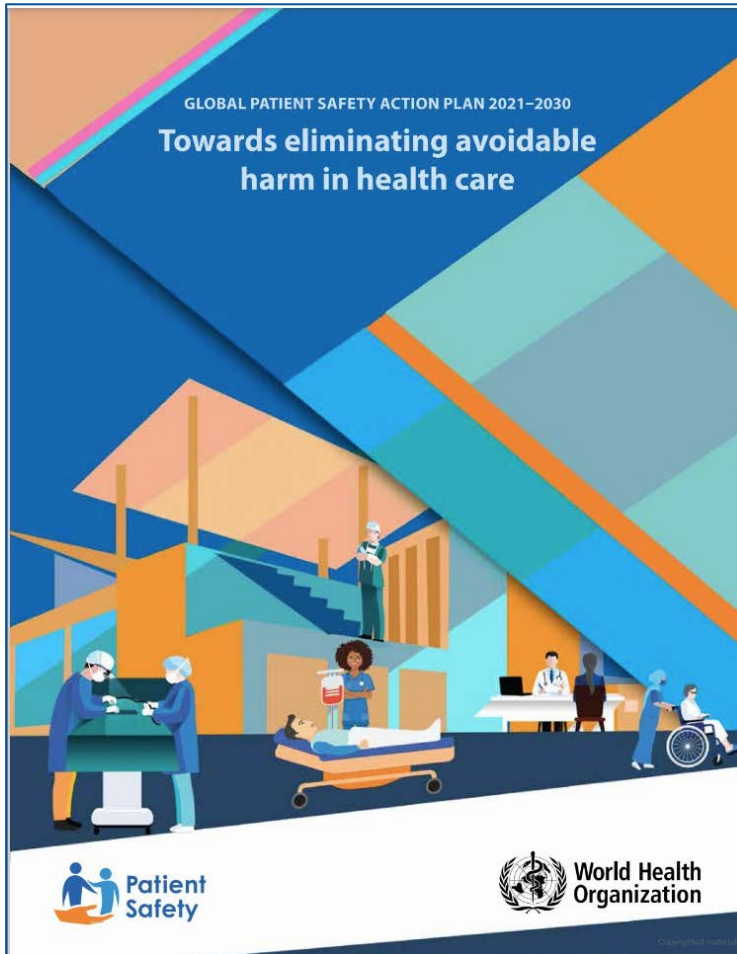


## Domain 5 Attestation: Patient and Family Engagement

“Our hospital incorporates patient and caregiver input about patient safety events or issues (such as patient submission of safety events, safety signals from patient complaints or other patient safety experience data, patient reports of discrimination).”



# World Health Organization (WHO) Global Patient Safety Action Plan 2021 - 2030

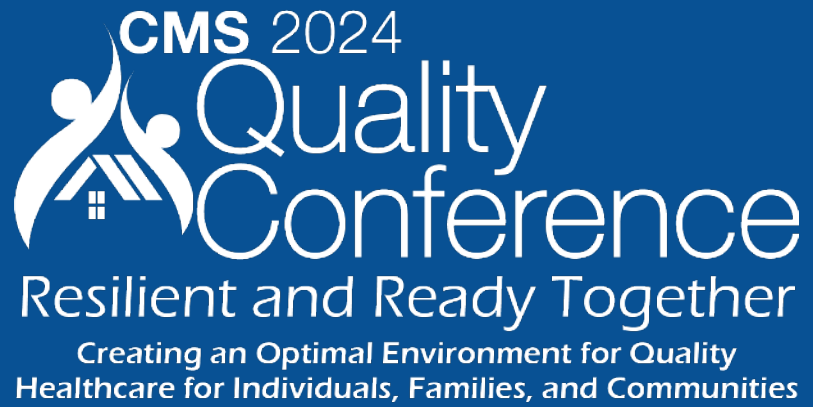


“Create mechanisms that collect patient reported experiences and outcomes that highlight patient safety”

# Global State of Patient Safety 2023



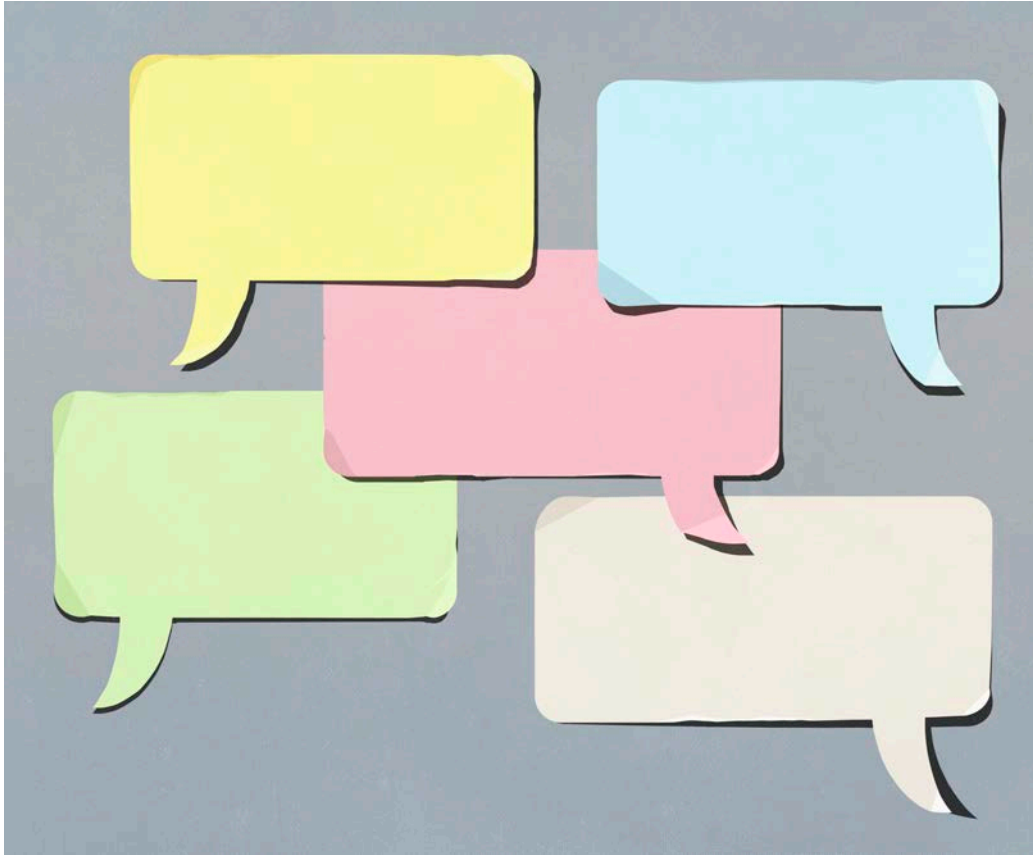
“...(data need to) better reflect the care journeys, perceptions, and experiences of patients”



# Origin and Rationale for Project PIVOT



# Why patient-reported measures of safety, diagnosis, and discrimination?



“Patient-reported measures contain valuable, detailed information from the patient who has a unique and unrivalled perspective of the entire health care journey and the cascade of happenings that lead to harm.”

Organization for Economic Co-operation and Development

# The Importance of HCAHPS



The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey was the first national, standardized, publicly-reported survey of patients' perspectives of hospital care, a pivotal step in improving quality of care.

# Getting Specific about Patient Safety



Patient-reported experience in safety measures (OECD\*) gather information via surveys on patient's views about patient safety including incident prevention, patient-reported incidents, and incident management.

"Measuring Patient Safety: Opening the Black Box", <https://www.oecd.org/health/health-systems/Measuring-Patient-Safety-April-2018.pdf>

\*2018 Organisation for Economic Co-operation and Development

# Getting Specific about Discrimination



Patient-reported experiences of discrimination measures gather information via surveys about patient's views on perceptions of discrimination.

Nong P, Raj M, Creary M, Kardia SLR, Platt JE. Patient-Reported Experiences of Discrimination in the US Health Care System. JAMA Netw Open. 2020 Dec 1;3(12):e2029650. doi: 10.1001/jamanetworkopen.2020.29650. PMID: 33320264; PMCID: PMC7739133

And the MMWR / April 21, 2023 / Vol. 72 / No. 16,  
<https://www.cdc.gov/mmwr/volumes/72/wr/pdfs/mm7216a5-H.pdf>

# Filling the Measurement Gap in Research, QI, and Reimbursement

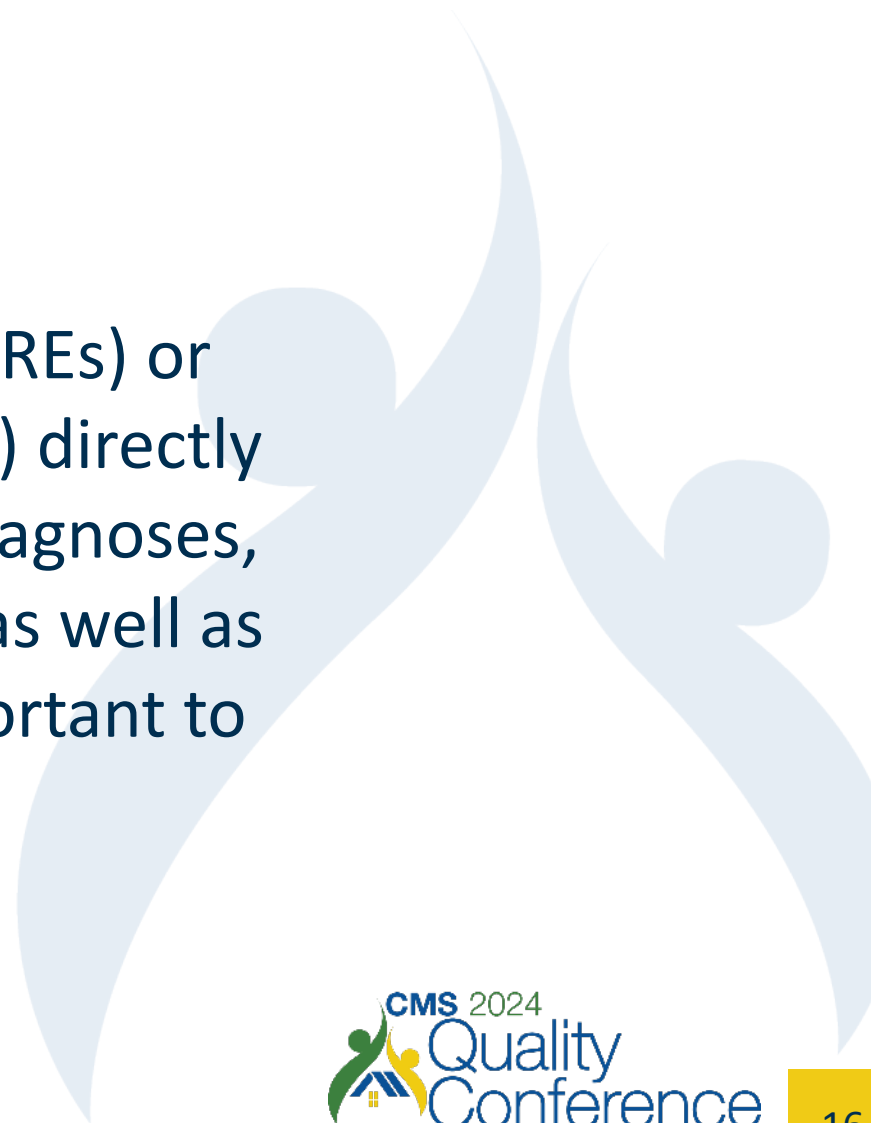


- Structural and process measures
- Readmissions
- HCAHPS
- *Safety, diagnostic quality, and discrimination data?*
- *Transparency concerns?*



# What are we missing?

Patient-Reported Experiences (PREs) or Patient-Reported Outcomes (PROs) directly related to concerns with safety, diagnoses, transparency, and discrimination as well as real-time reporting, which is important to patients.



# How does Project PIVOT propose to fill that gap?

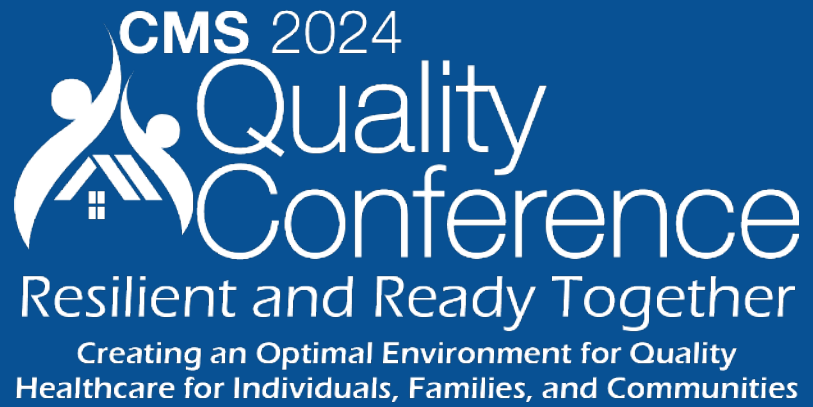
Ask patients what experiences and outcomes matter most to them with relation to safety, accurate and timely diagnoses, and experiences with discrimination or lack of transparency, and how and when they prefer to report that information.



# In a Process Driven by Diverse Patients and Communities



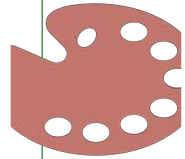
Foundational Expectations for Partnerships, "PCORI 2024 & Beyond Webinar", February 7, 2024, Patient-Centered Outcomes Research Institute, accessed at: <https://www.pcori.org/events/2024/pcori-2024-beyond>



# Building the Community and Next Steps



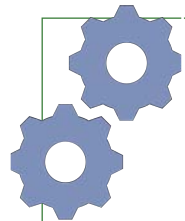
# Building the Project PIVOT Community



Designers



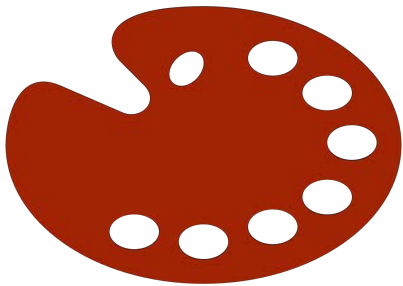
Refiners



Implementers

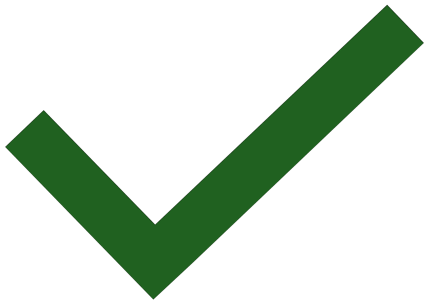


# Designers



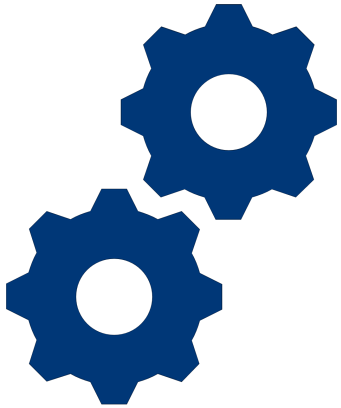
- United Spinal Association\*
- Disability Rights Oregon\*
- National Down Syndrome Society\*
- MoMMA's Voices\*
- Equity Before Birth\*
- AARP\*
- WomenHeart\*
- Beryl Institute
- Greater National Advocates
- HIV community
- PFCC Partners
- Sepsis Alliance\*
- Patient Safety Movement Foundation
- Society to Improve Diagnosis in Medicine

# Refiners and Advisors



- Researchers from:
  - Harvard Medical School,
  - Johns Hopkins Schools of Medicine and Nursing,
  - University of Texas Health Sciences Center
  - Northwestern University
  - Geisinger Health System
  - Cardiff University, Wales
  - Amsterdam Public Health Research Institute
  - Imperial College of London, Institute of Global Health Innovation
  - Breach Candy Hospital, Mumbai India
- OECD
- CAHPS Consortium members
- International Consortium for Health Outcomes Measurement (ICHOM)
- Consortium of Accredited Healthcare Organizations/ P4PSF India

# Implementers

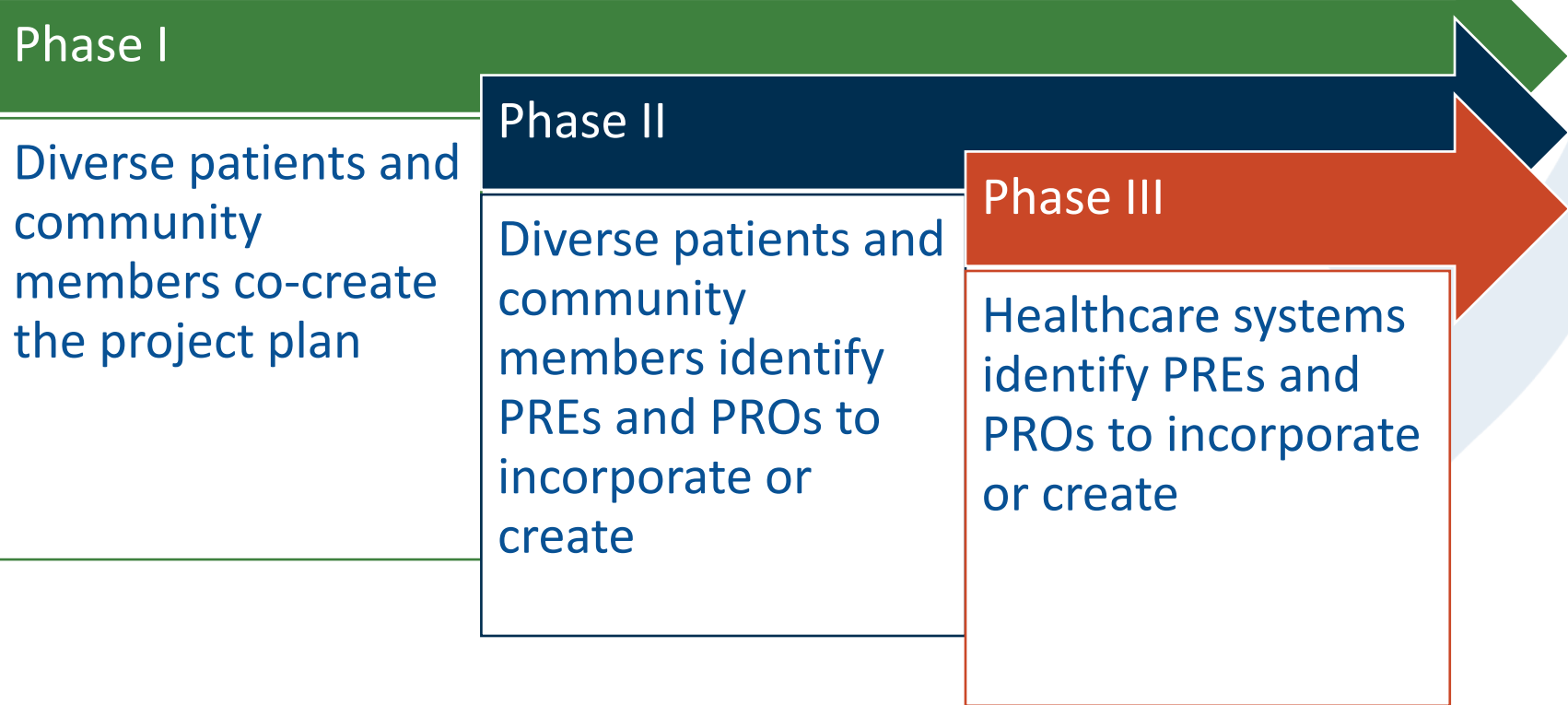


- CMS
- AHRQ
- OIG
- NQF
- IHI
- Leapfrog Group
- PCORI
- WHO





# The Project PIVOT Process (1 of 2)



# The Project PIVOT Process (2 of 2)



Identified and to-be-created PREs and PROs

## Dissemination and Implementation

- Patient Advocacy Groups
- Publishers
- Research and QI
- Measure Developers
- Purchasers
- Health Systems/Clinician Groups
- Payors
- Congress
- WHO

# How can Project PIVOT contribute to safer care, improved diagnosis, and equity?



- Fill reporting gaps
- Align reimbursement with safety and equity
- Increase transparency
- Enhance research and QI
- Effectuate safety and equity policy

# How can you get involved in Project PIVOT?



[www.pfps.us](http://www.pfps.us)

- Read more at our website
- Become a Project PIVOT partner!
- Submit ideas for PREs, PROs, and other project concepts to Sue Sheridan at [ssheridan@pfps.us](mailto:ssheridan@pfps.us)

Questions?



Thank you!

