Building Data Capacity for PCOR

Researcher Perspectives on Data Needs

Kurt C. Stange, MD, PhD

Family & Public Health Physician
Neighborhood Family Practice

Director, Center for Community Health Integration
Distinguished University Professor
Professor of Family Medicine & Community Health, Population & Quantitative Health Sciences, Sociology and Oncology
Case Western Reserve University
Cleveland, Ohio, USA
kcs@case.edu

Problem

- Fragmented data = fragmented research & care
- Top-down data = depersonalized research & care

Stange KC. The problem of fragmentation and the need for integrative solutions. Ann Fam Med 2009; 7(2): 100-103.

Stange KC. A science of connectedness. Ann Fam Med 2009; 7: 387-395.

Stange KC. The paradox of the parts and the whole in understanding and improving general practice. Int J Qual Health Care, 2002; 14(4):267-268.

Looking ahead, what are the main data needs?

- Data to support
  - integrating,
  - personalizing,
  - prioritizing care

  for whole people
- Data to support care for people whose health needs aren't met by a single disease or risk label
- Link different sectors affecting health

Vital Signs:
Core Metrics for Health and Health Care Progress

BOX S-2 Criteria for Core Measure

Criteria for core measures

- Importance for health
- Strength of linkage to progress
- Understandability of the measure
- Technical integrity
- Potential for broader system impact
- Utility at multiple levels

- **Criteria for the set**
- Systemic reach
- Outcomes-oriented
- Person meaningful
- Parsimonious
- Representative
- Utility at multiple levels

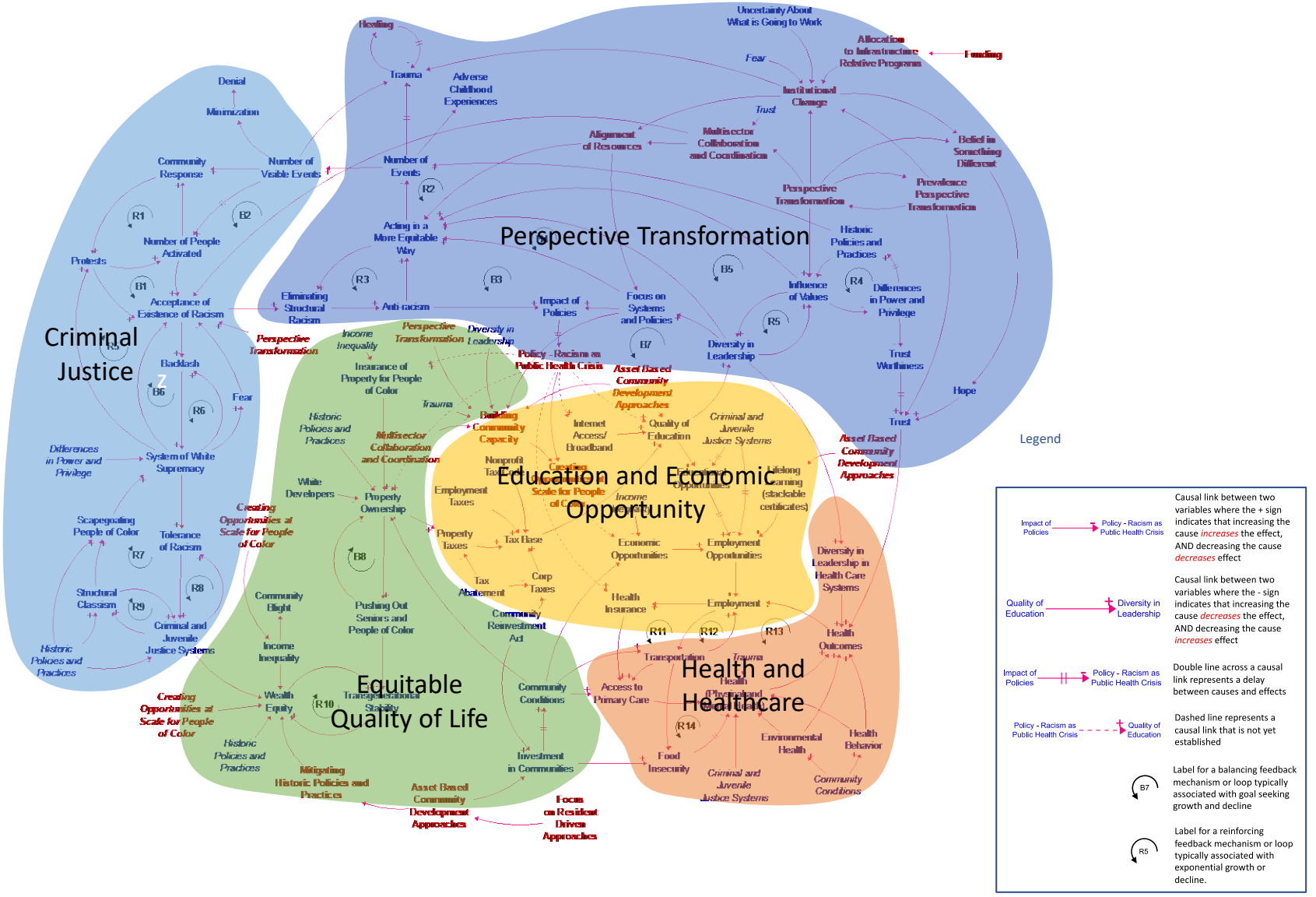
Institute of Medicine. **Vital Signs: Core Metrics for Health and Health Care Progress**. Washington, DC: National Academies Press; 2015. http://www.iom.edu/coremetrics.

TABLE S-1 Core Measure Set

Domain	Key Element	Core Measure Focus	Best Current Measure	Current national performance[i]
Healthy people	Length of life	 Life expectancy	Life expectancy at birth	79 year life expectancy at birth
	Quality of life	 Wellbeing	Self-reported health	66% report being healthy
	Healthy behaviors	 Overweight and obesity	Body mass index	69% of adults with BMI 25 or greater
		 Addictive behavior	Addiction death rate	200 addiction deaths per 100,000 people age 15+
		 Unintended pregnancy	Teen pregnancy rate	27 births per 1,000 females aged 15 to 19
	Healthy social circumstances	 Healthy communities	High school graduation rate	80% graduate in 4 years
Care quality	Prevention	 Preventive services	Childhood immunization rate	68% of children vaccinated by age 3
	Access to care	 Care access	Unmet care need	5% report unmet medical needs
	Safe care	 Patient safety	Hospital acquired infection rate	1,700 HAIs per 100,000 hospital admissions
	Appropriate treatment	 Evidence-based care	Preventable hospitalization rate	10,000 avoidable per 100,000 hospital admissions
	Person-centered care	 Care match with patient goals	Patient-clinician communication satisfaction	92% satisfied with provider communication
Care cost	Affordability	 Personal spending burden	High spending relative to income	46% spent >10% income on care, or uninsured in 2012
	Sustainability	 Population spending burden	Per capita expenditures on health care	$9,000 health care expenditure per capita
Engaged people	Individual engagement	 Individual engagement	Health literacy rate	12% proficient health literacy
	Community engagement	 Community engagement	Social support	21% inadequate social support

Stakeholder Wisdom + Population Health Data + System Science:

A Community Health Improvement Plan to Eliminate Structural Racism



HIP-Cuyahoga & RWJF **Cross-sector Innovation Initiative** https://hipcuyahoga.org

What are the implications of the (recently broadened) statutory scope for PCOR?

- An opportunity to
  - focus on the whole as well as the parts
  - support frontlines contextualized care
  - support relationship-centered care

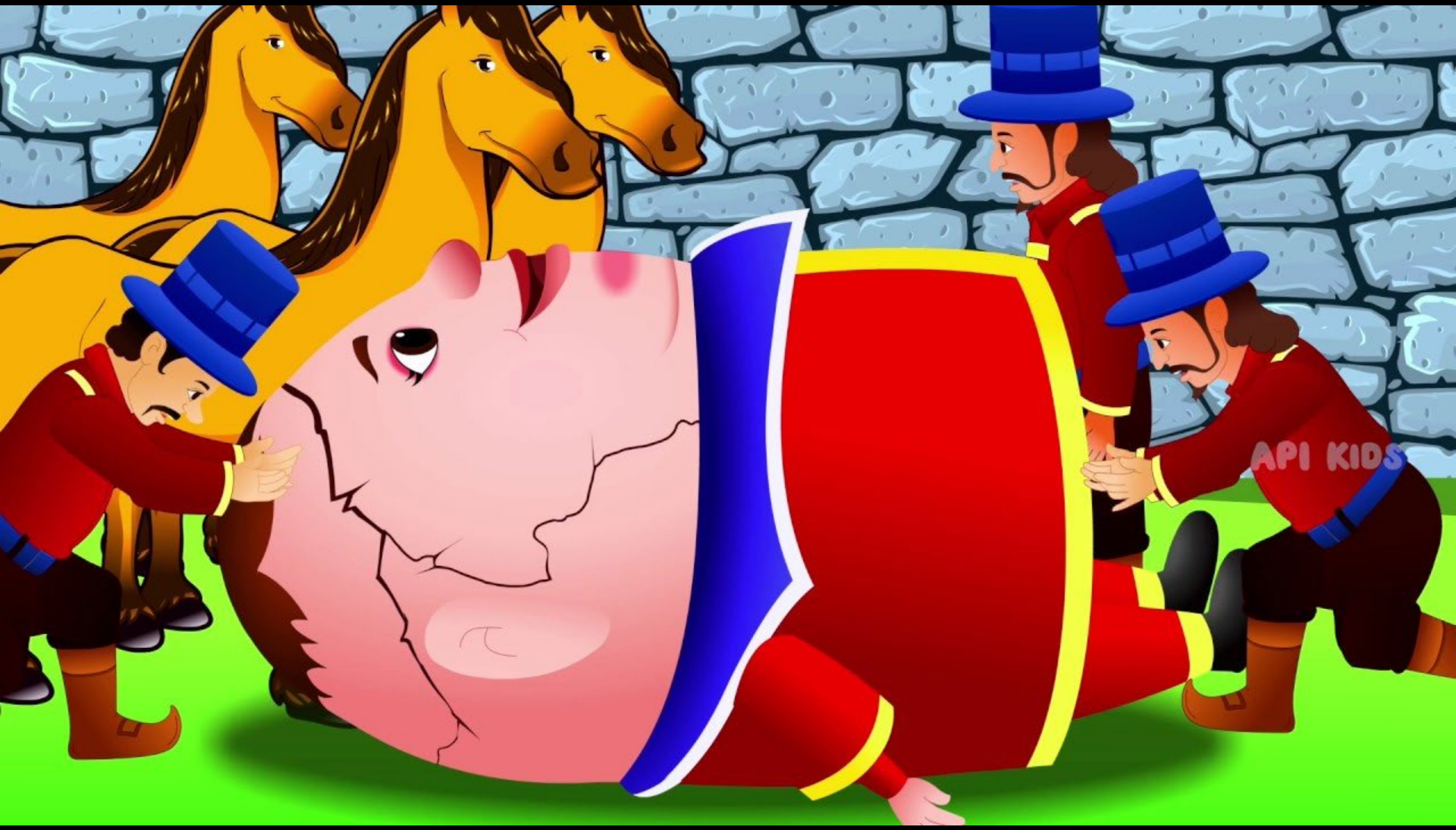
- *"Research shall be designed… to take into account and capture the full range of clinical and patient-centered outcomes relevant to, and that meet the needs of…"*
- *"include the potential burdens and economic impacts of… services"*

What questions cannot be answered and who is not served by the current PCOR data infrastructure?

- How do we understand and support *integrated, personalized, prioritized* care of *whole people?*

- Who is not served?
  - People living with multiple chronic conditions
  - People disadvantaged by SES, minority status, isolation…
  - People who are not helpfully defined by their disease or by other data collected for another purpose


PLAYSKOOL


API KIDS

What new data sources could be incorporated into the PCOR data infrastructure?

- Person-Centered Primary Care Measure
- Developed from what hundreds of patients, clinicians, and payors say is important in health care
- Pending NQF (July) CMS (Nov) final endorsement for use in CMS Quality Payment Program

Stange KC, Etz RS, Gullett H, Sweeney SA, Miller WL, Jaen CR, Crabtree BF, Nutting PA, Glasgow RE. Metrics for assessing improvements in primary health care. *Annual Review of Public Health.* 2014;35:423-442.

Etz RS, Zyzanski SJ, Gonzalez MM, Reves SR, O'Neal JP, Stange KC. A New Comprehensive Measure of High-Value Aspects of Primary Care. *The Annals of Family Medicine*. 2019;17(3):221-230. www.annfammed.org/content/17/3/221

Larry A. Green Center for the Advancement of Primary Health Care for the Public Good. *Measures*. https://www.green-center.org/pcpcm

Person-Centered Primary Care Measure

- My practice makes it easy for me to get care.
- My practice is able to provide most of my care.
- In caring for me, my doctor considers all of the factors that affect my health.
- My practice coordinates the care I get from multiple places.
- My doctor or practice know me as a person.
- My doctor and I have been through a lot together
- My doctor or practice stand up for me.
- The care I get takes into account knowledge of my family.
- The care I get in this practice is informed by knowledge of my community.
- Over time, my practice helps me stay healthy
- Over time, my practice helps me to meet my goals.

Etz RS, Zyzanski SJ, Gonzalez MM, Reves SR, O'Neal JP, Stange KC. A New Comprehensive Measure of High-Value Aspects of Primary Care. *The Annals of Family Medicine*. 2019;17(3):221-230. www.annfammed.org/content/17/3/221

What data capacity challenges is HHS best positioned to address in the context of their public mission, authorities, programs, and data resources?

- Reframe data use to support *primary care* as a force for integration and equity for individuals and families
- Reframe data use to support *public health* as a force for integration and equity for communities & populations
- Support the integration of primary care & public health
- Use PCOR Trust Fund for AHRQ to meet its role to support primary care research about the *care of whole people*
- Bring together ASPE, CDC (NCHS) and NCVHS in their Congressionally-mandated role to update HIPAA to make data sharing safe and less onerous.
- Raise the budget cap for R01s