RESEARCH CONSORTIUM
for Health Care Value Assessment

Enhancing Health Care Value Through Data, Measurement and Evaluation of Services and Procedures

November 3, 2021

VBIDHEALTH

ALTARUM

Welcome!

- Thank you for joining
- Thank you to PhRMA for funding
- Format of the presentation
  - There will be a Q&A directly after each speaker
- Write any questions in the chat box

Find the Blog Series on Health Affairs!

https://www.healthaffairs.org/topic/ss210

Today's Agenda

- **1:15 – 1:30 pm**: *Value Defects in the Health Services Sector*
  - William Padula, PhD: Assistant Professor, Department of Pharmaceutical and Health Economics, USC School of Pharmacy
  - Peter Pronovost MD, PhD: University Hospitals Cleveland Medical Center
- **1:30 – 1:45pm**: *Challenges and Barriers to Measuring Effectiveness of Health Service Interventions*
  - R. Brett McQueen, PhD: pValue, University of Colorado
- **1:45 – 2:00pm**: *Challenges and Barriers to Cost Effectiveness of Health Service Interventions*
  - Christopher Whaley: PhD, RAND
- **2:00 – 2:15pm**: *Why Are There So Few Value Assessments on Health Services and Procedures and What Should Be Done?*
  - Peter Neumann, PhD: CEVA, Tufts Medical Center
  - Daniel Ollendorf, PhD: CEVA, Tufts Medical Center

Today's Agenda, cont.

- **2:15 – 2:30 pm**: *Emerging Health Technology Assessment Methods and Evidence Generation on Patient-Driven Values in Healthcare Services*
  - Susan dosReis, PhD: PAVE, University of Maryland
  - Julia Slejko, PhD: PAVE, University of Maryland
  - Alejandro Amill-Rosario, PhD: PAVE, University of Maryland
- **2:30 – 2:45pm**: *A Blueprint to Advance Patient-Centered Core Impact Sets (PC-CIS)*
  - Eleanor M. Perfetto, PhD: National Health Council; University of Maryland
  - Elisabeth Oehrlein: National Health Council
  - T. Tose Love: University of Maryland
  - Silke Schoch: National Health Council
  - Jennifer Bright: Innovation and Value Initiative
  - Annie Kennedy: Everylife Foundation for Rare Diseases
  - Suz Schrandt: Exppect
- **2:45 – 3:00pm**: *The Ongoing Search for Value in Health Care – The Rise of Social Context*
  - Michael Rozier, PhD: Saint Louis University
  - Kimberly Enard, PhD: Saint Louis University

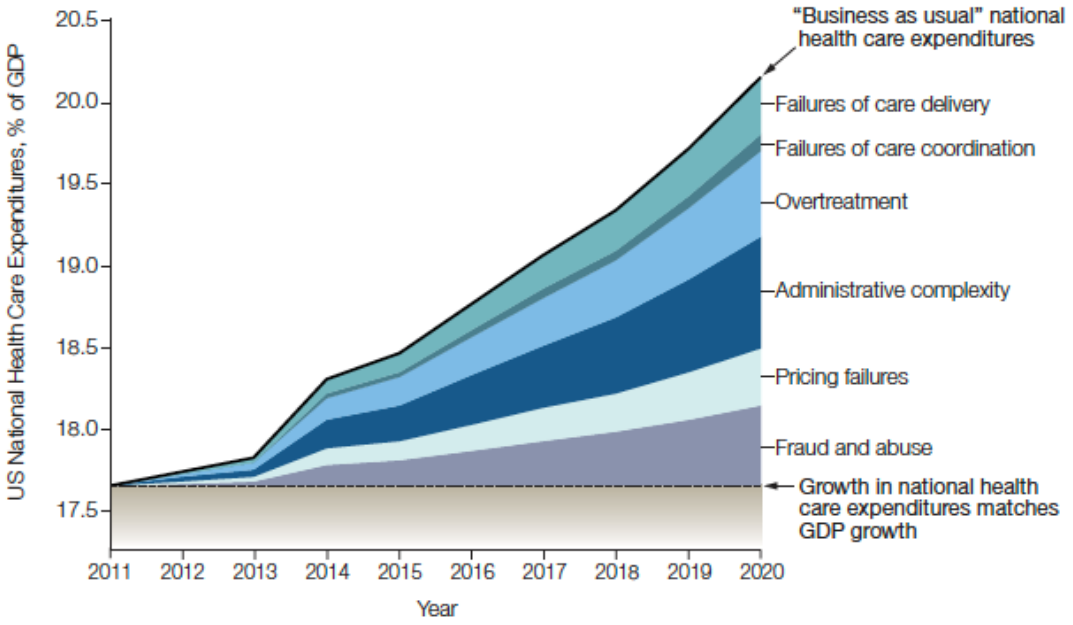
Value Defects in the Health Services Sector

William Padula, PhD, Assistant Professor
University of Southern California Los Angeles, CA

Peter Pronovost, MD, PhD, Chief Clinical Transformation Officer
University Hospitals, Cleveland, OH

Wasteful spending is prevalent in healthcare

- Berwick & Hackbarth (JAMA 2012) chart wasteful spending on healthcare tripling over the last decade

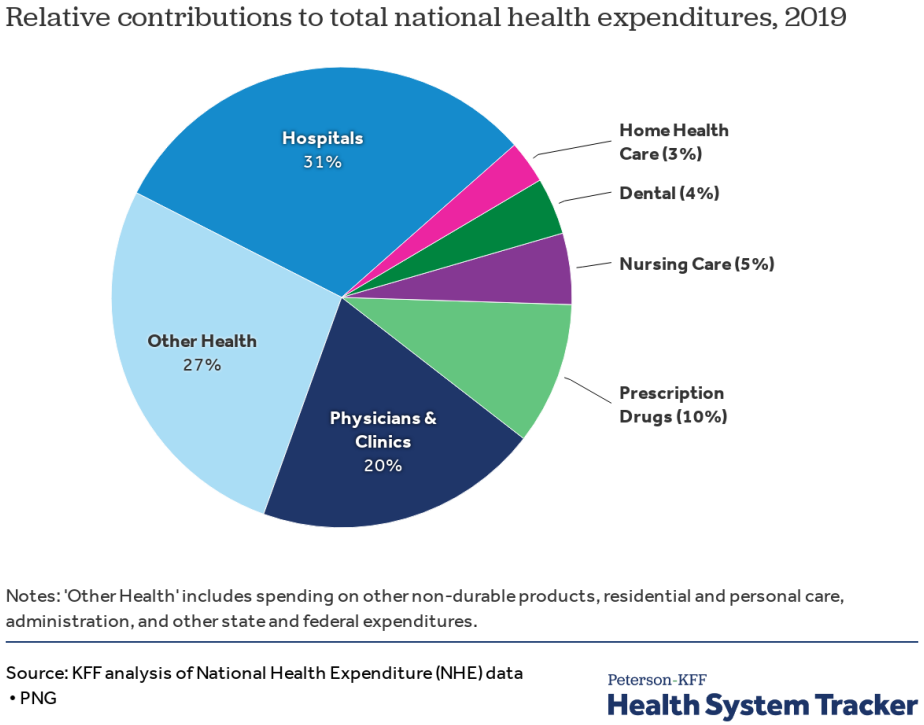


- Shrank and colleagues (JAMA 2019) estimate that wasteful spending could currently exceed $900 billion;
- Only 25% of this cost is reinvested to fix current sources of waste

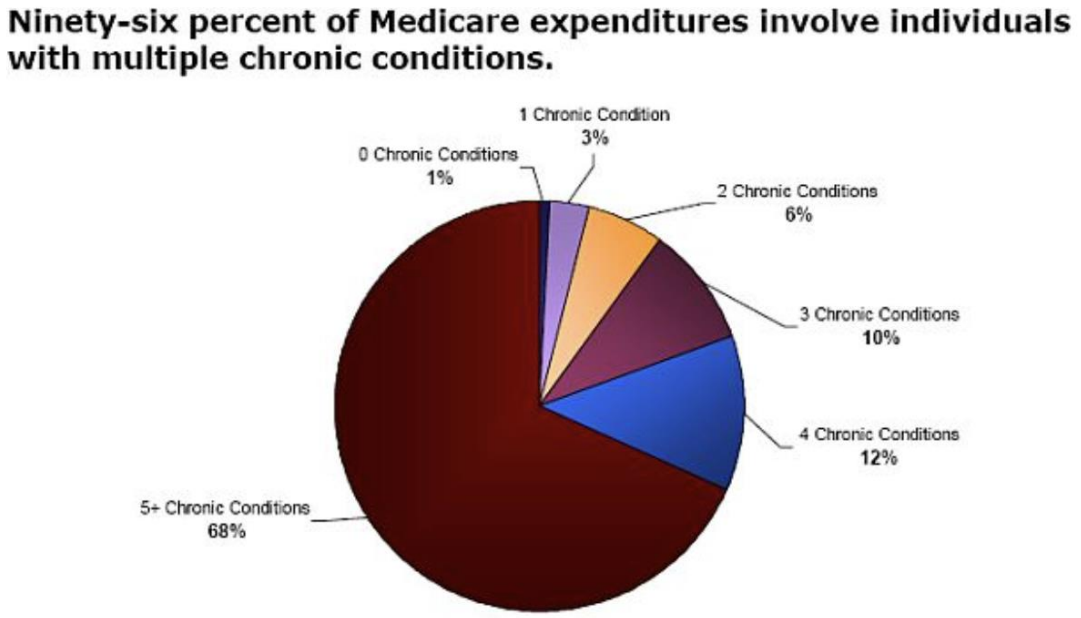
In this review based on 6 previously identified domains of health care waste, the estimated cost of waste in the US health care system ranged from $760 billion to $935 billion, accounting for approximately 25% of total health care spending, and the projected potential savings from interventions that reduce waste, excluding savings from administrative complexity, ranged from $191 billion to $282 billion, representing a potential 25% reduction in the total cost of waste. Implementation of effective measures to eliminate waste represents an opportunity to reduce the continued increases in US health care expenditures.

Where is most wasteful spending likely to occur? On healthcare services for complex patients

- Relative Contributions of Total National Health Expenditures in 2019



- Over 50% of Medicare expenditures are attributable to only 14% of beneficiaries with 6+ chronic conditions



Reducing waste doesn't necessarily mean cutting costs, it means designing health systems to deliver value

NEJM Catalyst | Innovations in Care Delivery

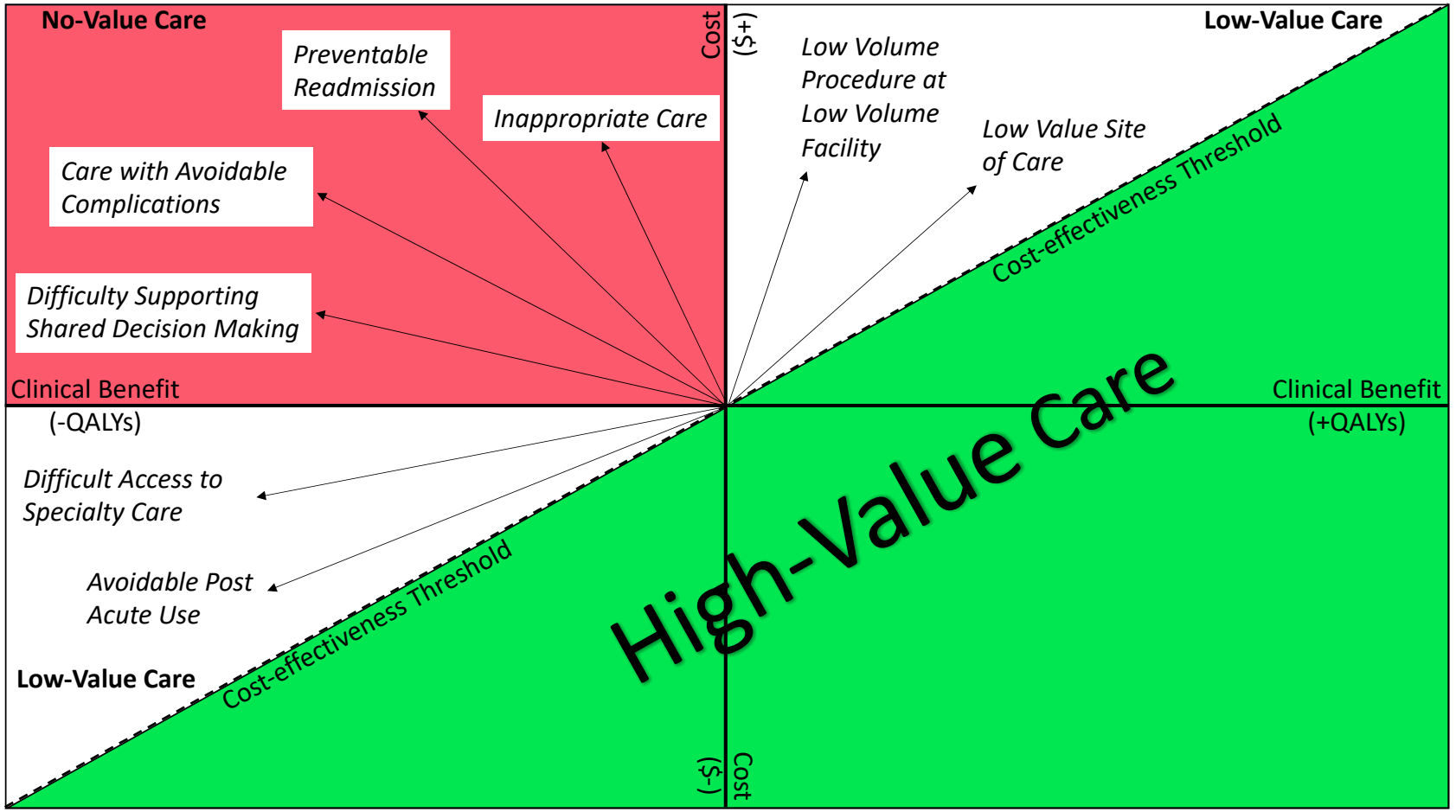
IN DEPTH

Designing for Value in Specialty Referrals: A New Framework for Eliminating Defects and Wicked Problems

Patrick Runnels, MD, MBA, Heather Wobbe, DO, MBA, Kipum Lee, MDes, Randy Jernejcic, MD, MMM, Peter Pronovost, MD, PhD

1. **Empathize** with the users of a process.
2. **Define** the users' needs, problems, and your own insights around them.
3. **Ideate** by challenging assumptions and generating ideas for innovative solutions.
4. **Prototype** rapidly to start creating solutions.
5. **Test** those solutions to illuminate how best to configure them.

Defects in value come in several forms, and vary in terms of expenditures and outcomes



How Innovation Can Help Healthcare Work Toward Zero Harm

Putting a Dent in the Trillion Dollar Problem

Peter Pronovost, MD, PhD, FCCM

Pronovost et. al. NEJM Catalyst 2020

By eliminating defects in value, we could save healthcare $1 trillion

Suboptimal Behavior	Estimated Total Cost of Suboptimal Behavior per Year	Estimated Avoidable Cost of Suboptimal Behavior per Year	Potential Impact on Patient Quality of Life if Appropriate Interventions Implemented
Developing and maintaining unhealthy habits[T1,T2]	$770 billion	$75 billion	Very high
Underutilizing preventive services[T3]	$55 billion	$5 billion	Very high
Not coordinating care[T3]	$340 billion	$50 billion	High
Not providing evidence-based care[T4]	$100 billion	$100 billion	High
Using suboptimal site of care	$10 billion	$2 billion	Moderate
Not providing evidence-based care[T5]	$20 billion	$5 billion	High
Not preventing avoidable readmissions[T6]	$40 billion	$25 billion	Moderate
Total cost	$1,335 billion	$262 billion	—

Note: T4 = “Secondary Prevention” ; T5 = “Acute Care”

In order to move towards value…

- Align around a common purpose and definition of value
- Create a common framework and analytical platform for measuring – and making transparent – defects in value and a disciplined management system to reduce defects
- Craft incentives to fundamentally change the system from one with uncoordinated incentives to one in which multiple stakeholders are incentivized toward the common purpose
- Ensure an appropriate population of attributable patients for whom creating this system change and alignment is tractable

Checklist for Eliminating Defects

STAY WELL

- [ ] Obtain annual wellness exam and close the gap
- [ ] Proactively reduce unhealthy habits
- [ ] Support healthy Habits
- [ ] Co-manage/co-locate behavioral health services
- [ ] Provider recommended preventative care, wellness and immunizations

GET WELL

OPTIMIZE HEALTH FOR PEOPLE WITH CHRONIC DISEASE

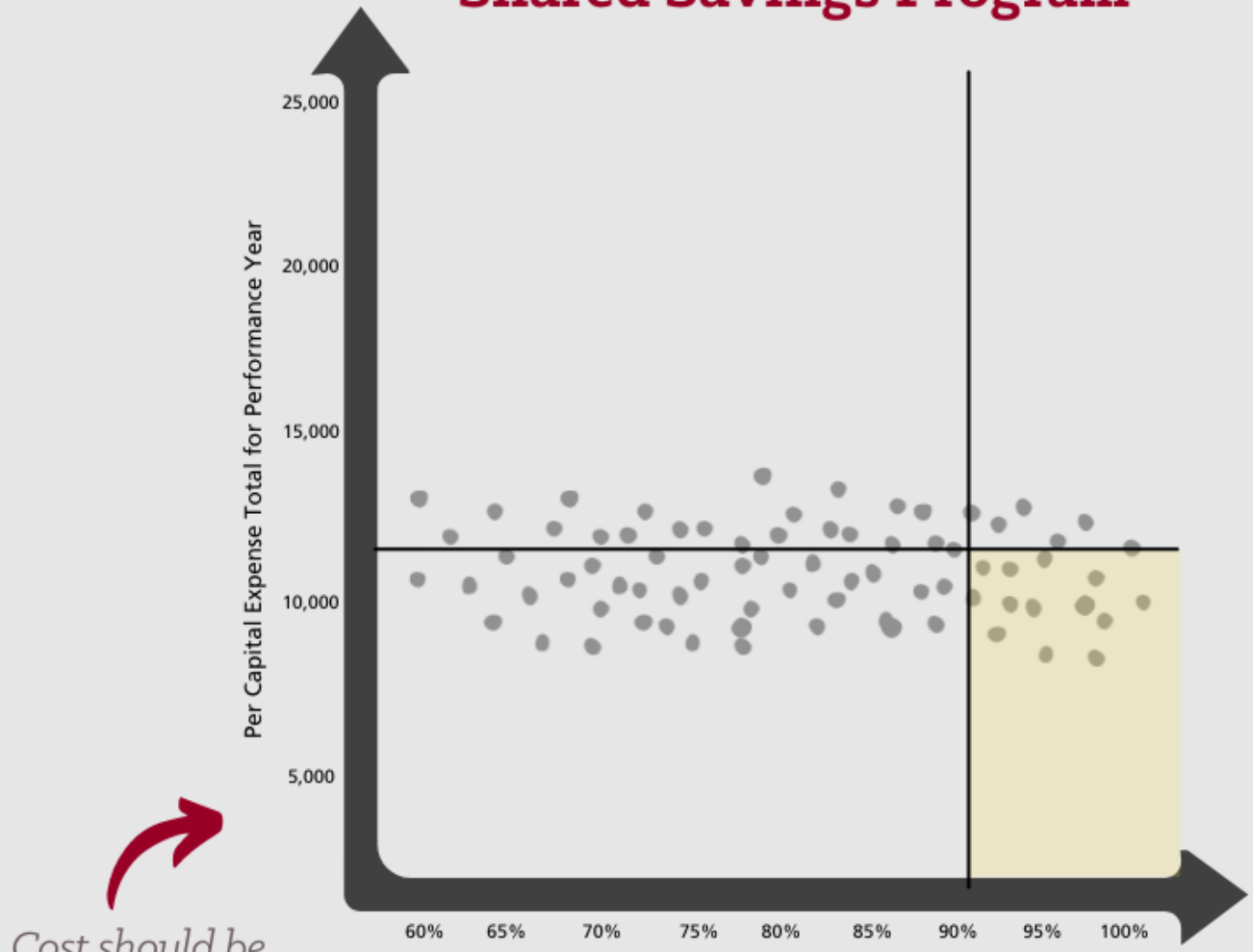
- [ ] Is the disease diagnosed?
- [ ] Is the patient treated with the recommended therapy?
- [ ] Is the patient active and able to use therapy?
- [ ] Is the patient's physiology controlled?
- [ ] Is the patient's utilization (ED, hospital admissions and readmissions) optimized?
- [ ] Is behavioral health co-managed/collocated?

GETTING BETTER *Managing Acute Conditions*

FOR ANY CONDITION ANYHERE IN THE CARE CONTINUUM

- [ ] Is care coordinated with PCP?
- [ ] Is the therapy beneficial?
- [ ] Is care being provided in the highest-value site of service?
- [ ] Is care provided by a high value provider using evidence-based medicine and shared decision making?
- [ ] Have we eliminated preventable harm?

Understanding Quality & Cost in the Medicare Shared Savings Program

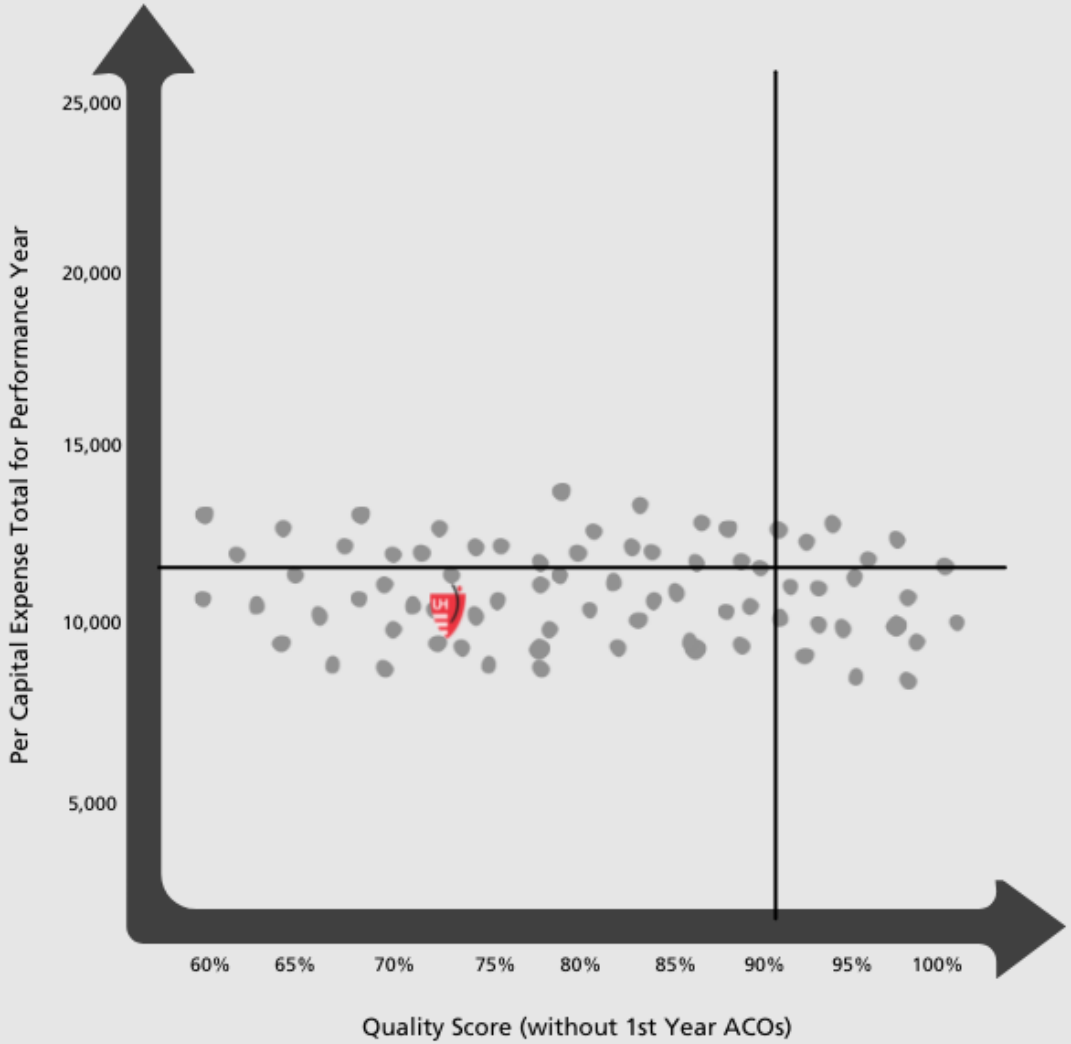


Cost should be low

This quadrant demonstrates the highest value

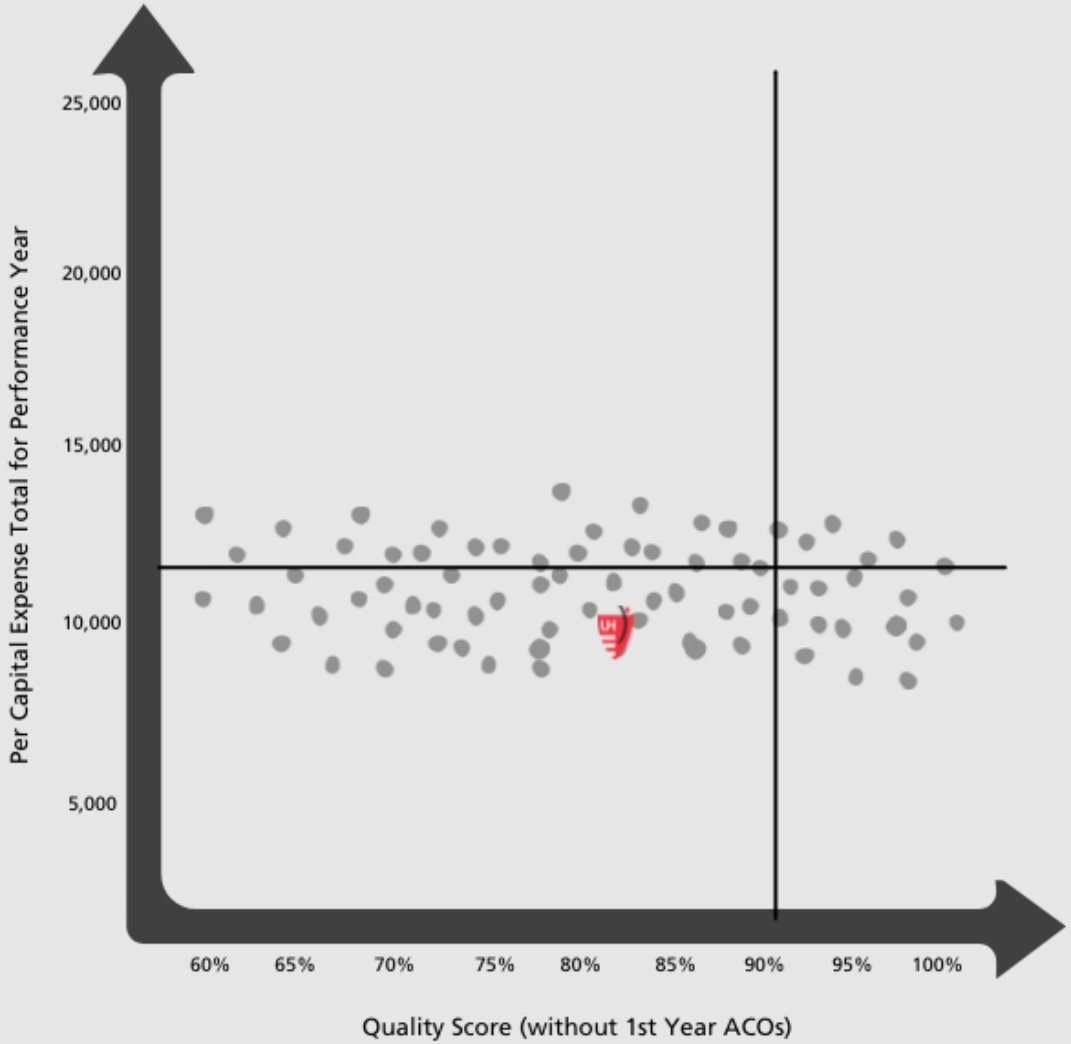
Quality should be high

University Hospitals in 2017



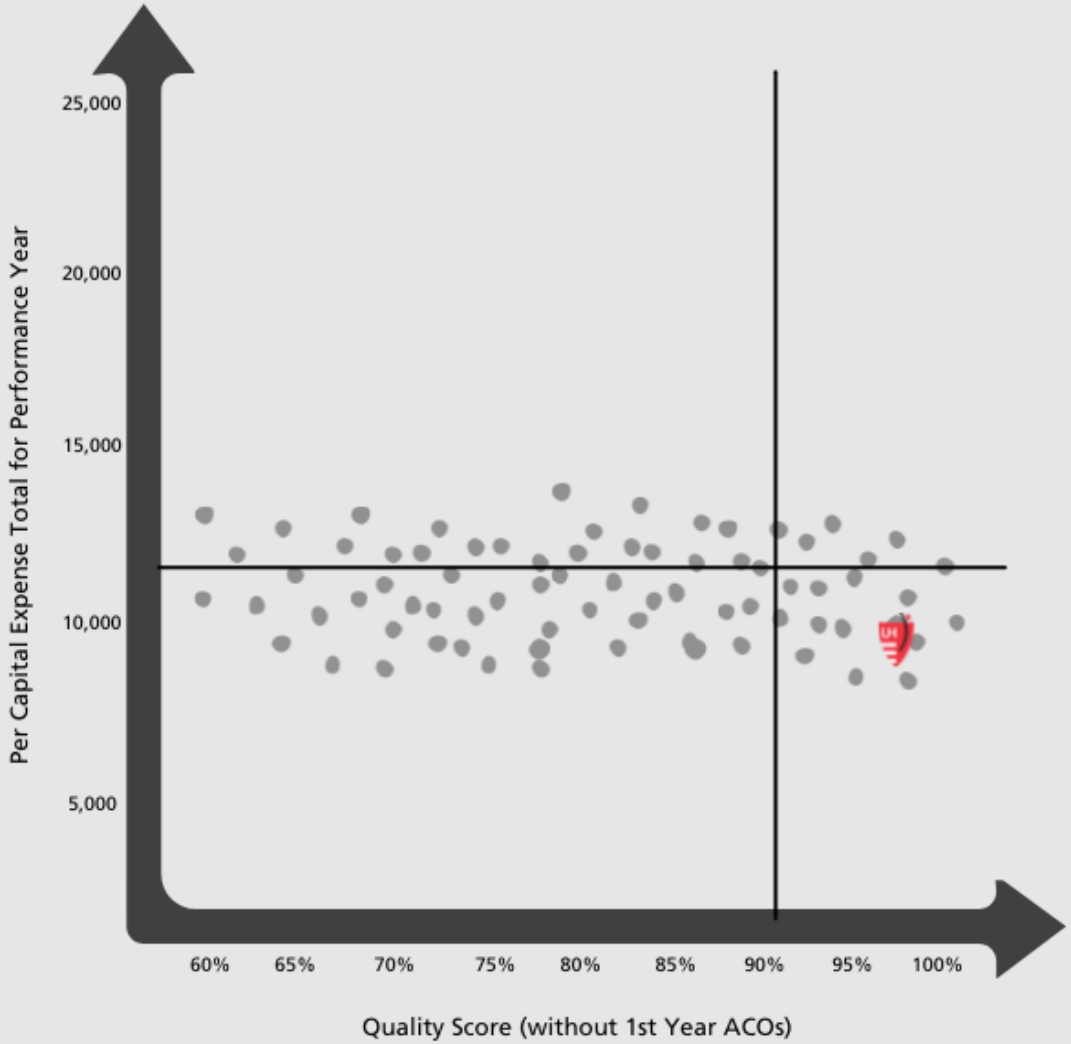
*This graph demonstrates approximate scores and does not reflect actual data from CMS. For final ACO data please visit: https://data.cms.gov

University Hospitals in 2018



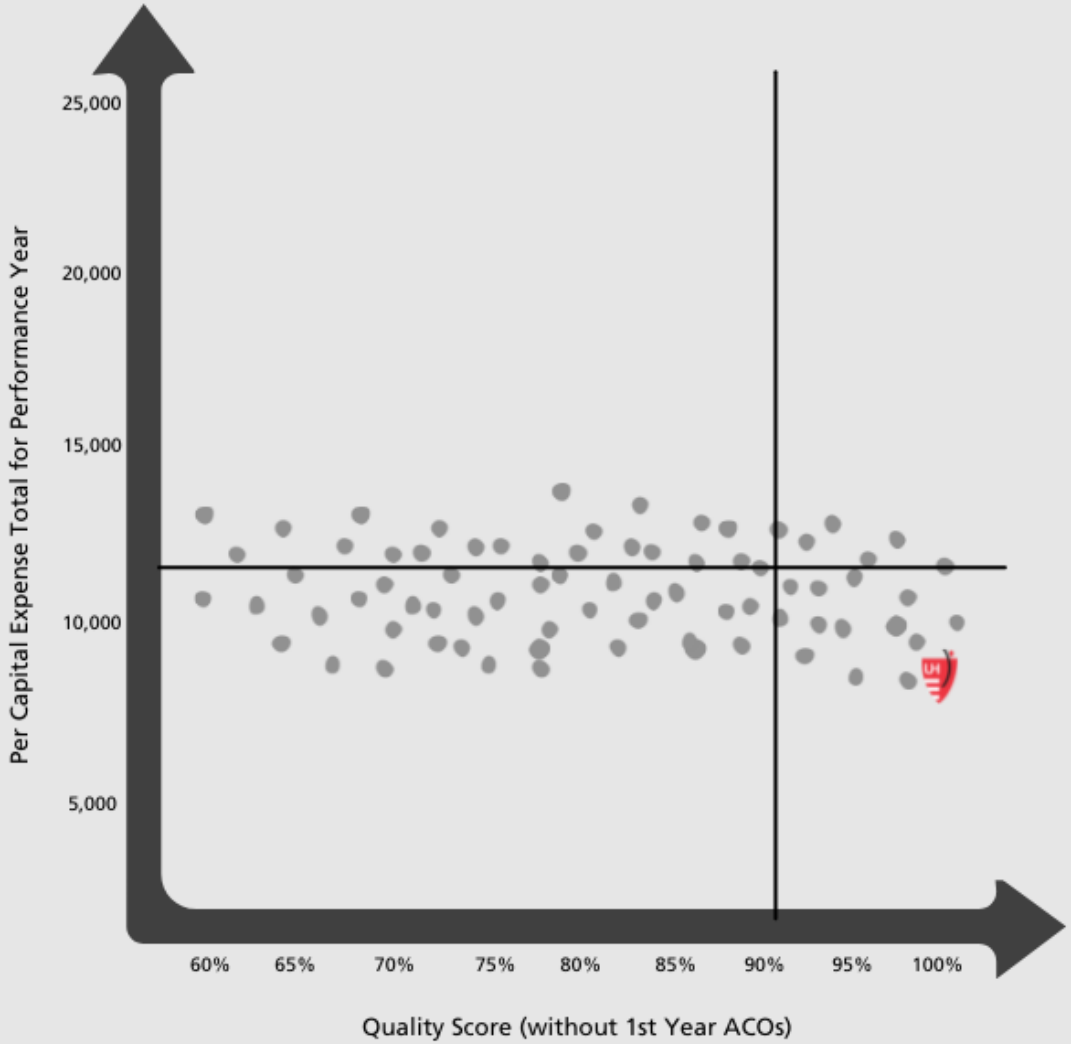
*This graph demonstrates approximate scores and does not reflect actual data from CMS. For final ACO data please visit: https://data.cms.gov

University Hospitals in 2019



*This graph demonstrates approximate scores and does not reflect actual data from CMS. For final ACO data please visit: https://data.cms.gov

University Hospitals in 2020



*This graph demonstrates approximate scores and does not reflect actual data from CMS. For final ACO data please visit: https://data.cms.gov

Questions?

Challenges and Potential Solutions to Measuring Effectiveness of Health Service Interventions

R. Brett McQueen, PhD, Assistant Professor

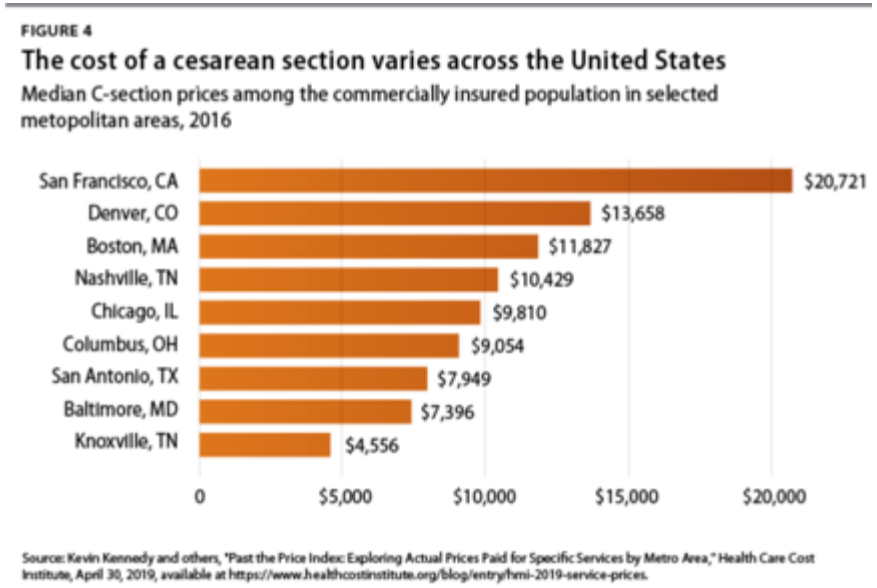
Skaggs School of Pharmacy and Pharmaceutical Sciences, University of Colorado

Disclosures and Acknowledgements

- Thank you to Altarum Institute for providing funding for this project
- Other relevant conflicts in value assessment:
  - Institutional funding from Institute for Clinical and Economic Review to conduct cost-effectiveness applications
  - Institutional funding from the PhRMA Foundation to apply and test novel methods for value assessment, including multi-criteria decision analysis

Health service interventions and cost-effectiveness in the United States

- Health service interventions (e.g., screening) underrepresented in cost-effectiveness literature as proportion of spending[1]
- Meaningful discussion around cost differences often ends without context to value



1 Baumgardner and Neumann. Balancing the Use of Cost-Effectiveness Analysis Across all Types of Health Care Innovations. Health Affairs Blog. April 14, 2017

Difficulties in measuring effectiveness for health service interventions

- Distinguishing effectiveness from broader quality of care
- Measuring health outcomes that matter most to patients
- Designing effectiveness studies with non-random allocation
- Measurement challenges based on existing data sources

Difficult to establish links from up-front screening → monitoring and education → lifetime risks and survival

Cost and Cost-Effectiveness of Large-Scale Screening for Type 1 Diabetes in Colorado

https://doi.org/10.2337/dc19-2003

R. Brett McQueen,[1] Cristy Geno Rasmussen,[2] Kathleen Waugh,[2] Brigitte I. Frohnert,[2] Andrea K. Steck,[2] Liping Yu,[2] Judith Baxter,[2] and Marian Rewers[2]

Defining effectiveness of health services

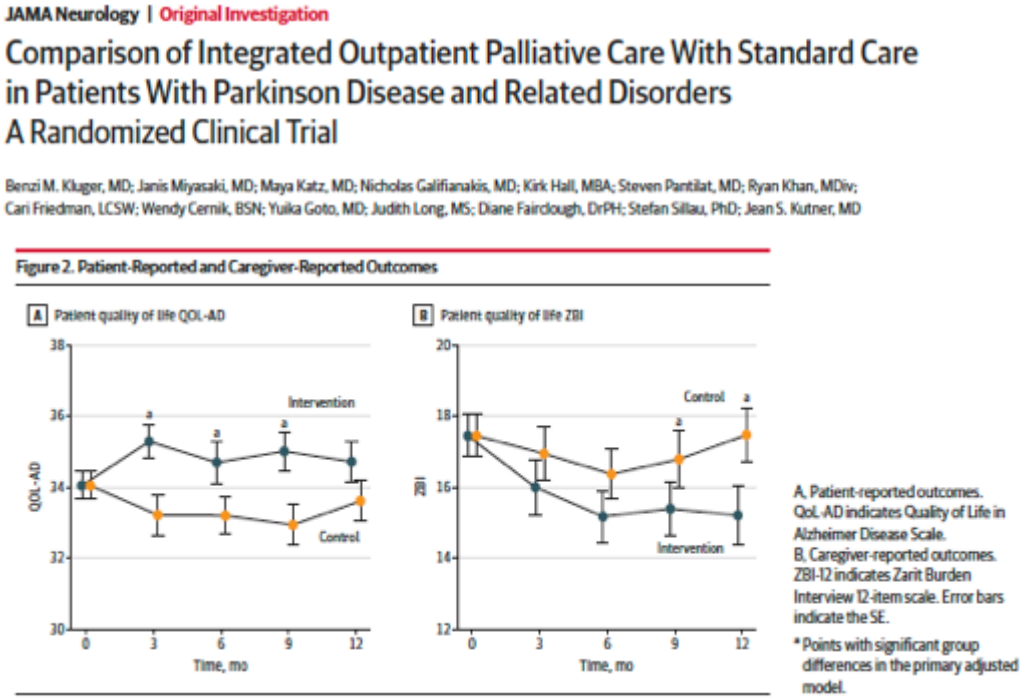
- Quality of interventions broader and shaped by setting, personnel, and sustainability, among many other factors
- *Effectiveness in context to value*, i.e., comparative effectiveness and cost-effectiveness research
  - Impact of a health service intervention (e.g., screenings, procedures) on health outcomes important to patients in real-world clinical practice settings

What health outcomes matter most to patients?

- The National Health Council (NHC):
  - “the broad range of impacts a disease and its treatment have on a patient’s daily life.”
- The International Consortium for Health Outcomes Measurement (ICHOM):
  - “the results people care about most when seeking treatment, including functional improvement and the ability to live normal, productive lives.”

Designing effectiveness studies

- Randomization ideal but health services often not required to undergo same regulatory approval steps as pharmaceuticals
- More feasible to rely on observational data sources
  - Health services research provides quasi-experimental solutions



JAMA Neurology | Original Investigation

Comparison of Integrated Outpatient Palliative Care With Standard Care in Patients With Parkinson Disease and Related Disorders
A Randomized Clinical Trial

Benzi M. Kluger, MD; Janis Miyasaki, MD; Maya Katz, MD; Nicholas Galifianakis, MD; Kirk Hall, MBA; Steven Pantilat, MD; Ryan Khan, MDiv; Cari Friedman, LCSW; Wendy Cernik, BSN; Yuika Goto, MD; Judith Long, MS; Diane Fairclough, DrPH; Stefan Sillau, PhD; Jean S. Kutner, MD

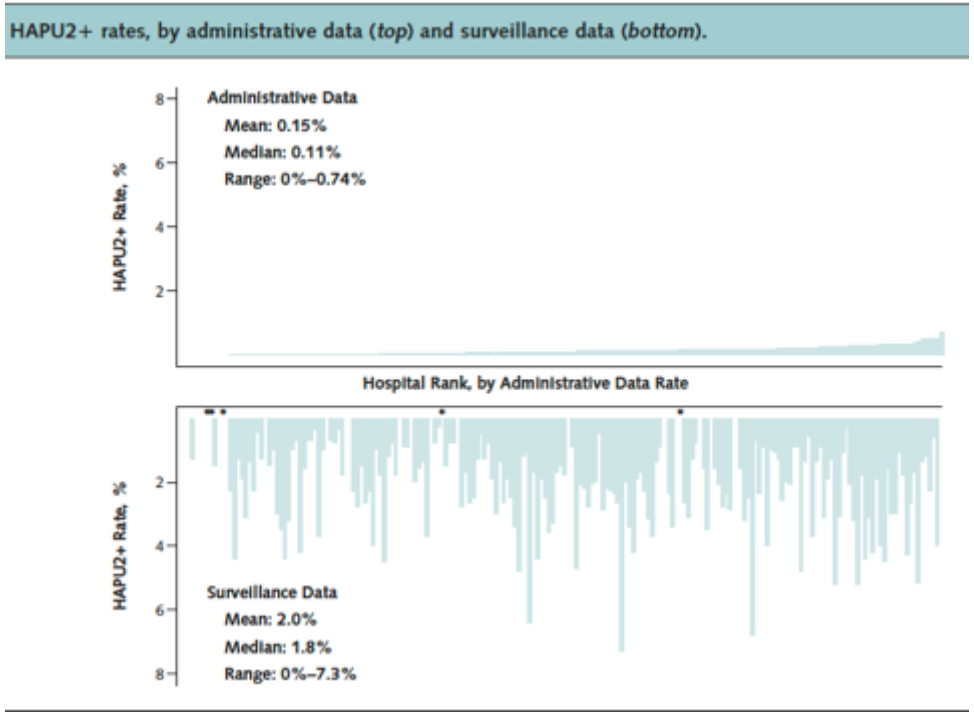
Figure 2. Patient-Reported and Caregiver-Reported Outcomes

A, Patient-reported outcomes. QoL-AD indicates Quality of Life in Alzheimer Disease Scale. B, Caregiver-reported outcomes. ZBI-12 indicates Zarit Burden Interview 12-item scale. Error bars indicate the SE.

* Points with significant group differences in the primary adjusted model.

Challenges in measuring exposures and outcomes

- Exposures and outcomes may reflect what is reimbursable rather than what resources were used and outcomes achieved
- Little information on severity of diagnoses and patient-reported health status

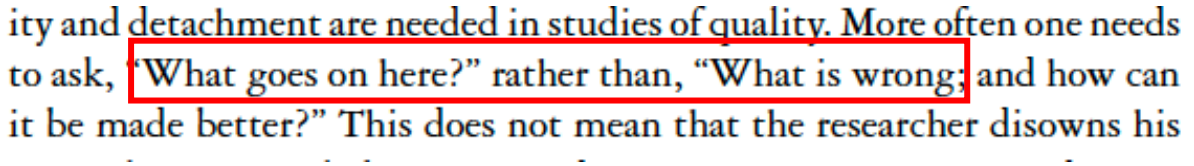


Hospital Report Cards for Hospital-Acquired Pressure Ulcers: How Good Are the Grades?

Jennifer A. Meddings, MD, MSc; Heidi Reichert, MA; Tim Hofer, MD, MSc; and Laurence F. McMahon Jr., MD, MPH

Understanding the full cycle of care

- Measure the full cycle of care to understand all the resources used when treating a patient up to the health outcomes ultimately achieved
- Time-driven activity based costing (TDABC)* can inform effectiveness data collection



ity and detachment are needed in studies of quality. More often one needs to ask, "What goes on here?" rather than, "What is wrong; and how can it be made better?" This does not mean that the researcher disowns his

*Kaplan and Porter. The Big Idea: How to Solve the Cost Crisis in Health Care. Harvard Business Review. September 2011; Keel G, Savage C, Rafiq M, Mazzocato P. Time-driven activity based costing in health care: A systematic review of the literature. Health Policy. 2017; 121(7): 755-763; Avedis Donabedian. Evaluating the Quality of Medical Care; The Milbank Quarterly. 2005; 83(4).

Future research needs

- Researchers: distinguish between overall quality and effectiveness
- Providers: define exposures and outcomes beyond sustainability or regulatory requirements
- Funders: continued funding for publicly available data infrastructure solutions including incentivization of common data models
  - Supplements needed to understand full cycle of care including measuring outcomes important to patients

Summary and conclusions

- Given scale of spending on hospital and provider services, effectiveness of health service interventions should be a national priority
- Significant investment and collaboration across multiple stakeholders could help change the core of our health care system from simply producing quality metrics to *producing value for patients*

Next Steps

- “A Roadmap to High-Value Healthcare” to complete the series
- Prioritize wasteful health service interventions for value assessment applications
- Identify data availability and gaps for inputs to value assessment

Questions?

Sources of Health Care Price Variation Create Barriers to Measuring Health Care Costs

Christopher Whaley, PhD

RAND

Employer-sponsored plans cover half of Americans

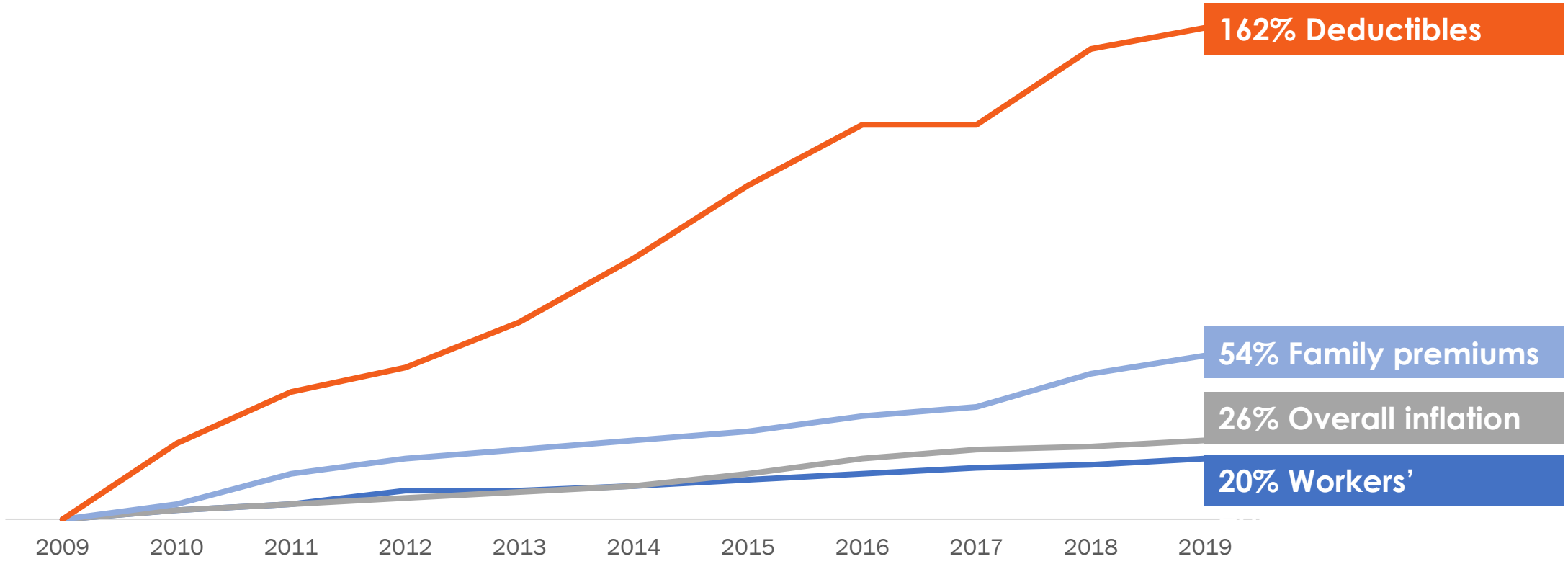
$1.2 trillion

health care costs in 2018

$480 billion

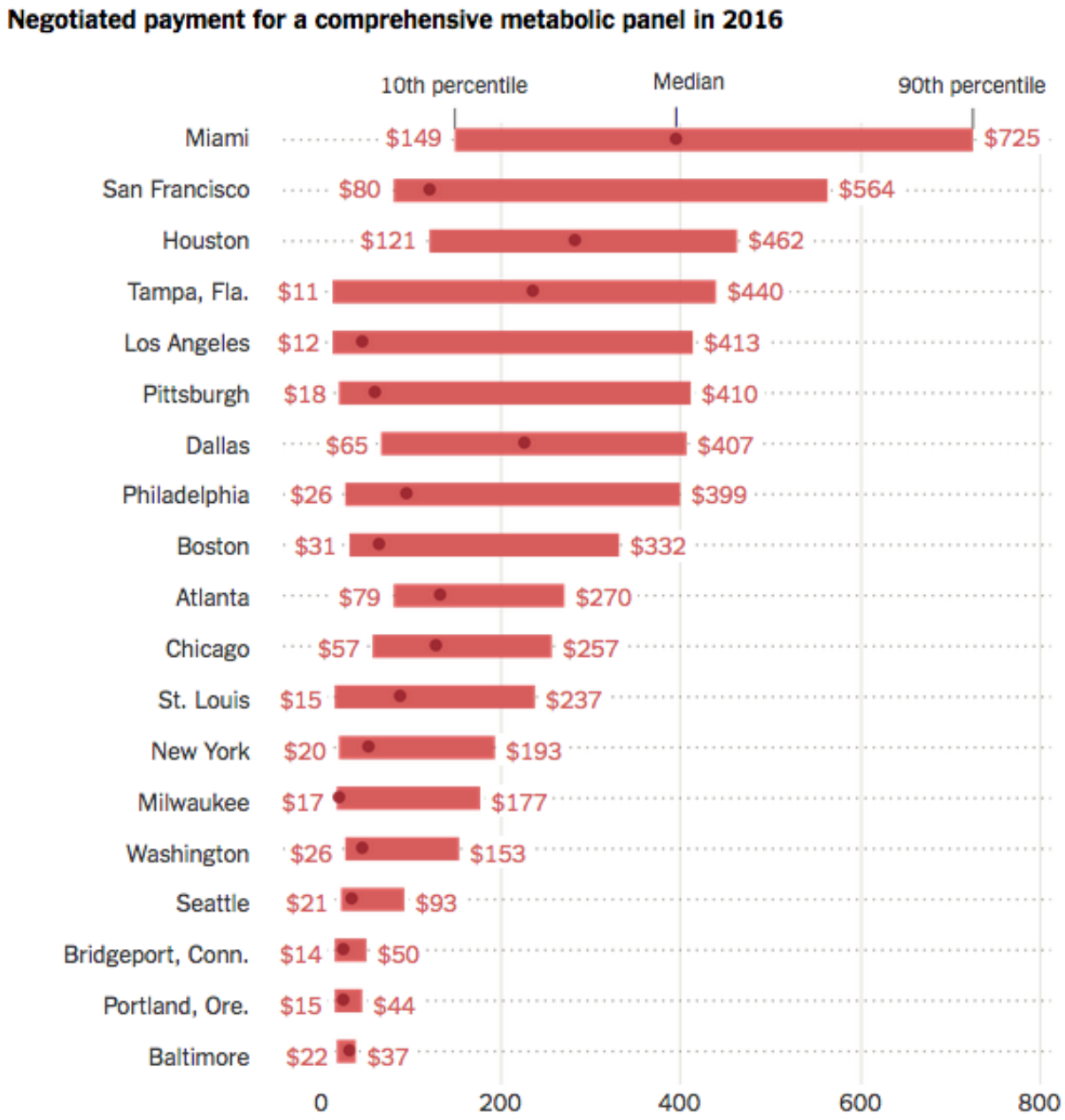
hospital costs in 2018

Over the past decade, premiums and deductibles have outpaced wages

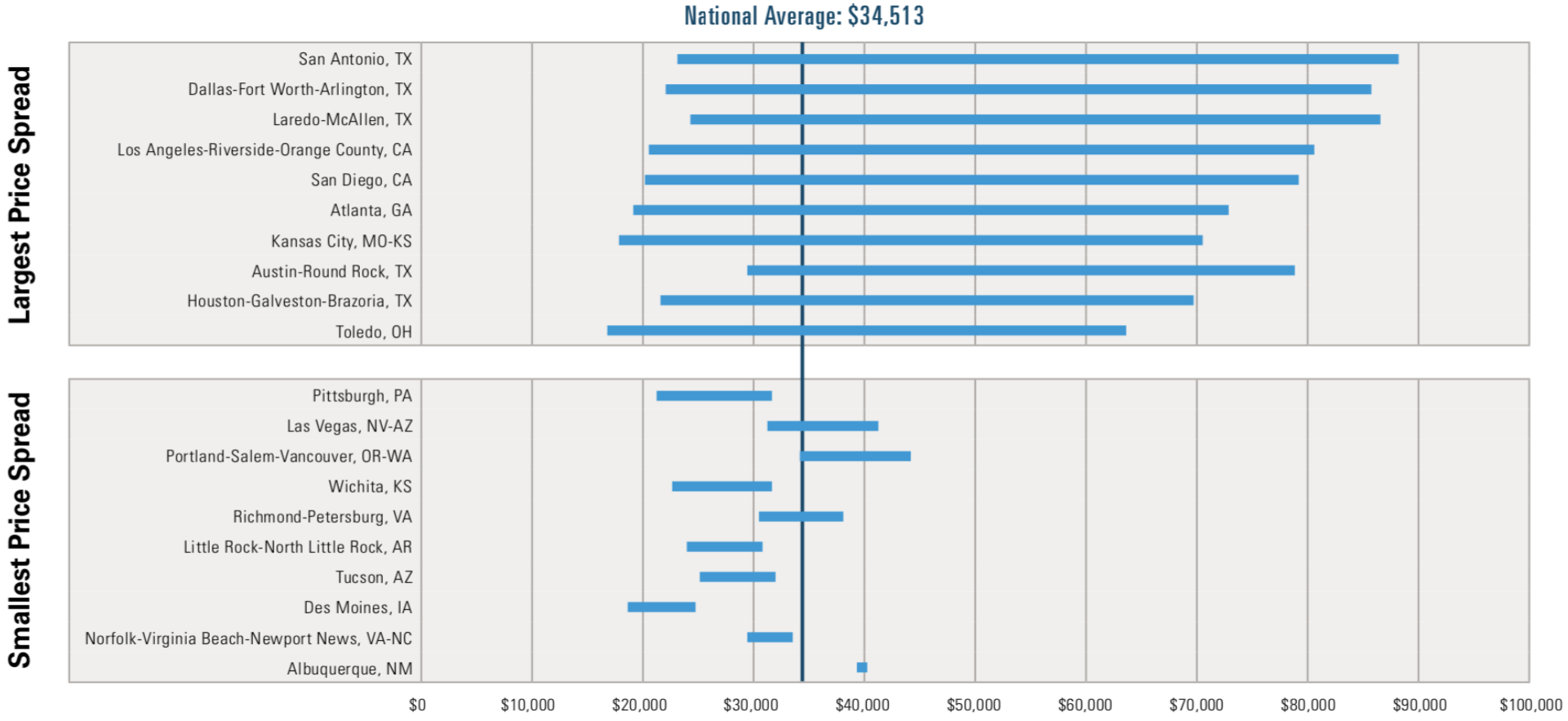


SOURCE: Kaiser Family Foundation. (2019) Health Benefits Survey

Health care prices vary widely



Price variation exists both within and between markets



Source: BCBS Health of America. Planned Knee and Hip Replacement Surgeries Are on the Rise in the U.S. 2019

It is difficult for patients to get accurate price information

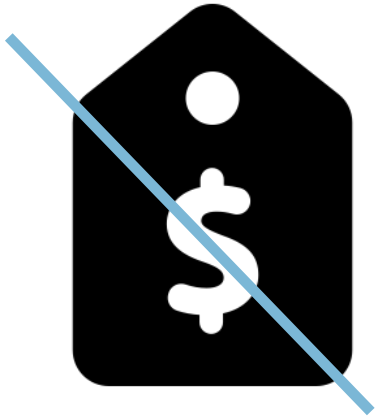
Table. Price Information for the Cost of Electrocardiograms (ECGs) and Parking

Hospital No.	Price, $	
	ECG	Parking
1	NP	~6 for 2 h, discounted
2	NP	NP
3	137	0
4	NP	0
5	NP	0
6	NP	0
7	1200	~15 for 2-3 h, discounted
8	NP	~15 for 2-3 h, discounted
9	NP	0
10	NP	0 for visitors
11	NP	0
12	NP	0 for visitors
13	NP	0 for visitors
14	NP	0 for visitors
15	600	0
16	NP	0
17	NP	0 for 30 min; 3 for 2-3 h, discounted
18	NP	2 for visitors with validation
19	NP	0
20	NP	3 for 1 h; 5 for 2-5 h

Abbreviation: NP, not provided.

What's different about health care?

Lack of information about prices



Lack of incentives to shop

Limited provider choices

Insurer contracts make it hard to compare data

Insurers negotiate prices for services

Gag clauses obscure price information sharing

Public price transparency policies have had limited success

◆ WSJ NEWS EXCLUSIVE | HEALTH

Hospitals Hide Pricing Data From Search Results

Webpages for hundreds of hospitals require users to click through to find prices, undermining federal transparency rule, Journal analysis shows

NYU Langone Health was among hospital systems that used blocking code preventing search engines from displaying pages with price lists.

PHOTO: BRENDAN MCDERMID/REUTERS

By Tom McGinty, Anna Wilde Mathews and Melanie Evans
March 22, 2021 5:30 am ET

Conclusion

- Rising health care costs place pressure on employers and worker wages—especially during the COVID-19 pandemic
- The wide variation in hospital prices presents a potential savings opportunity for employers
- Health care purchasers need to push for data on the prices that they, and their workers, are paying

Christopher Whaley

cwhaley@rand.org

Questions?

Enhancing Health Care Value Through Data, Measurement & Evaluation of Services and Procedures

Peter J. Neumann, ScD & Daniel A. Ollendorf, PhD

CEVA, Tufts Medical Center

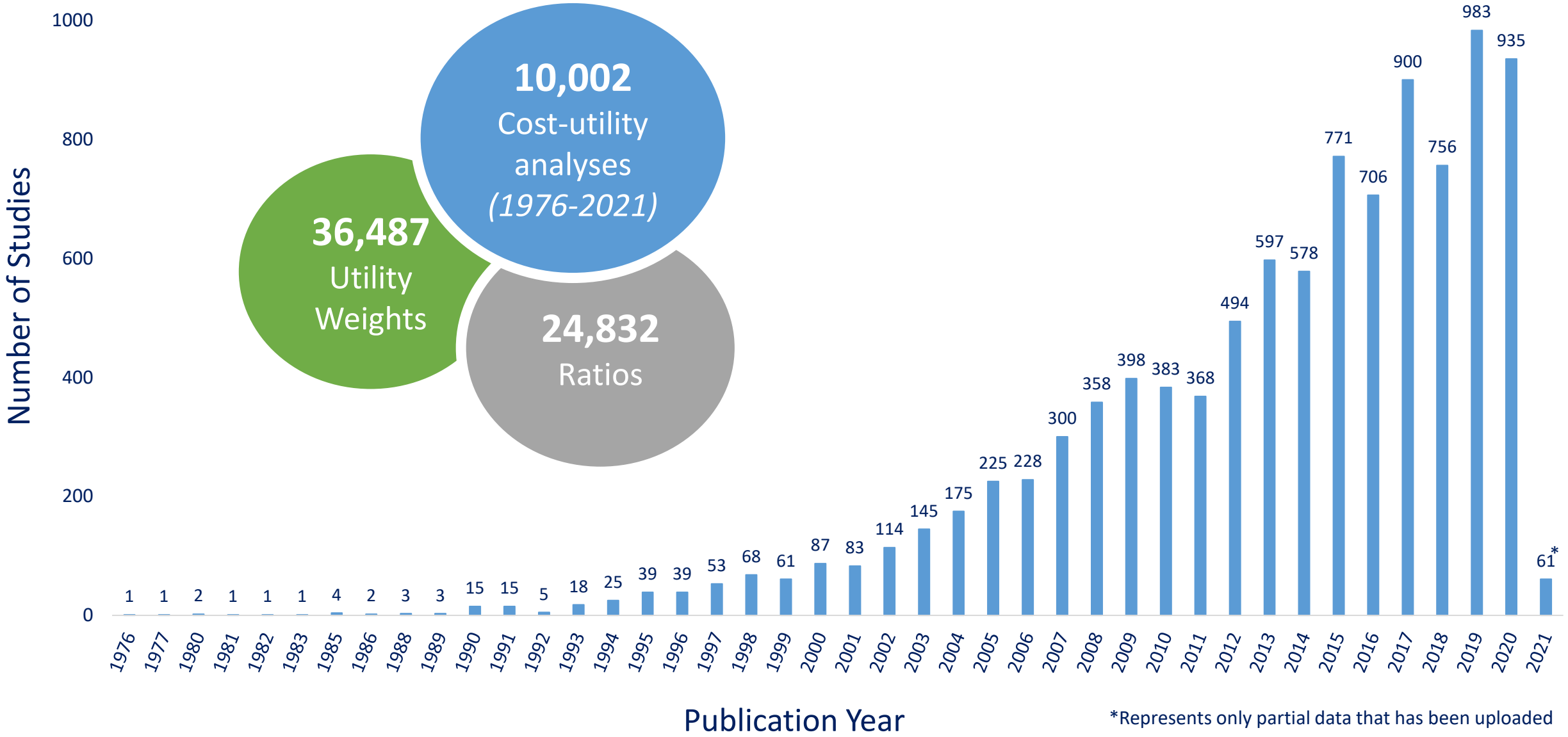
Overview

- Cost-effectiveness analyses have focused mostly on pharmaceuticals
- Why the “under study” of health services and procedures?
- What to do?

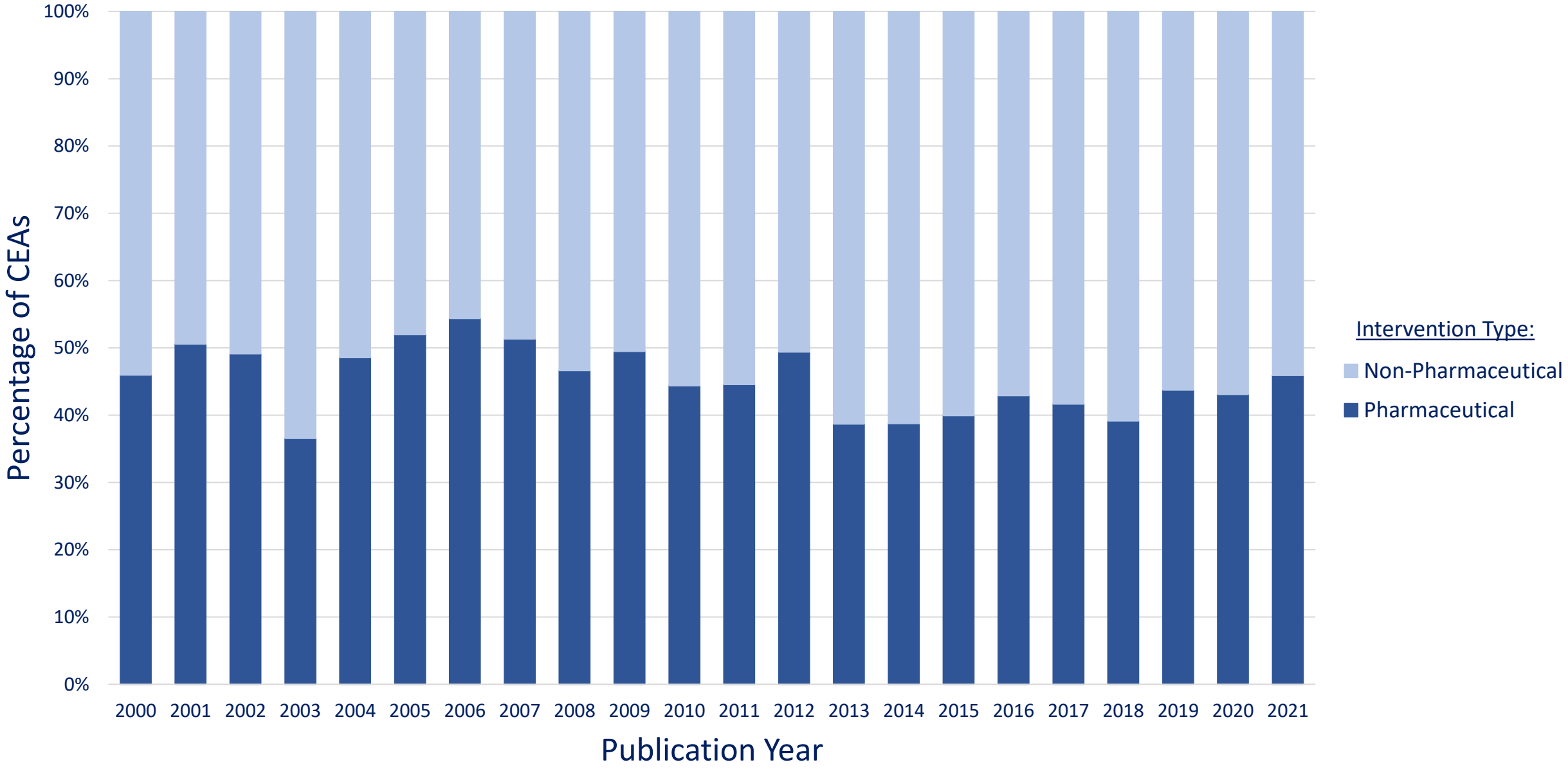
Overview

- Cost-effectiveness analyses have focused mostly on pharmaceuticals
- Why the “under study” of health services and procedures?
- What to do?

Number of CEAs Over Time



% of CEAs Focused on Pharmaceuticals



Key takeaway

Pharmaceuticals comprise 15% of health spending, but 43% of CEAs have focused on pharmaceuticals.

Source: OECD, World Bank

Overview

- Cost-effectiveness analyses have focused mostly on pharmaceuticals
- Why the “under study” of health services and procedures?
- What to do?

Explaining the “understudy” of health services and procedures”

- Lack of suitable data
- Nature of the intervention

Lack of suitable data on services/procedures

- Few RCTs supporting services & procedures
- Assumptions/uncertainty with RWE
- Clinician effects
- No standard sources for cost, other data

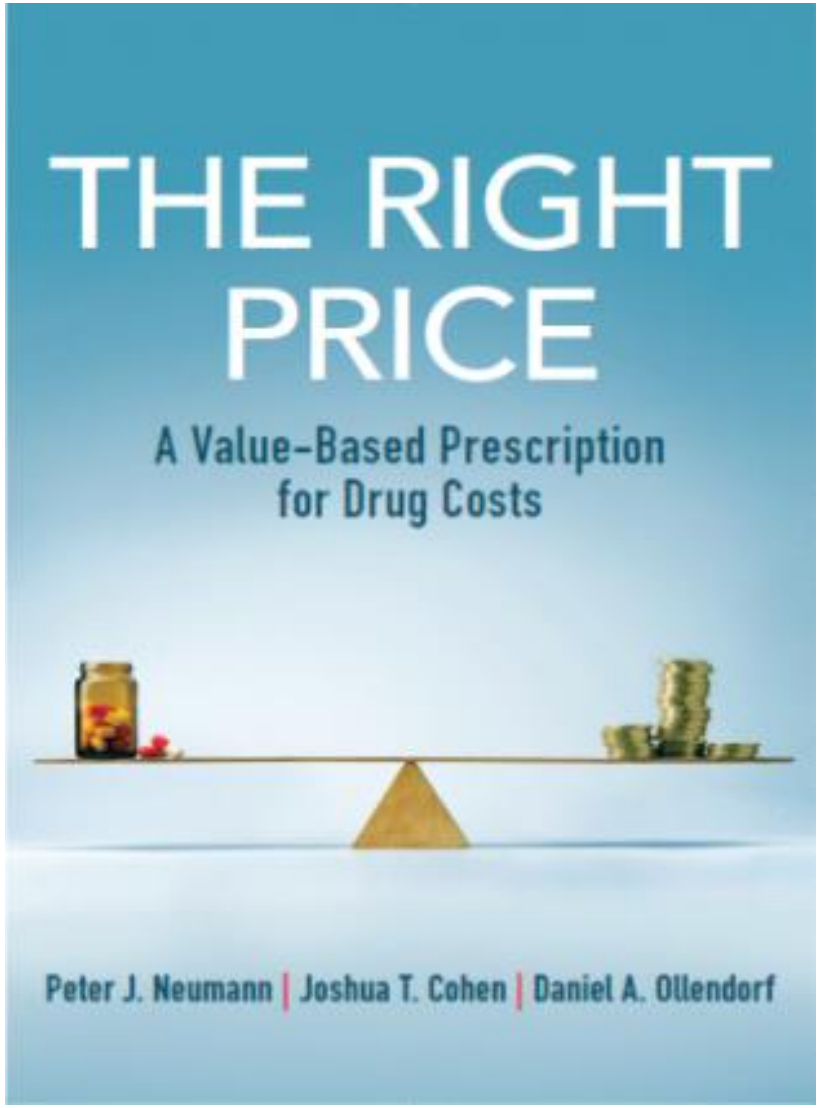
Nature of the intervention

- Drugs→temporary monopolies→incentives for value demonstration

- Services/procedures:
  - Typically no property rights
  - Payment mechanisms align price with *cost*
  - No generic competition

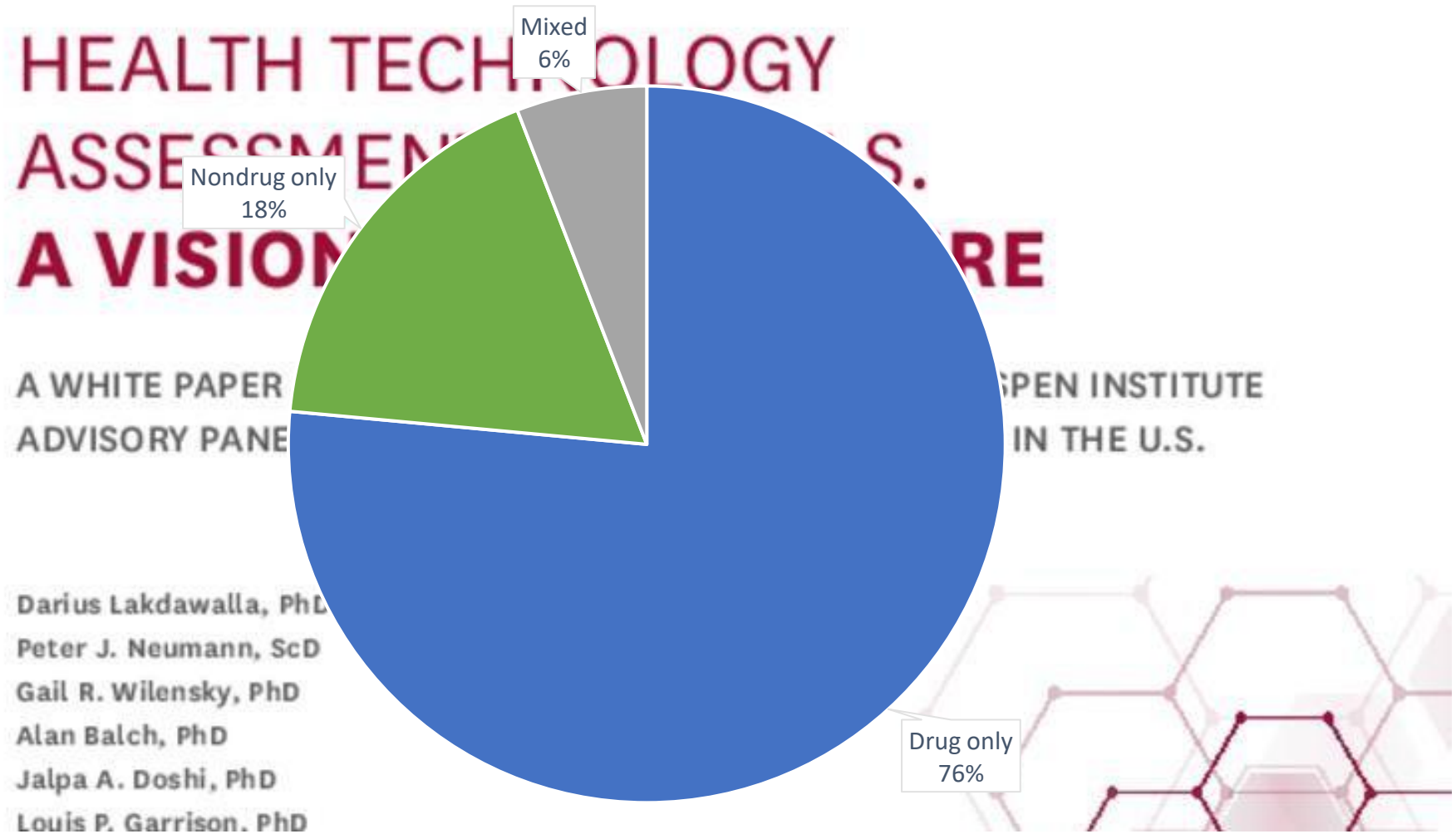
Overview

- Cost-effectiveness analyses have focused mostly on pharmaceuticals
- Why the “under study” of health services and procedures?
- What to do?


THE RIGHT PRICE
A Value-Based Prescription for Drug Costs
Peter J. Neumann | Joshua T. Cohen | Daniel A. Ollendorf

US HTA

ICER Reviews since 2015



Private payers

- Augment “low-value” care initiatives with CEA
- Add technology “adoption” activities
- Tie reimbursement to evidence and value

Research community

- Standardization of RWE datasets
- Methods guidance for costs and effects
- Increase in sponsored research

Journal editors

- Be more accepting of all CEA!
- Prioritize service/procedure CEA
- Calls for papers & special issues

Questions?

PAVE
PATIENT-DRIVEN
VALUES in HEALTHCARE
EVALUATION
engagement ★ education ★ research ★ dissemination

Health Technology Assessment & Methods for Evidence Generation on Patient-Driven Values in Healthcare Services

Susan dosReis, PhD
Julia F. Slejko, PhD
Alejandro Amill-Rosario, MPH, PhD

PAVE Center, School of Pharmacy, University of Maryland Baltimore

Acknowledgements

PAVE PATIENT-DRIVEN VALUES *in* HEALTHCARE EVALUATION

engagement ★ education ★ research ★ dissemination

PhRMA FOUNDATION

PAVE Center is funded by the PhRMA Foundation as a Center of Excellence in Value Assessment

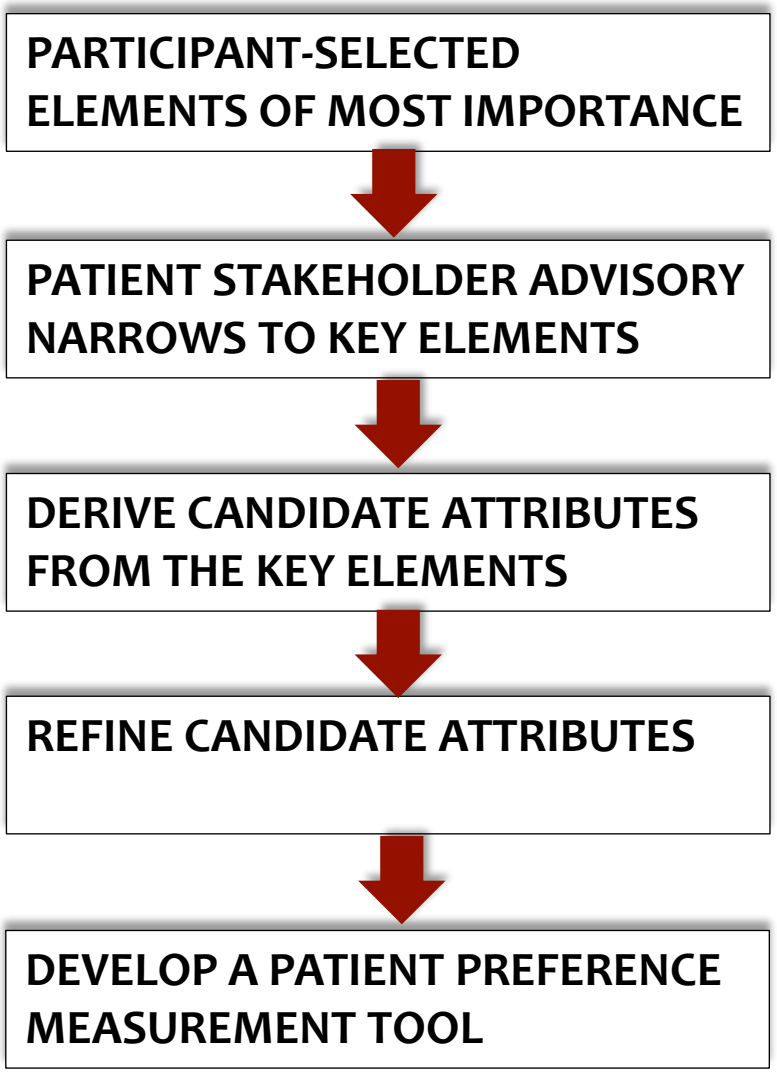
We are grateful to the patient communities and stakeholders who contributed their expertise, without which this work would not be possible

Objectives

- Illustrate how stated preference methods can assess the relative importance of treatment effects, outcomes, and costs across population segments
- Explore the potential translation of patient-centered economic evaluation
- Discuss the prospects for evidence generation for patient-centered health technology assessment (HTA)

Performance Measurement Steps

PAVE
PATIENT-DRIVEN VALUES in HEALTHCARE EVALUATION
engagement ★ education ★ research ★ dissemination



Eliciting Patient Preferences

PAVE PATIENT-DRIVEN VALUES in HEALTHCARE EVALUATION
engagement ★ education ★ research ★ dissemination

- PAVE's patient-informed value elements are disease agnostic but can be tailored to specific conditions, treatments, and/or service delivery models/interventions

DOMAIN	PATIENT-INFORMED VALUE ELEMENTS		
Short and Long-term Treatment Effects	**Tolerability** Medication Frequency Length of Treatment Side effects	**Disease Burden** Age of Onset Symptom Importance Intermediate/Surrogate Outcomes	**Forecasting** Impact on Education Impact on Career Predictable Healthcare Needs Inability to Plan Life Expectancy
Treatment Access	**Accessibility of Care/Treatment** New Therapeutic Option Available Treatment Provider Willing to Deliver Care Proximity to Care Location Appropriateness of Care System Navigation	**Healthcare Service Delivery** Provider Relationship & Trust Care Transitions Consistency of Care Explanation of Treatment (Risks & Benefits)	
Treatment Costs	**Cost Incurred by the Patient** Affordability Cost of Treatment-Related Side Effects Long-term Costs Reimbursed Care	**Cost Incurred by the Family** Sibling Costs Long-term Effects on the Family Relocation Costs Autonomy/Dependence	
Life Impact	**Personal Well-Being** Fatigue Ability to Work Physical Abilities Emotional Status	**Stigma** Embarrassment/Self-Consciousness Rejection by Family Rejection by Society	
Social Impact	**Social Well-Being** Support Network Relationship with Family Relationship with Peers Maintain Social Activities	**Personal Values** Cultural Barriers Religious Beliefs	

The Patient - Patient-Centered Outcomes Research
https://doi.org/10.1007/s40271-020-00433-8

ORIGINAL RESEARCH ARTICLE

Stakeholder-Engaged Derivation of Patient-Informed Value Elements

Susan dosReis[1] · Beverly Butler[2] · Juan Caicedo[3] · Annie Kennedy[4] · Yoon Duk Hong[1] · Chengchen Zhang[1] · Julia F. Slejko[1]

Key Points for Decision Makers

Value assessment framework recommendations call for improving value measures to better align with what is important to patients.

This paper presents patient-informed value elements that were developed with continuous patient engagement throughout the process.

The work will advance the field of value assessment because it provides a set of novel and measurable patient-informed value elements that can be incorporated into existing value frameworks and economic evaluations to improve the health technology assessment, data-generation, and decision-making processes.

Eliciting Patient Preferences

PAVE PATIENT-DRIVEN VALUES in HEALTHCARE EVALUATION

engagement ★ education ★ research ★ dissemination

Activity 4: Identify the elements of Treatment Costs

Treatment Costs	Please select all elements that are important to you	Please select the FIVE elements that are most important to you
Affordability	0	0
Cost of Treatment-related Side Effects	0	0
Long-term Costs	0	0
Reimbursed Care	0	0
Sibling Costs	0	0
Long-term Effects on the Family	0	0
Relocation Costs	0	0
Autonomy/Dependence	0	0

Activity 5: identify the elements of Life Impact

Life Impact	Please select all elements that are important to you	Please select the FIVE elements that are most important to you
Fatigue	0	0
Ability to Work	0	0
Physical Abilities	0	0
Emotional Status	0	0
Embarrassment/Self-Consciousness	0	0
Rejection by Family	0	0
Rejection by Society	0	0

The Patient - Patient-Centered Outcomes Research
https://doi.org/10.1007/s40271-021-00495-2

ORIGINAL RESEARCH ARTICLE

Prioritization and Refinement of Patient-Informed Value Elements as Attributes for Chronic Obstructive Pulmonary Disease Treatment Preferences

Julia F. Slejko[1] · Yoon Duk Hong[1] · Jamie L. Sullivan[2] · Robert M. Reed[3] · Susan dosReis[1]

Accepted: 7 January 2021

Key Points

A comprehensive list of condition-agnostic value elements was tailored for patients with chronic obstructive pulmonary disease to reflect the element that matters most for their healthcare decision making.

We used an iterative process as formative work to develop attributes for stated-preference instrument development.

Patients with chronic obstructive pulmonary disease key attributes of value-based decision making are physical endurance, treatment side effects, care access, and cost.

Language Refinement

PAVE PATIENT-DRIVEN VALUES in HEALTHCARE EVALUATION
engagement ★ education ★ research ★ dissemination

Example of Language Refinement to Identify Statements for the Patient Preference Instrument

Attribute	Explanation of the Attribute to the Patient Experience	Attribute Statement
New Therapeutic Option	Does the treatment replace another one in the regimen?	Reduce/increase the # of meds in regimen
Physical Abilities - Endurance	Does the treatment affect my endurance?	Distance one can walk; walking up stairs;
Physical Abilities - Symptom Control	Does the treatment control symptoms so that I can function in daily activities?	Shortness of breath; staying employed; go to work; fatigue
Side Effects	How will I deal with side effects if they occur?	Change or add medication

How do the important elements relate to the specific condition?

Preference Measurement Tool

PAVE PATIENT-DRIVEN VALUES in HEALTHCARE EVALUATION
engagement ★ education ★ research ★ dissemination

- Quantify:
  - Relative importance of treatment attributes
  - Trade-offs between benefits/risks & costs
  - Preferences across population segments

If these were the ONLY options to treat your COPD, which ONE is most acceptable to you? Click below on the option you like the most.

	Option A	Option B	Option C
	You manage side effects by adding another medicine	You manage side effects by lowering the medicine dose	You manage side effects by making no changes to your medicines
	You pay out-of-pocket $90 per month	You pay out-of-pocket $30 per month	You pay out-of-pocket $120 per month
	Your doctor replies within 48 hours	Your doctor replies within 24 hours	Your doctor replies within 72 hours
	The medicine is taken 1 time per day	The medicine is taken 3 times per day	The medicine is taken 2 times per day
	You learn about treatment options from a patient support group	You learn about treatment options from your provider or pharmacist	You learn about treatment options from the media
	Your CAT symptom score improves by 4 points	Your CAT symptom score improves by 2 points	Your CAT symptom score improves by 6 points
Your choice	○	○	○

If you could only choose 1 option for treating depression, which do you most prefer?

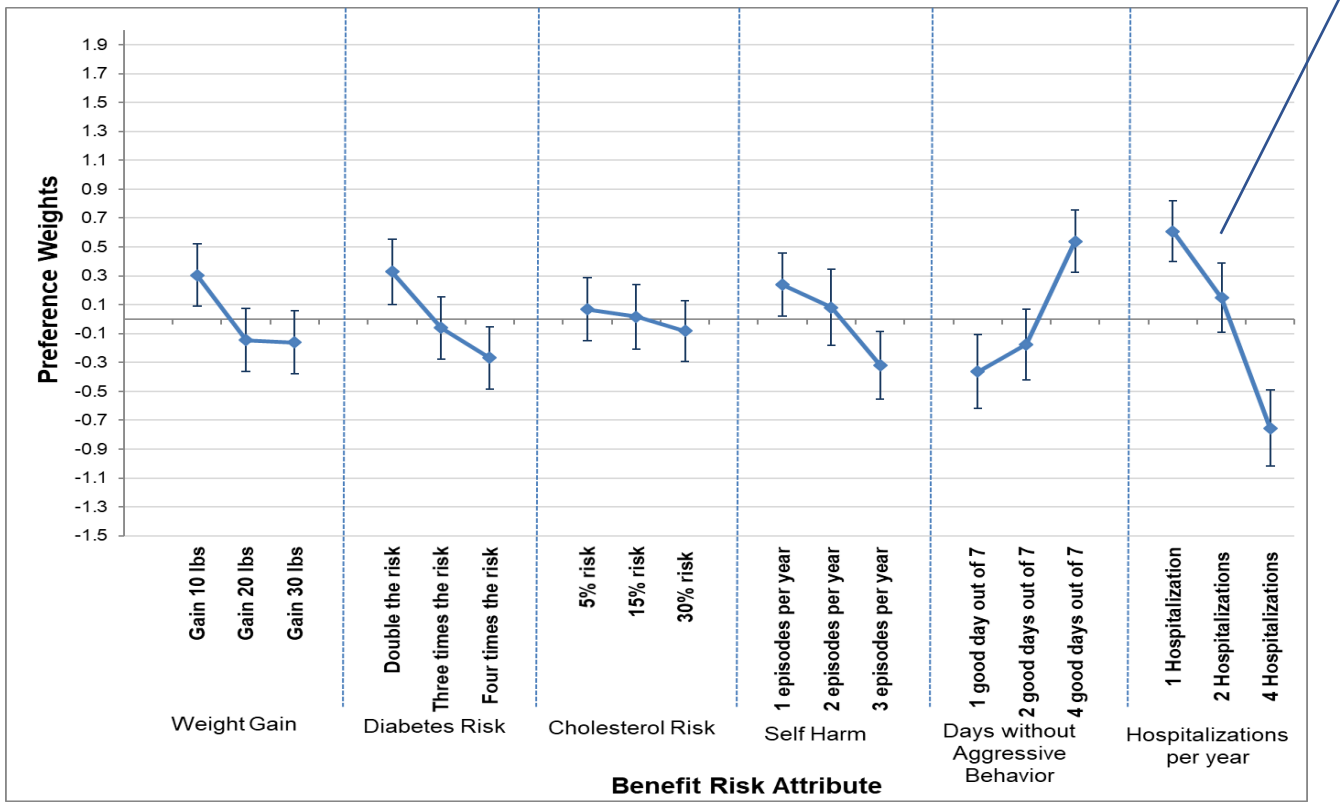
OPTION A
Treatment is Medicine & Psychotherapy
Feel some effects in 9 weeks
Hopeful 6 days/week
Productivity increases 40%
Better relations with people important to you
$270 monthly out-of-pocket costs ○

OPTION B
Treatment is Medicine, Psychotherapy, & Other Services
Feel some effects in 4 weeks
Hopeful 2 days/week
Productivity increases 90%
Strained relations with people important to you
$30 monthly out-of-pocket costs ○

OPTION C
Treatment is Medicine
Feel some effects in 6 weeks
Hopeful 4 days/week
Productivity increases 60%
Relations with people important to you stay the same
$90 monthly out-of-pocket costs ○

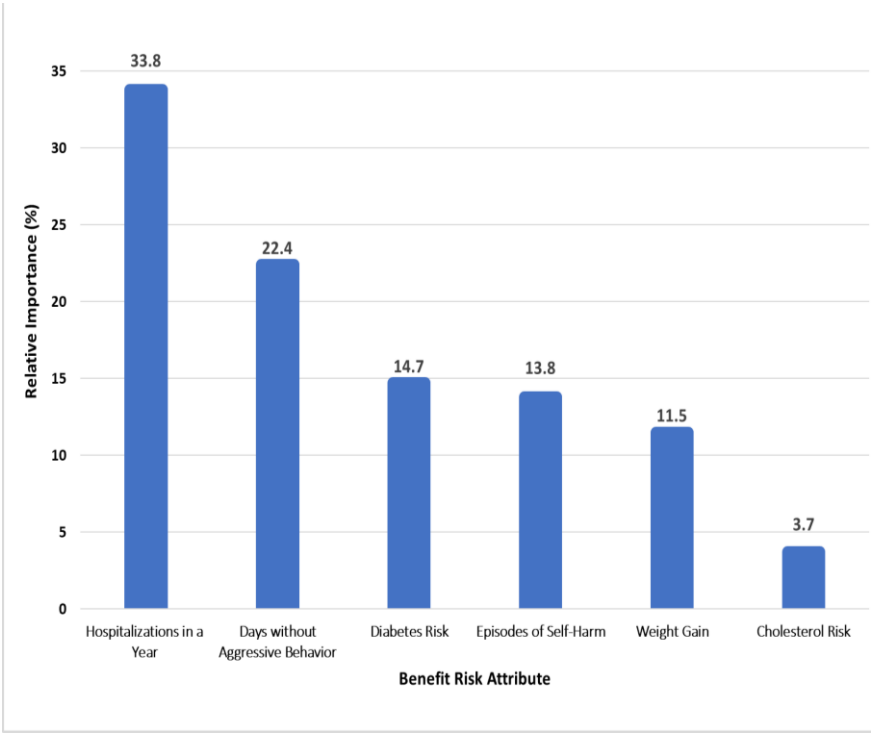
Quantify Preferences for HTA

PAVE PATIENT-DRIVEN VALUES in HEALTHCARE EVALUATION
engagement ★ education ★ research ★ dissemination



A large change in preference weights across levels indicates that people are sensitive to the level change

>change the > importance of the attribute

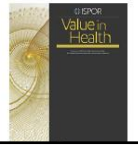


Quantify Preferences for HTA

PAVE PATIENT-DRIVEN VALUES in HEALTHCARE EVALUATION
engagement ★ education ★ research ★ dissemination

Notions of "Value" in Healthcare

Future of Patients in Healthcare Evaluation: The Patient-Informed Reference Case



Julia F. Slejko, PhD,[1,*] T. Joseph Mattingly II, PharmD, MBA,[2] C. Daniel Mullins, PhD,[1] Eleanor M. Perfetto, PhD, MS,[1,3] Susan dosReis, PhD[1]

[1]Department of Pharmaceutical Health Services Research, University of Maryland School o
Science, University of Maryland School of Pharmacy, Baltimore, MD, USA; [3]National Heal

ABSTRACT

The "Reference Case" was developed to facilitate comparabili
contribute to decisions about the broad allocation of healthcare
for Reference Case analyses, empirical estimations rarely ade
healthcare system or payer perspectives are used. In this comr
the past 20 years and how it now needs to further evolve. This
realignment of the societal perspective to better include patier
Engaging patients to both derive patient-informed value elen
methods will lead to patient inclusion in the societal perspect

Keywords: patient perspective, Reference Case, societal perspe

VALUE HEALTH. 2019; 22(5):545–548

Quantify and Translate Patient Preferences to Economic Evaluation

Implementing the Patient-Informed Reference Case

Patient-Informed Elements Existing in the Societal Perspective	Novel, Patient-Informed Value Elements
• Patient costs • Costs and impacts of side effects	• Medication frequency • Preferences for provider interaction
Valuation of Health States	**Patient Engagement in VA**
• Physical abilities adequately captured? • Preference heterogeneity	• How to operationalize side effects? • Does the model reflect reality?

Thank You

PAVE PATIENT-DRIVEN VALUES in HEALTHCARE EVALUATION

engagement ★ education ★ research ★ dissemination

Contact Information

- Susan dosReis  sdosreis@rx.umaryland.edu
- Julia Slejko  jslejko@rx.umaryland.edu
- Alejandro Rosario  aamill-rosario@rx.umaryland.edu

Questions?

A Blueprint to Advance Patient-Centered Core Impact Sets (PC-CIS)

Eleanor M. Perfetto, Elisabeth Oehrlein, T. Rose Love, Silke C. Schoch, Jennifer Bright, Annie Kennedy, and Suz Schrandt

National Health Council

Background…

Goal: Accountability for all stakeholders to make care affordable and high value to patients

But, what is “high value” to patients?

Background… cont.

- Current environment:
  - Haphazard approach at targeting what to measure for which diseases
  - Numerous measures and endpoints used to study and monitor health
  - Often misaligned with what patients report matters to them
  - Are they capturing high value?

Key question: To capture what is *really* “high value” to patients, what *should* be measured and monitored?

Background… cont.

Problem: Misalignment between

- what patients (& care partners & families) say is important and data collected
- existing data and data needs

Result:

- patient views often not considered
- right data not collected
- data gaps identified but not filled

Proposed Solution

Patient-Centered Core Outcome Sets (PC-CIS):

- A patient-prioritized list of the impacts a disease and/or its treatments have on patients, carers, and families.
- Serves as a guide for a multitude of downstream uses

Project Overview

Objective:

Lead a multi-stakeholder effort to create a **blueprint and toolkit** the patient community and others can use to develop a PC-CIS for a specific disease, related diseases, or population(s).

Vision

Create a smooth pathway for PC-CIS development by patient groups and their partners (e.g., patient-group consortia, medical-product companies, government entities, others) so the patient voice can be enhanced throughout a number of uses. e.g.,

- Clinical Trails
- Real-World Studies
- Regulatory Decisions
- Outcomes Research
- Value Assessment & Economic Modeling
- Clinical-Decision Support, practice guidelines
- Quality-measure development, studies
- Etc.

A Framework for Developing Disease-Specific Patient-Centered Core Impact Sets (PC-CIS)

Pool of Potentially Important Impacts

Examples of the wide range of things patients might report as important about the impact a disease or treatment has on their life.

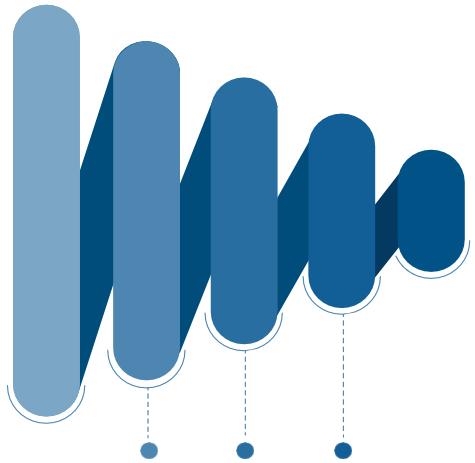
Examples of health impacts of a disease/condition/treatment

- **Symptoms** (things only patients can feel/know, includes stress/ burden)
- **Death/ mortality**
- **Treatment-related adverse events**
- **Signs** (observed by others or the patient, e.g., tremors, clinical tests, seizures)

Examples of other meaningful impacts

- **Financial**
- **Career/ personal goals**
- **Carer and family stress/ burden**
- **Other**

Important Considerations: Equity, Representativeness, SDOH, Health literacy & numeracy, Culture, Religion, Baseline characteristics, etc.



Patient/Carer/ Family Engagement
to get to the most important impacts

Most Important Impacts
reported by patients/carers/ families

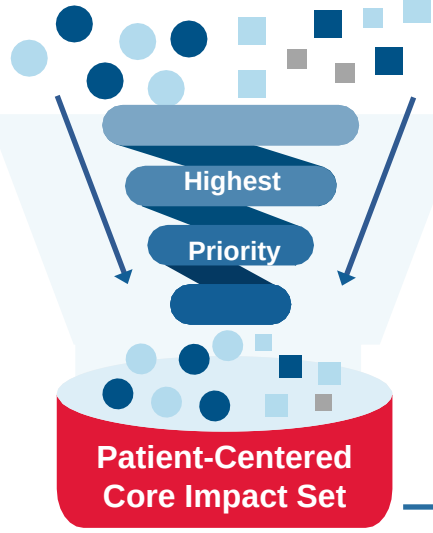
Stakeholder Engagement
Impacts that matters to other stakeholders

Environmental Scan
Impacts, outcomes, measures and endpoints studied or need to be studied

Prioritization Process

✓ Structured ✓ Transparent ✓ Multi-stakeholder

Pool of Important Impacts from all Stakeholders



Align Possible Uses

+ Clinical Trials
+ RWE/RWD Studies
+ Product Development
+ Audit
+ Quality Measurement
+ Value Assessment
+ Value-Based Arrangements
+ Clinical Decision Support
+ Regulatory Decisions

PC-CIS Blueprint Development Plan and Timeline

- Multi-Stakeholder Advisory Committee
- Environmental scan:
  - Do PC-CIS already exist?
  - What resources exist to support PC-CIS development?
- Foundational Principles
- Draft blueprint outline
- Four workgroups

Background	Methods
Resources	Pilots and Use Cases

Draft Principles Sample

- The process must begin by engaging patients, carers, and families to identify what is important to them (they should be engaged at the earliest planning/buy-in stage).
- The process must gather all impacts, not just health-specific impacts
- Patients and patient groups must be in leadership and governance positions
- Diversity and equity must be considered in all stages of PC-CIS development and leadership (diversity in experiences, backgrounds, disease expression, gender, sexual orientation, race, socioeconomic status, age, etc.).
- There should be consistent communication with patients and patient groups involved in the work at every stage.
- Those impacts important to patients must be considered primary, before those of other stakeholders (including researchers and clinicians), but not in place of.
- Patient views should not be able to be "out-voted" or "over-powered" in the process.
- There should be a patient-friendly PC-CIS results report presented in a health literate manner.
- PC-CIS are living documents that will evolve as new or different applications or information develop (i.e., new methods, new data, previously untapped patient communities)

Early Environmental Scan Findings

- PC-CIS, as we have defined it, do not currently exist
- However, a multitude of resources exist that can be leveraged for:
  - Developing the Blueprint
  - Creating a taxonomy of “impacts”
  - Supporting Blueprint implementation and uptake of disease-specific PC-CIS by researchers

Plans for 2022 and beyond

- Draft Blueprint ready for Spring 2022
- Pilot testing begins Spring 2022
- Public comment period and possible conference Summer 2022
- Final Blueprint document with resources by Fall 2022
- Dissemination
  - Continue to socialize and gain support
  - Encourage use and uptake
- Future: Infrastructure, methods development, maintenance, etc.

Uses: Patient-Centered Value Assessment

- “Lack of data on the impacts patients care about”
- Two elements needed:
  - Impacts important to patients (& carers and families)
  - Data that captures those impacts
- PC-CIS can provide value assessors guidance on the patient-centered impacts that need to be considered and - over time - the data needed.

Uses: Use and Analyses of Real-World Evidence (RWE)

- Ongoing rheumatoid arthritis pilot by the Learning Ecosystem Accelerator for Patient-centered, Sustainable innovation (LEAPS)
- Challenge: lack of consistent patient-important impacts embedded in upstream data-collection efforts
- Had to develop and use proxy measures for how patients feel and/or function
- PC-CIS could help address this gap in RWD, and spill over into other uses

A Blueprint to Develop a PC-CIS Will:

Establish a consensus-based approach for how patient-centered impacts are collected, measured, and prioritized for a disease/population

Potentially, improve understanding of data that should be collected across *all* diseases or groups of diseases

Increase support and assistance to healthcare stakeholders in identifying impacts beyond clinical outcomes that should be collected and considered based on a patient-centered approach

Acknowledgements

Authors:

Funders:

Thank you!

Eleanor Perfetto: eperfetto@nhcouncil.org

Alejandro Rosario: aamill-rosario@rx.umaryland.edu

Questions?

Leveraging Community Benefit to Increase the Value of Health Care

Michael Rozier, PhD & Kimberly Enard, PhD

Department of Health Management and Policy, Saint Louis University

What is Community Benefit?

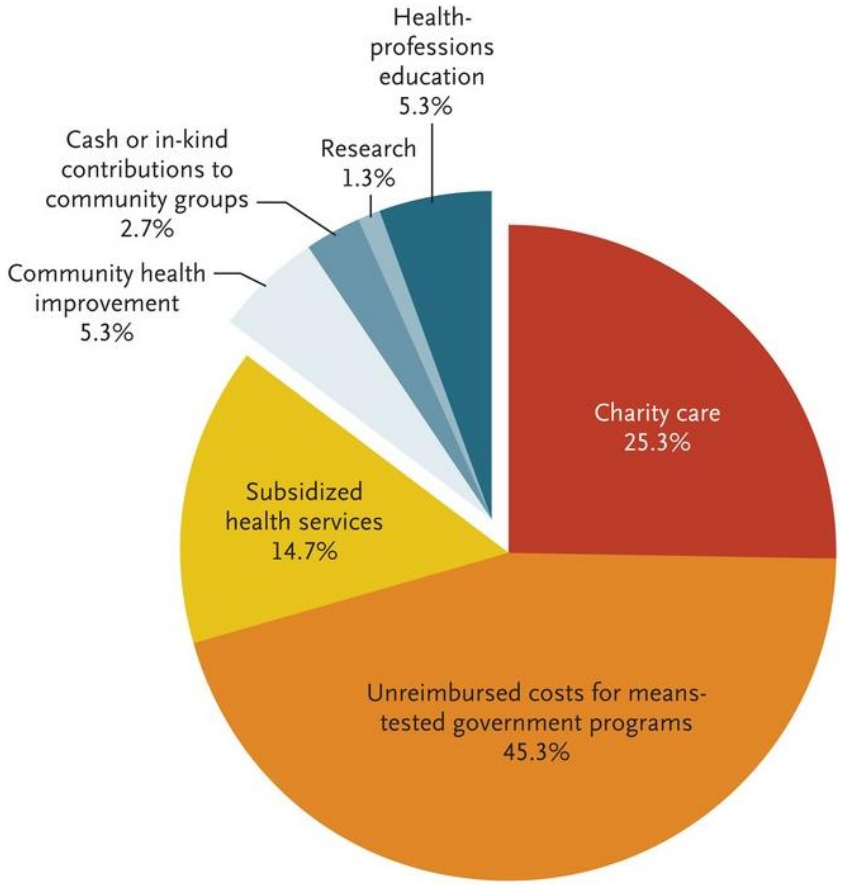
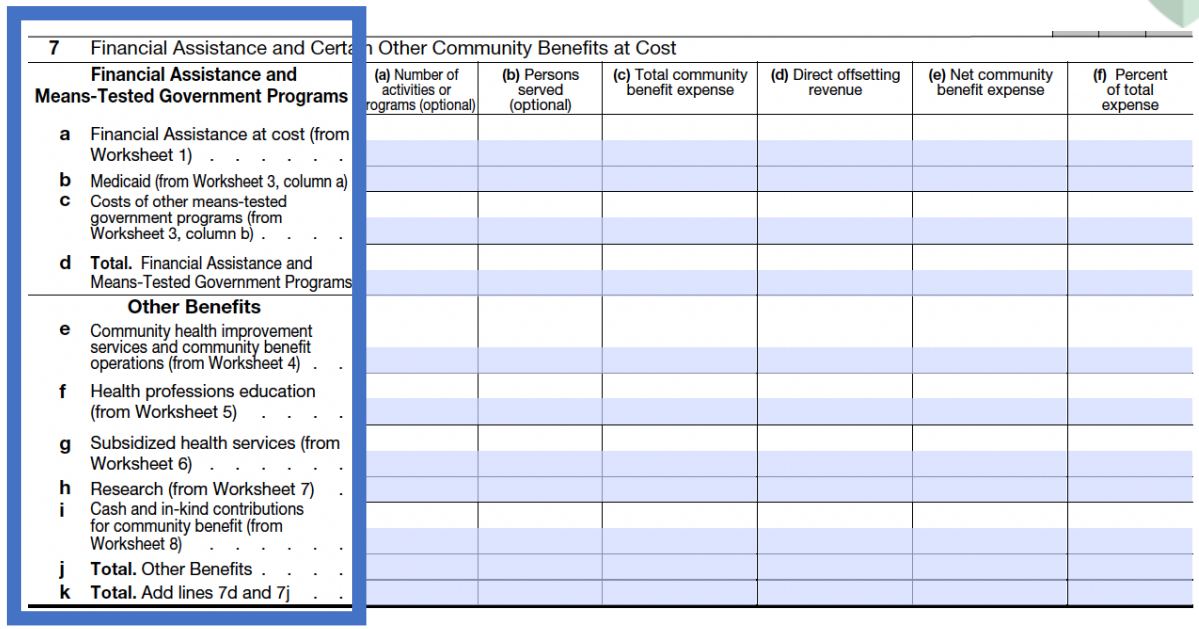


Image from Young, et al (2013)
Available: https://www.nejm.org/doi/full/10.1056/nejmsa1210239

- A primary justification for tax exemption
  - $64 billion spent per year
- The majority of spending is related to clinical care
  - Typically around 84%
- Very high variance across hospitals / health systems
  - On average, 8% of operating expenses
- Distribution did not change after Affordable Care Act
  - Spending on uninsured shifted to uncompensated costs of Medicaid patients

Annual Reporting

Most public advocacy focused on Community Benefits as a percentage of operating expenses



7 Financial Assistance and Certa	n Other Community Benefits at Cost					
Financial Assistance and Means-Tested Government Programs	(a) Number of activities or rograms (optional)	(b) Persons served (optional)	(c) Total community benefit expense	(d) Direct offsetting revenue	(e) Net community benefit expense	(f) Percent of total expense
a Financial Assistance at cost (from Worksheet 1)						
b Medicaid (from Worksheet 3, column a)						
c Costs of other means-tested government programs (from Worksheet 3, column b)						
d **Total.** Financial Assistance and Means-Tested Government Programs						
Other Benefits						
e Community health improvement services and community benefit operations (from Worksheet 4)						
f Health professions education (from Worksheet 5)						
g Subsidized health services (from Worksheet 6)						
h Research (from Worksheet 7)						
i Cash and in-kind contributions for community benefit (from Worksheet 8)						
j **Total.** Other Benefits						
k **Total.** Add lines 7d and 7j						

Part II **Community Building Activities** Complete this table if the organization conducted any community building activities during the tax year, and describe in Part VI how its community building activities promoted the health of the communities it serves.

	(a) Number of activities or programs (optional)	(b) Persons served (optional)	(c) Total community building expense	(d) Direct offsetting revenue	(e) Net community building expense	(f) Percent of total expense
Physical improvements and housing						
Economic development						
Community support						
Environmental improvements						
Leadership development and training for community members						
Coalition building						
Community health improvement advocac						
Workforce development						
9 Other						
10 **Total**						

Other activities can be reported, but organizations see little benefit in reputation in doing so

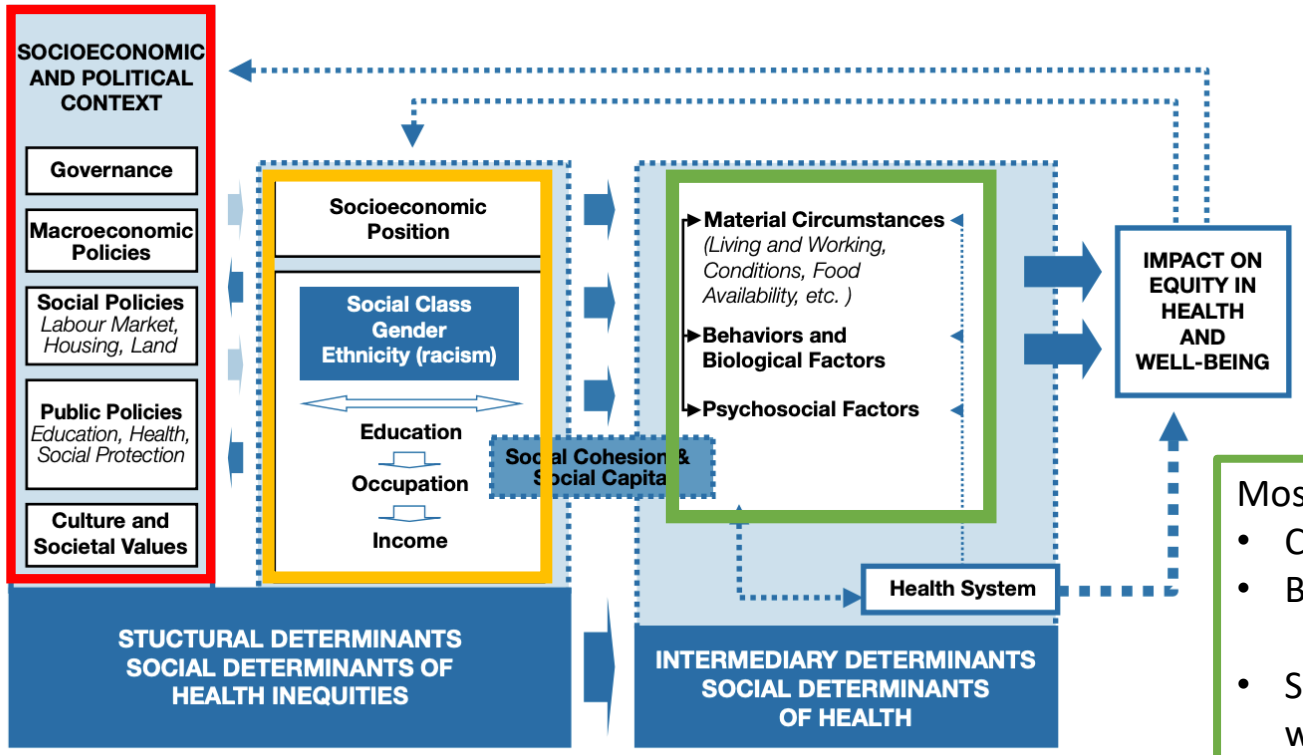
https://www.hcvalueassessment.org

Social Location of Community Benefit

Occasional CB activities
- Supporting early childhood education
- Using anchor institution status to increase prevailing wages and increase local purchasing

Rare CB activities
- Advocacy on public policy other than health care delivery
- Helping increase democratic engagement

Figure A. Final form of the CSDH conceptual framework



Most common CB activities, such as
- Community gardens and kitchens
- Bike safety programs

- Supporting community coalitions working on similar issues

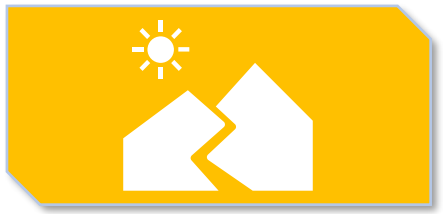
Figure available at:
https://www.who.int/sdhconference/resources/ConceptualframeworkforactiononSDH_eng.pdf

Priorities and Value with Community Benefit

Benefit Location

In a fee-for-service environment

- If it prevents care altogether, provider may not realize value
- It if makes care more effective, provider may realize some value



Time Horizon

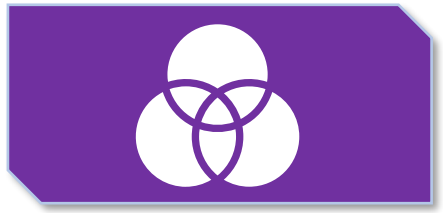
Many outcomes are not measurable in the short-term even though that is what is incentivized

We must still find a way to evaluate effectiveness (process measures, output measures)

Efficiency v Equity

Equity and efficiency can sometimes be in conflict with one another

The search for the highest ROI will devalue efforts that may be essential for advancing equity for vulnerable populations



Community Nuance

Community programs have similar questions as those essential to determining clinical nuance

- Who receives the intervention?
- Who delivers the intervention?
- What is the context where the intervention takes place?

Recommendations

01 Encourage or require evaluation of more community-based programs

02 Explicitly state that community-building programs count as CB expenditures

03 Identify ways to align incentives of providers with prevention of care, especially for unattributed individuals

Questions?

RESEARCH CONSORTIUM
for Health Care Value Assessment

VBIDHEALTH

ALTARUM