



# Reducing Disparities in Palliative and End of Life Cancer Care Delivery – The Effect of Community and Academic Partnerships

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# Decades of Descriptions of Disparities

## Racial and Ethnic Disparity in Palliative Care and Hospice Use

### **Evaluation of Racial Disparities in Hospice Use and End-of-Life Treatment Intensity in the REGARDS Cohort**

Racially Associated Disparities in Hospice and Palliative Care Access:  
Acknowledging the Facts While Addressing the Opportunities to Improve

### **Racial and Ethnic Disparities in Palliative Care**

Drivers of racial/ethnic differences in perceived end-of-life care quality: More questions than answers

Racial and ethnic disparities in palliative care utilization among gynecological cancer patients

Racial and Ethnic Disparities in Palliative Care: A Systematic Scoping Review

COMMENTARY | [VOLUME 34, 100833, APRIL 01, 2021](#)

Denied the right to comfort: Racial inequities in palliative care provision

## Disparities in Palliative Care

### **Examining Regional Differences in Nursing Home Palliative Care for Black and Hispanic Residents**

Does ethnicity affect pain management for people with advanced disease? A mixed methods cross-national systematic review of 'very high' Human Development Index English-speaking countries

# Far, Far Fewer Interventions

**Effect of *Apoyo con Cariño* (Support With Caring) Trial of a Patient Navigator Intervention to Improve Palliative Care Outcomes for Latino Adults With Advanced Cancer**  
A Randomized Clinical Trial

**A randomized trial of a multi-level intervention to improve advance care planning and symptom management among low-income and minority employees diagnosed with cancer in outpatient community settings**

Manali I. Patel, MD MPH MS<sup>1,2,3</sup>, Sana Khateeb, MPH<sup>1</sup>, Tumaini Coker, MD MPH MBA<sup>4,5</sup>

[THE BLOG](#) [HEALTHY LIVING](#) [HOSPICE](#) [END OF LIFE CARE](#)

## **Project HOPE: Overcoming Demographic Barriers to Hospice Care**

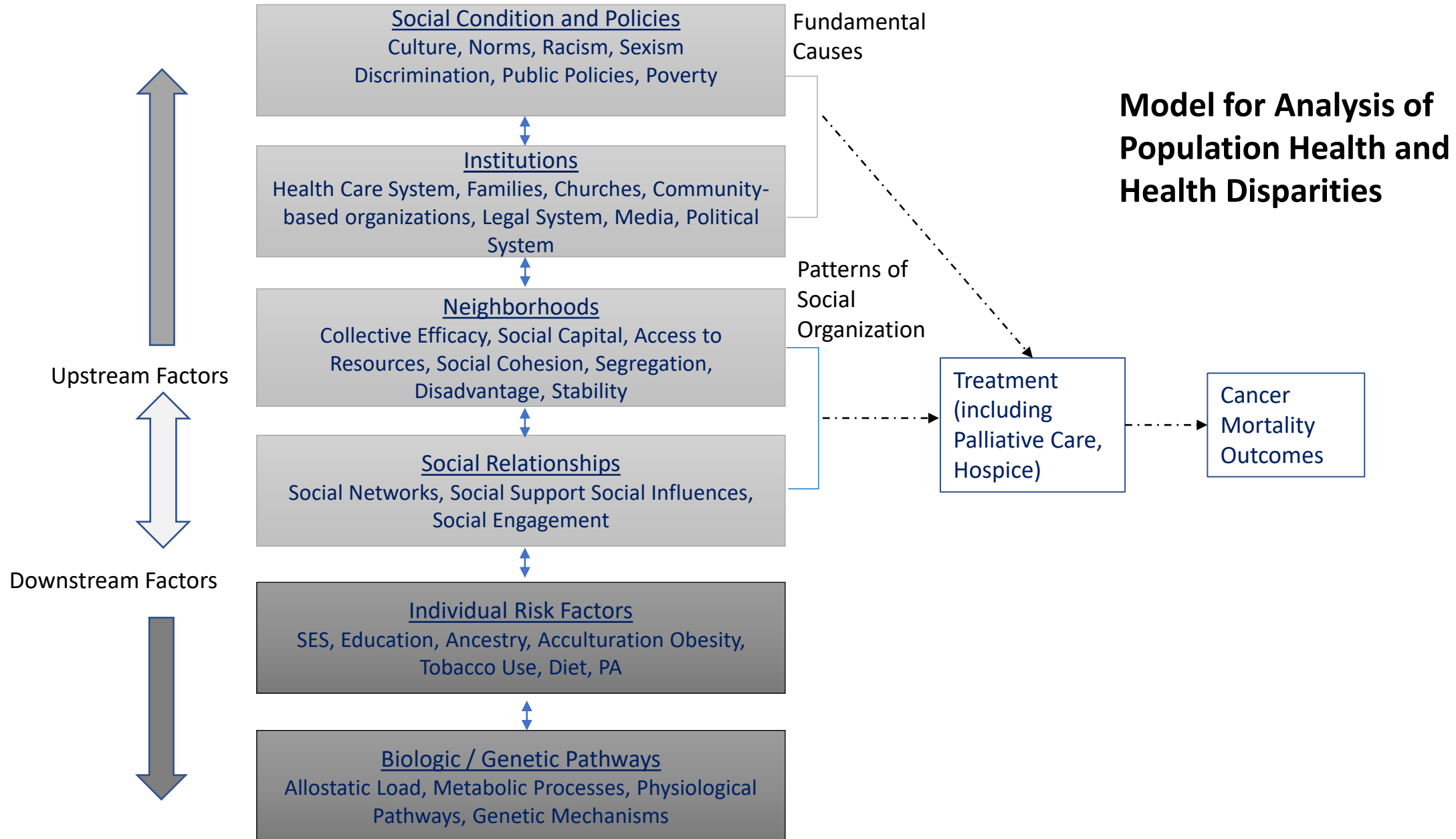
**Gundersen Health System Leads the Way in Documenting Patients' End-of-Life Wishes**

Project Equity: Improving Health Equity for People with Serious Illness

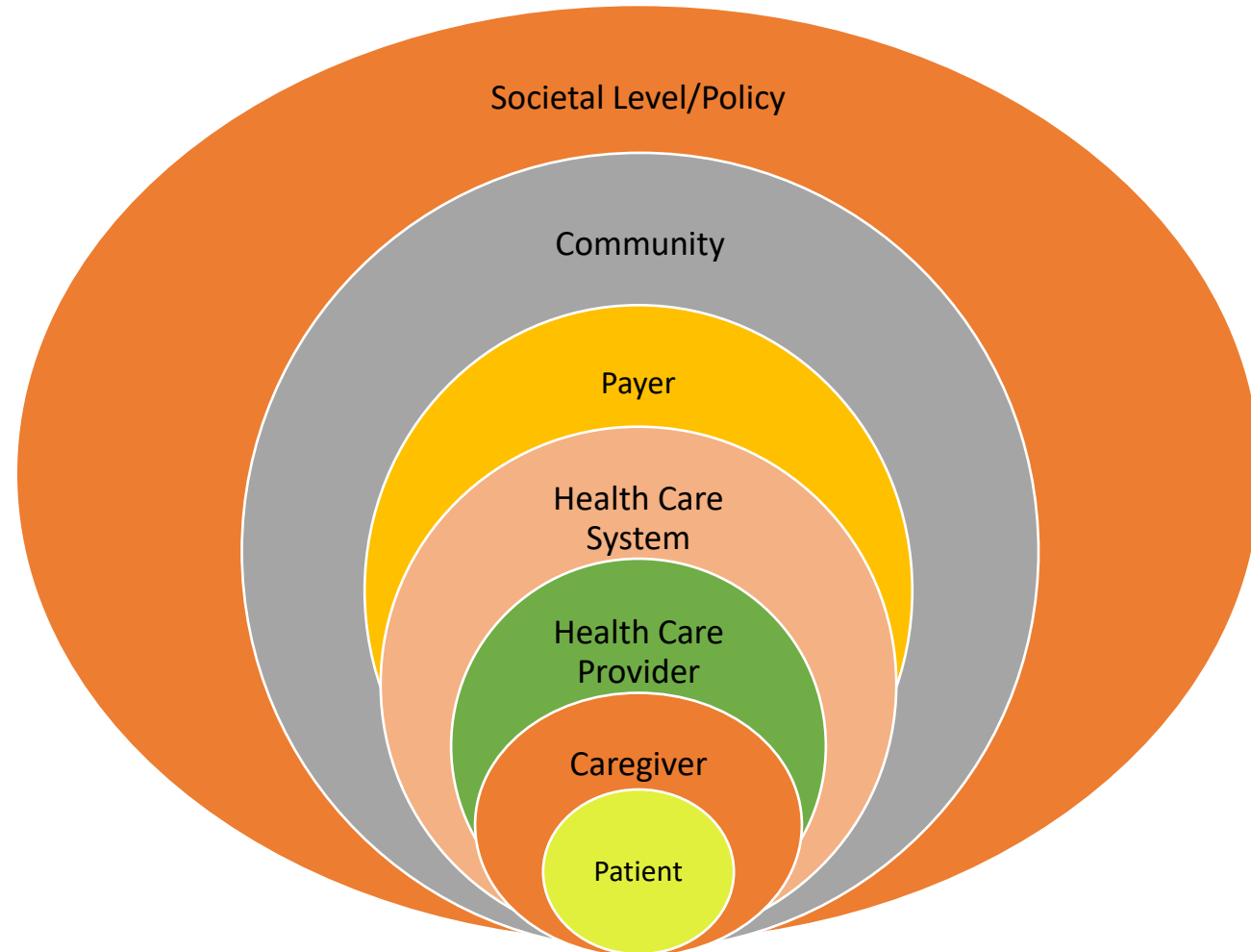
Improving Health Equity for People with Serious Illness



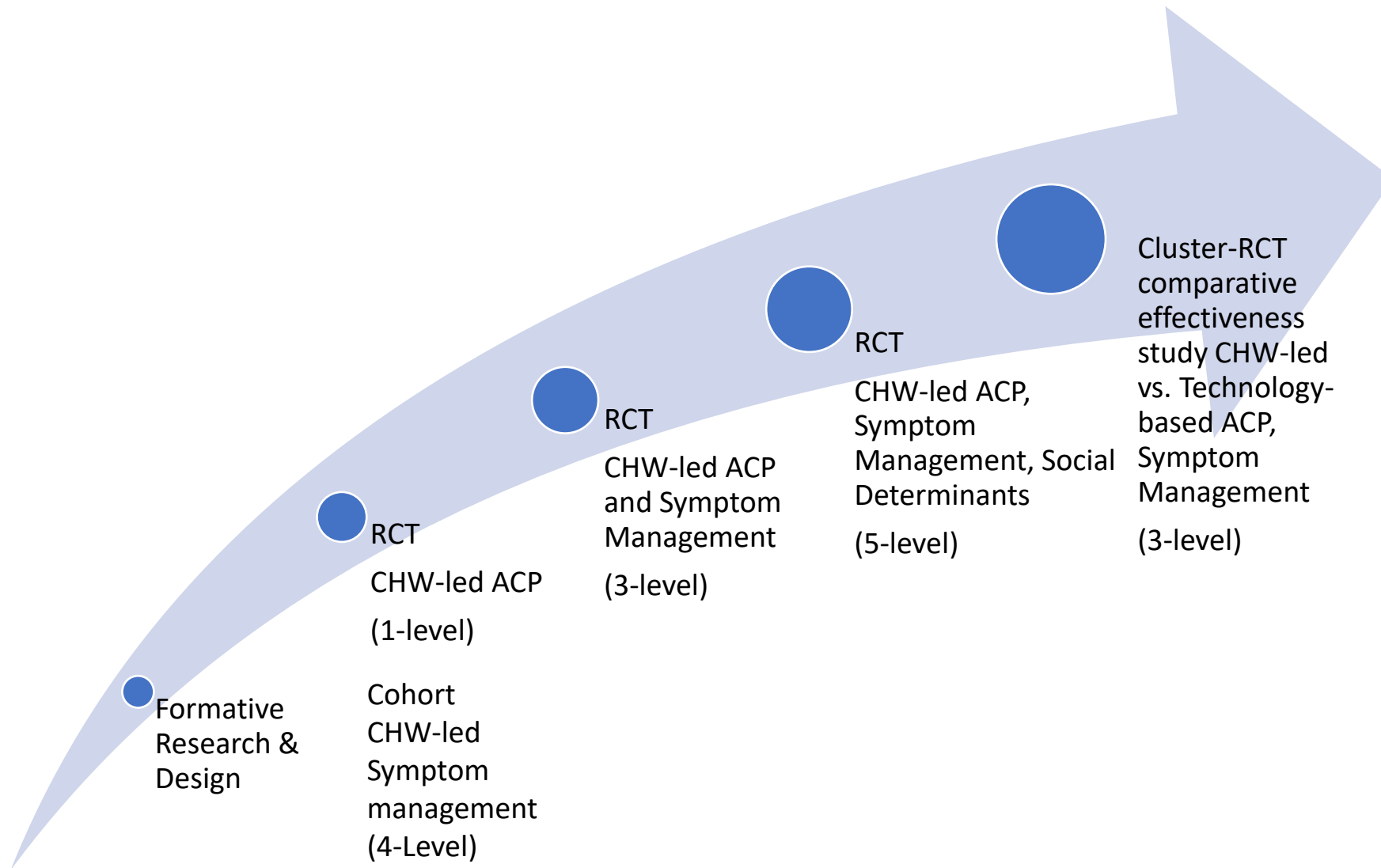
# To Achieve Health Equity, We Need a Paradigm Shift



# Health Equity is a Multi-level Choice



# Progression of Multilevel Stakeholder-Engaged Research



# Formative Research

Original Contribution | CARE DELIVERY

## Redesigning Cancer Care Delivery: Views From Patients and Caregivers

*Manali I. Patel, Vyjeyanthi S. Periyakoil, Douglas W. Blayney, David Moore, Andrea Nevedal, Steven Asch, Arnold Milstein, and Tumaini R. Coker*

Original Article

## Delivering End-of-Life Cancer Care: Perspectives of Providers

American Journal of Hospice  
& Palliative Medicine®  
2018, Vol. 35(3) 497-504  
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DOI: 10.1177/1049909117719879  
journals.sagepub.com/home/ajh



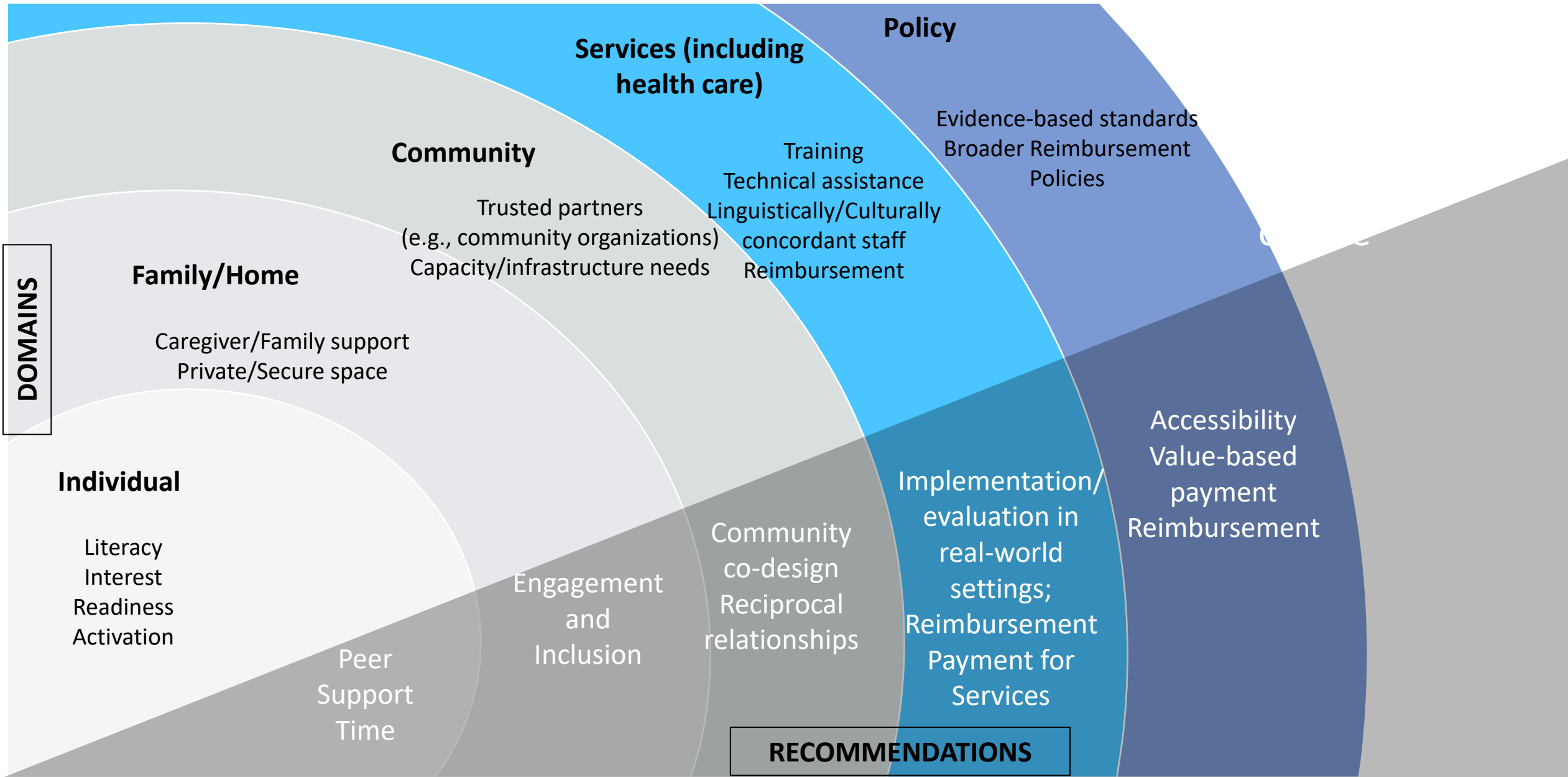
**Manali I. Patel, MD, MPH, MS<sup>1,2</sup>, Vyjeyanthi S. Periyakoil, MD<sup>2</sup>,  
David Moore, PhD<sup>3</sup>, Andrea Nevedal, PhD<sup>2</sup>, and Tumaini R. Coker, MD, MPH<sup>4</sup>**

CARE DELIVERY

original contr

## Perspectives of Health Care Payer Organizations on Cancer Care Delivery Redesign: A National Study

**Manali I. Patel, MD<sup>1,2</sup>; David Moore, PhD<sup>1</sup>; Jay Bhattacharya, MD, PhD<sup>1</sup>; Arnold Milstein, MD<sup>1</sup>; and Tumaini R. Coker, MD<sup>3</sup>**





# Intervention Design



## Well-trained Community Health Worker

- Educates and Engages Patients and Caregivers
- Goals of care, Advance Directives, Palliative Care



## Proactive Symptom Assessment

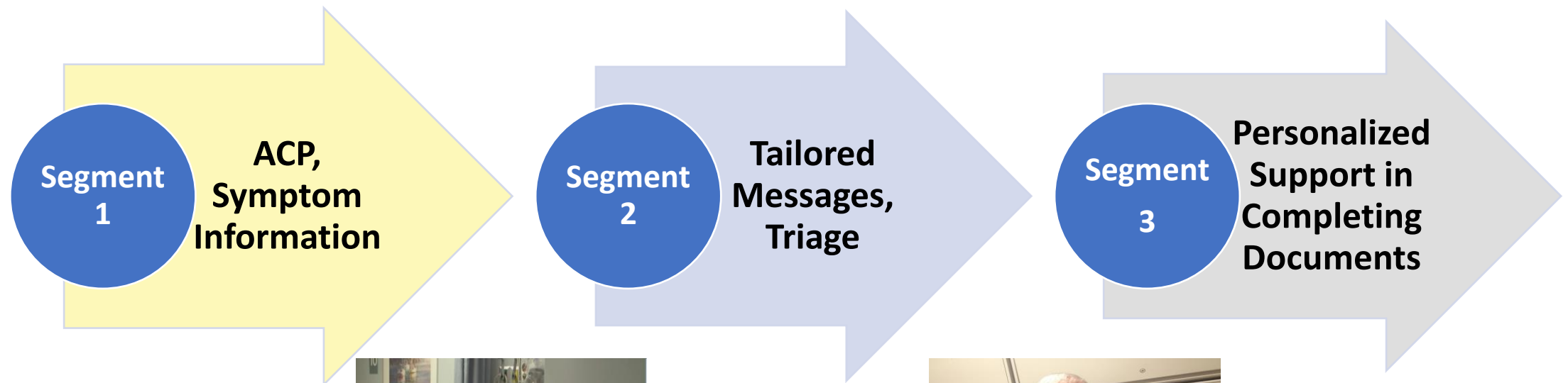
- Symptom Algorithms
- Medication Bundles



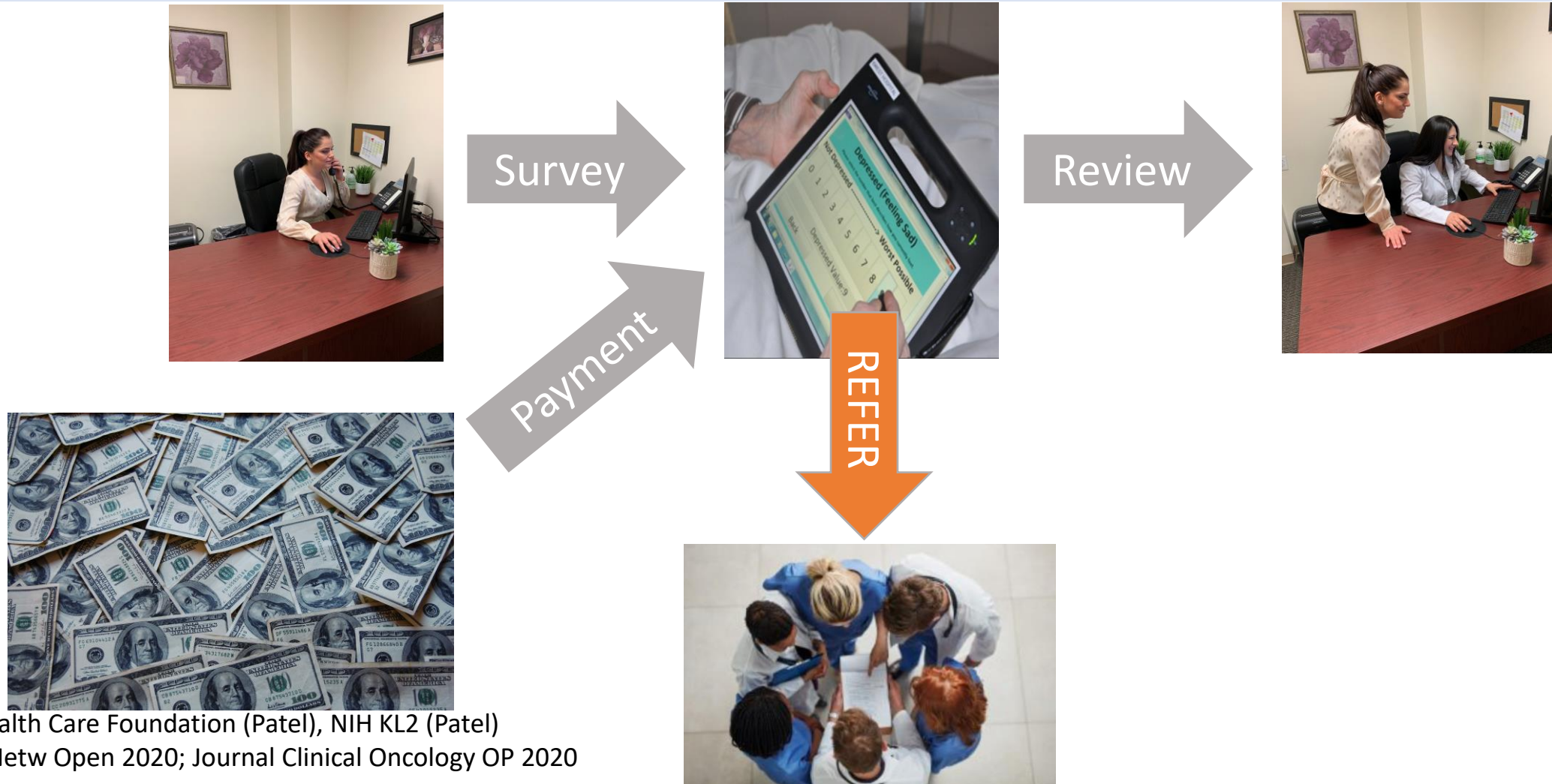
## Home and Community-based Care

- Delivery of treatments and visits in home
- Leverage telemedicine

# Community Health Worker-Led Advance Care Planning



# Community Health Worker-Led Symptom Management



## Original Investigation

October 2018

# Effect of a Lay Health Worker Intervention on Goals-of-Care Documentation and on Health Care Use, Costs, and Satisfaction Among Patients With Cancer A Randomized Clinical Trial

Manali I. Patel, MD, MPH, MS<sup>1,2,3,4</sup>; Vandana Sundaram, MPH<sup>5</sup>; Manisha Desai, PhD<sup>5</sup>; [et al](#)

[Author Affiliations](#) | [Article Information](#)

*JAMA Oncol.* 2018;4(10):1359-1366. doi:10.1001/jamaoncol.2018.2446

JAMA Network | **Open**

Original Investigation | Health Policy

## Association of a Lay Health Worker Intervention With Symptom Burden, Survival, Health Care Use, and Total Costs Among Medicare Enrollees With Cancer

Manali I. Patel, MD, MPH, MS; David Ramirez, MD; Richy Agajanian, MD; Hilda Agajanian, BA; Tumaini Coker, MD, MPH, MBA

EQUITY IN CANCER CARE ReCAP

# Association of a Lay Health Worker–Led Intervention on Goals of Care, Quality of Life, and Clinical Trial Participation Among Low-Income and Minority Adults With Cancer

Manali I. Patel, MD, MPH, MS<sup>1,2,3</sup>; Sana Khateeb, MPH<sup>1</sup>; and Tumaini Coker, MD, MBA<sup>4,5</sup>

original contribution

CARE DELIVERY

## Lay Health Worker-Led Cancer Symptom Screening Intervention and the Effect on Patient-Reported Satisfaction, Health Status Health Care Use, and Total Costs: Results From a Tri-Part Collaboration

Manali I. Patel, MD, MPH, MS<sup>1,2</sup>; David Ramirez, MD<sup>3</sup>; Richy Agajanian, MD<sup>4</sup>; Hilda Agajanian<sup>4</sup>; Jay Bhattacharya, MD, PhD<sup>1</sup>; and Kate M. Bundorf, PhD<sup>1</sup>

## Original Investigation

June 30, 2022

# Effect of a Community Health Worker Intervention on Acute Care Use, Advance Care Planning, and Patient-Reported Outcomes Among Adults With Advanced Stages of Cancer A Randomized Clinical Trial

Manali I. Patel, MD, MPH, MS<sup>1,2,3</sup>; Kristopher Kapphahn, MS<sup>4</sup>; Marilyn Dewland, RN<sup>5</sup>; [et al](#)

[Author Affiliations](#)

*JAMA Oncol.* 2022;8(8):1139-1148. doi:10.1001/jamaoncol.2022.1997



## Lay Health Workers' Perspectives on Delivery of Advance Care Planning and Symptom Screening Among Adults With Cancer: A Qualitative Study

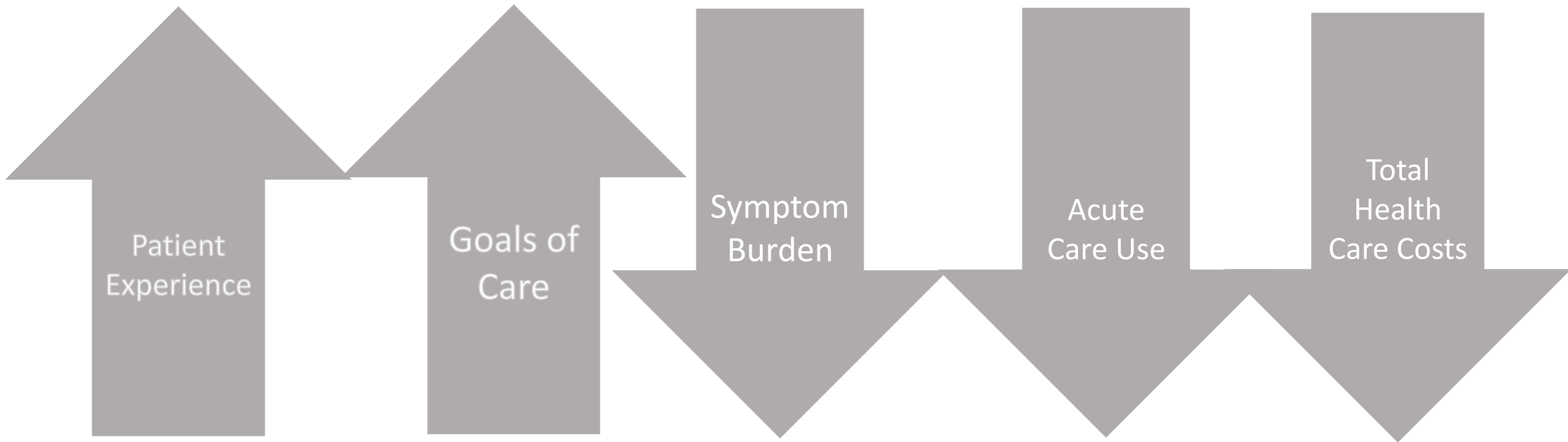
Manali I. Patel, MD, MPH, MS<sup>1,2,3</sup>, Sana Khateeb, MPH<sup>1</sup>, and Tumaini Coker, MD, MBA<sup>4,5</sup>



## End-of-Life Cancer Care Redesign: Patient and Caregiver Experiences in a Lay Health Worker–Led Intervention

Manali I. Patel, MD, MPH, MS<sup>1,2,3</sup>, David Moore, PhD<sup>4</sup>, and Tumaini R. Coker, MD, MBA<sup>5,6</sup>

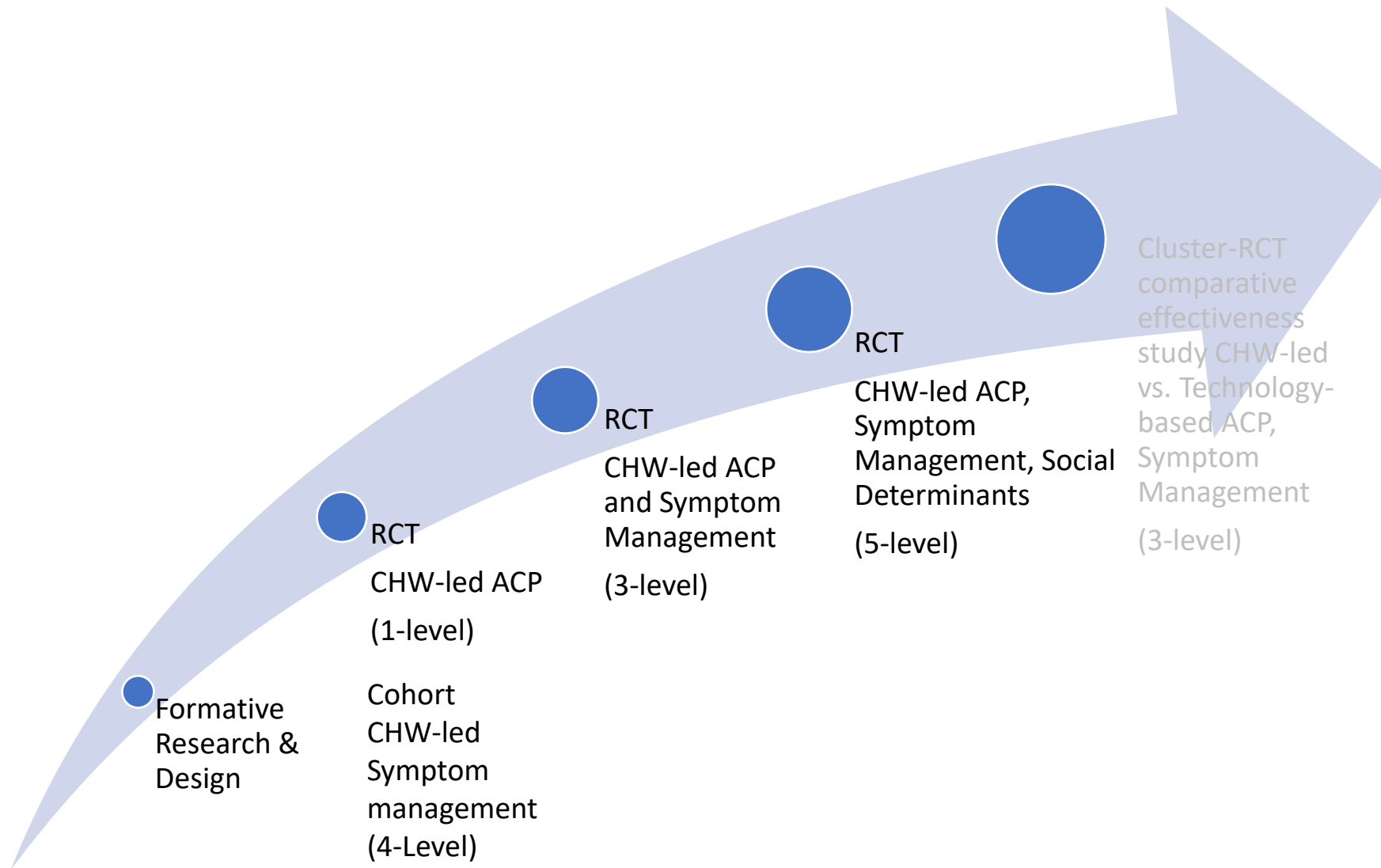
## Summary of Findings



Annual COST SAVINGS \$2.5 Million – \$3.34 Million



# Progression of Community-Based Research



# Community-Led Adaptation of Evidence-Based Interventions



## Free cancer care services

Starting **June 1, 2018**, you'll get **FREE** outstanding clinical care and supportive care services that help you heal — in mind, body, and spirit — at MD Anderson Cancer Center at Cooper.

Call **(609) 345-8212** to find out more and join the program.

Journal of Community Health (2019) 44:912–920  
<https://doi.org/10.1007/s10900-019-00632-x>

ORIGINAL PAPER

A Community-Partnered, Evidence-Based Approach to Improving Cancer Care Delivery for Low-Income and Minority Patients with Cancer

Manali Patel<sup>1,2,3</sup> • Nevedal Andrea<sup>2</sup> • Bhattacharya Jay<sup>3</sup> • Tumaini R. Coker<sup>4,5</sup>



UNITE HERE  
HEALTH

Atlantic City Casinos Plan 102



### Introduciendo el Programa de Cuidado del Cáncer

Un equipo de confianza para acompañarle a usted y a su familia

Ser diagnosticado con cáncer es difícil y aterrador. Pero gracias a su fondo de salud, usted no tiene que enfrentarlo solo(a). ¡Permítanos ayudarle!

#### Acerca de nuestro Programa de Cuidado del Cáncer

Nuestro Programa de Cuidado del Cáncer *gratuito* está diseñado para miembros que son diagnosticados con cáncer. Una vez hayamos evaluado sus necesidades, le buscaremos el equipo que más se adapte a usted, formado por asesores y enfermeras quienes le acompañarán a usted y a su familia en todo el proceso. Nos aseguramos de que *usted* entienda sus opciones y que *los médicos* sepan lo que usted quiere.

#### Asesores del paciente y cómo le ayudamos

Nosotros, sus asesores, entendemos la jornada que debe recorrer. Le servimos como guías compasivos y fuentes de información confiables. Le ayudaremos a asegurarle de que sus necesidades están siendo satisfechas:

- Hablando con sus proveedores de atención a la salud y ayudándole a obtener respuestas a sus preguntas;
- Averiguar más sobre los procedimientos y tratamientos;
- Orientándolo a los recursos y servicios de su comunidad;
- Apoyándole a comunicarse cuando hay barreras culturales o de idioma;
- Ayudándole a que pueda tomar la decisión que mejor le convenga;
- Dándole apoyo emocional.

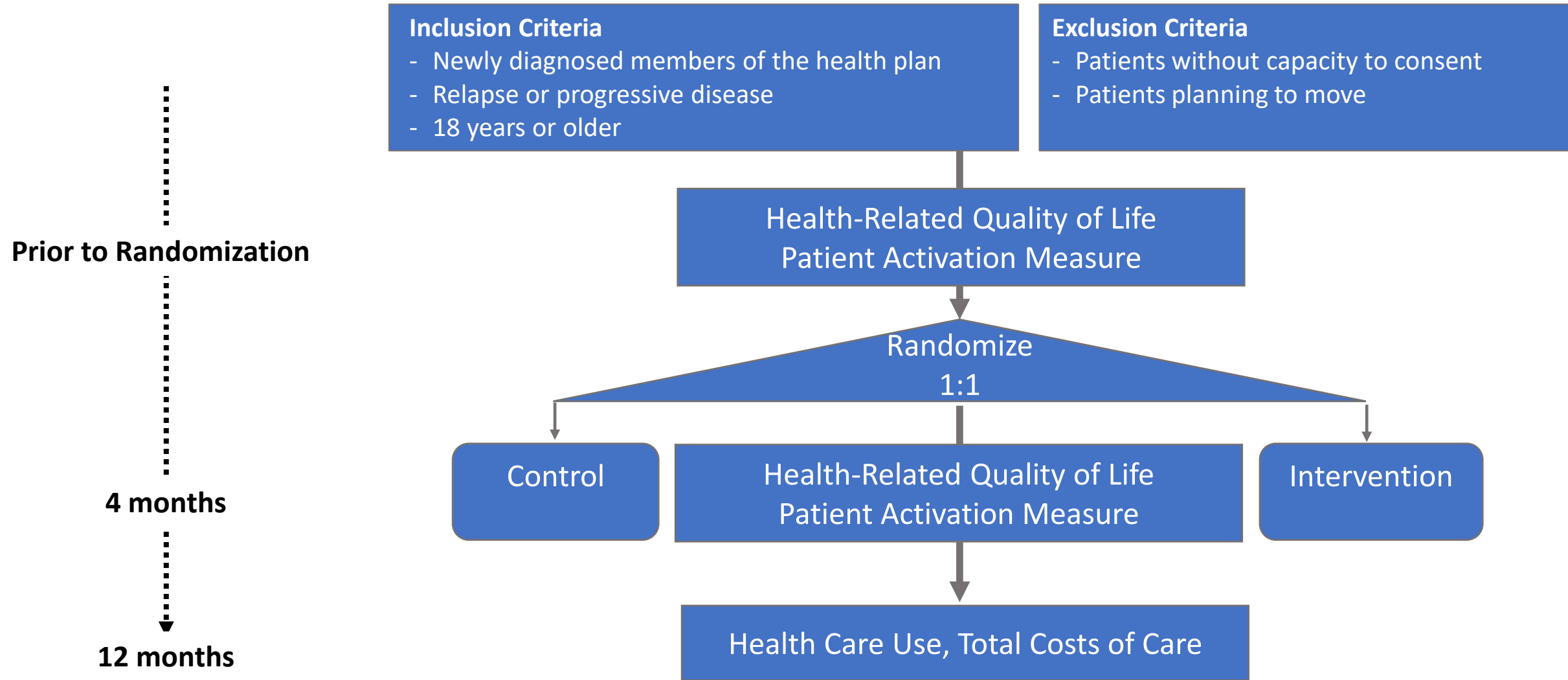
“Los asesores del paciente y enfermera de oncología fueron de ayuda incalculable durante la batalla contra el cáncer pancreático que sufría mi esposo. Sin ellos no habríamos podido navegar en el sistema. Se los voy a agradecer siempre.”

—Lo que dicen los miembros de familias

¡Comuníquese con nosotros para más información!

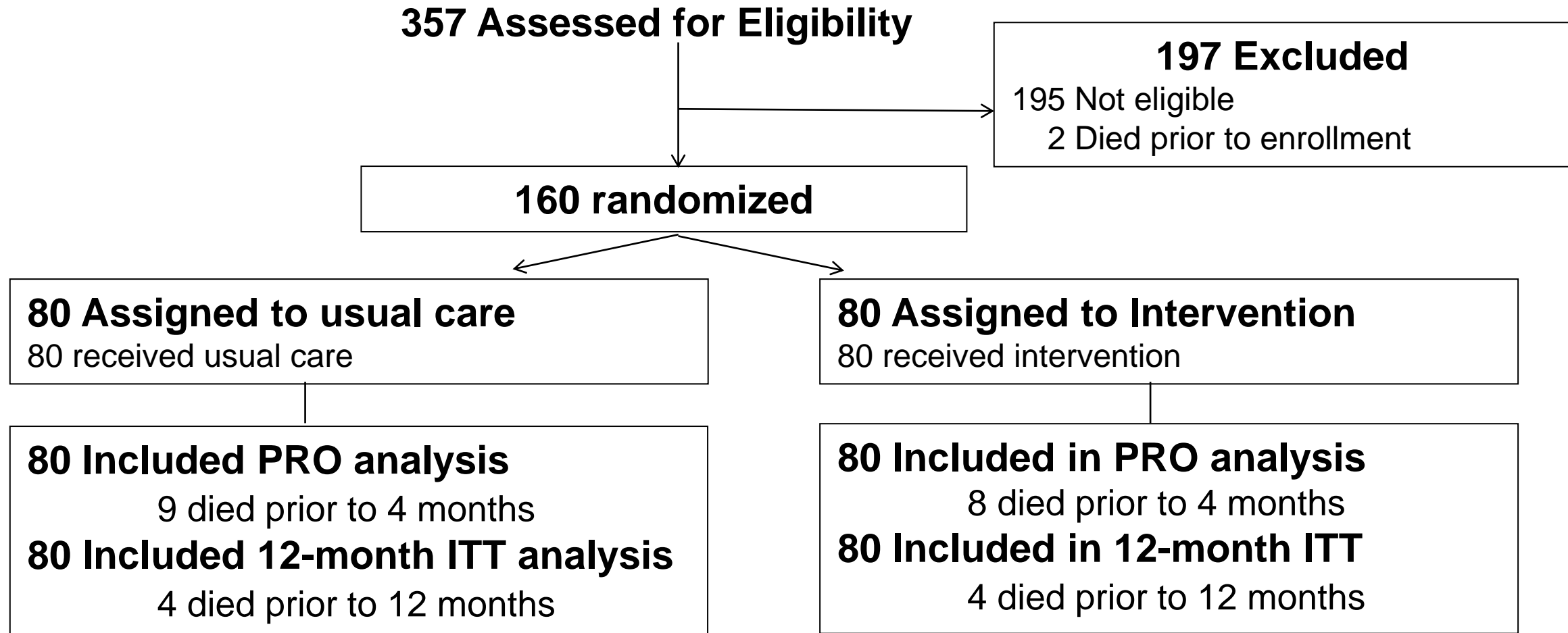
Oficina del Fondo de Chicago

# Methods





# Results: Consort Diagram



# Results: Demographic Characteristics

Characteristics	Overall n=160	Control n=80	Intervention n=80
<b>Sex—no (%)</b>			
Female	85 (53.1)	43 (53.8)	42 (52.5)
<b>Age—median years (range)</b>	58 (21-89)	58 (31-89)	58 (21-80)
<b>Ethnicity – no (%)</b>			
Latino or Hispanic	47 (29.4)	21 (26.3)	26 (32.5)
<b>Race and Ethnicity—no (%)</b>			
→ Black or African American	44 (27.5)	23 (28.8)	21 (26.3)
White	35 (21.9)	17 (21.3)	18 (22.5)
American Indian	2 (1.3)	0 (0.0)	2 (2.5)
Southeast Asian	12 (7.5)	7 (8.8)	5 (6.3)
Vietnamese	10 (6.3)	6 (7.5)	4 (5.0)
Chinese	9 (5.6)	5 (6.3)	4 (5.0)
Native Hawaiian	1 (0.6)	1 (1.3)	0 (0.0)

# Results: Demographic Characteristics

Characteristics	Overall n=160	Control n=80	Intervention n=80
<b>City—no (%)</b>			
→ Atlantic City	108 (67.5)	53 (66.3)	55 (68.8)
Chicago	52 (32.5)	27 (33.8)	25 (31.3)
<b>Annual Household Income (USD)— no (%)</b>			
Less than \$25,000	24 (15.0)	10 (12.5)	14 (17.5)
→ \$25,000 to \$34,999	103 (64.4)	50 (62.5)	53 (66.3)
\$35,000 to \$49,999	33 (20.6)	20 (25.0)	13 (16.3)
<b>Education Level—no (%)</b>			
→ Less than High School	129 (80.6)	61 (76.3)	68 (85.0)
High School	25 (15.6)	15 (18.8)	10 (12.5)
2-year college or Bachelor's Degree	6 (3.8)	4 (5.0)	2 (2.5)



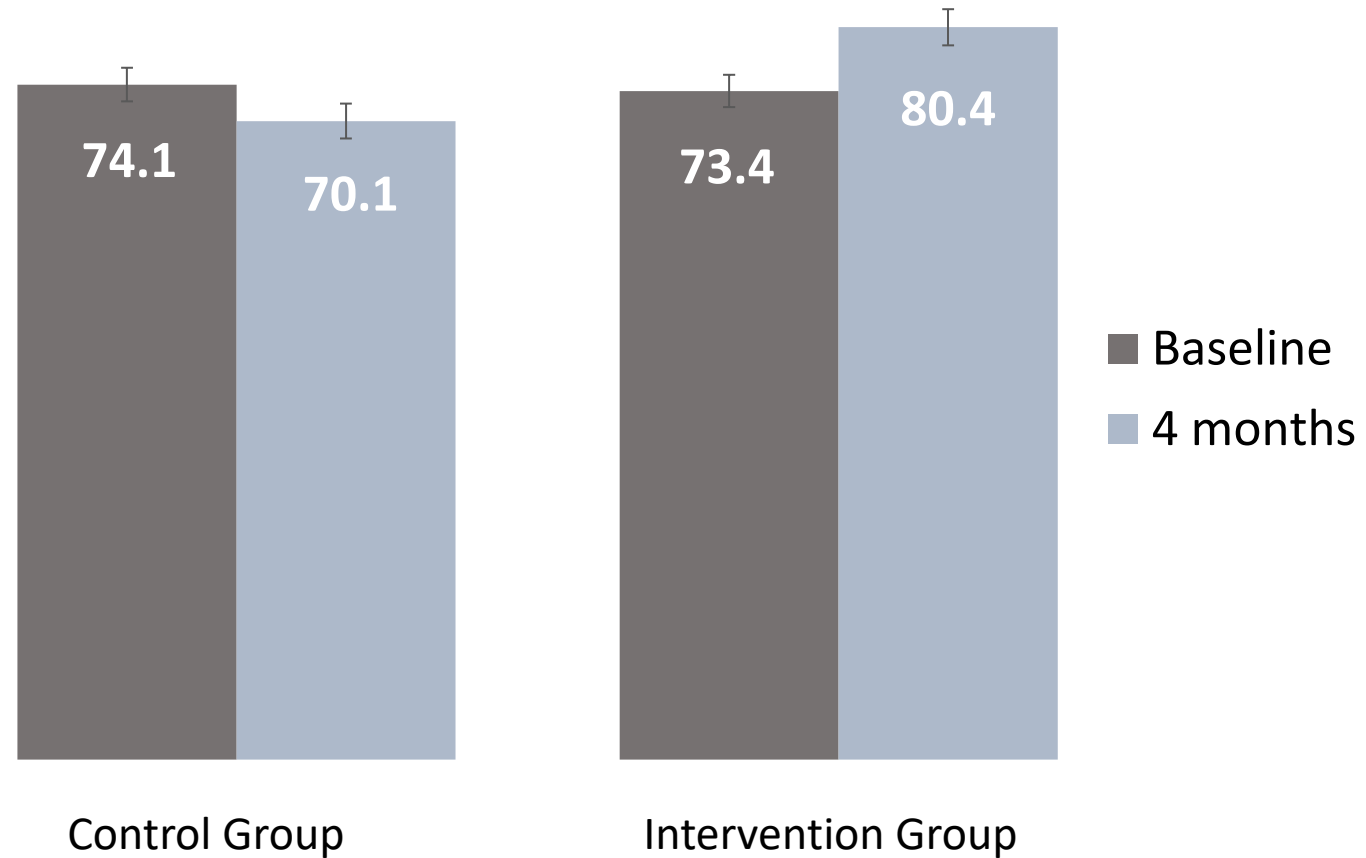
# Results: Clinical Characteristics

Characteristics	Overall N=160	Control Group n=80	Intervention Group n=80
<b>Cancer Diagnosis—no (%)</b>			
→ Breast	37 (23.1)	22 (27.5)	15 (18.8)
→ Gastrointestinal	30 (18.8)	16 (20.0)	14 (17.5)
Genitourinary	19 (11.9)	10 (12.5)	9 (11.3)
Lung	21 (13.1)	10 (12.5)	11 (13.8)
Ovarian	13 (8.1)	5 (6.3)	8 (10.0)
Malignant Hematologic	18 (11.3)	7 (8.8)	11 (13.8)
Head and Neck	18 (11)	2 (2.5)	5 (6.3)
Other (skin, soft tissue, brain)	15 (9.4)	8 (10.0)	7 (8.8)
<b>Cancer Stage—no (%)</b>			
I	29 (20.3)	18 (25.4)	11 (15.3)
II	23 (16.1)	14 (19.7)	9 (12.5)
III	25 (17.5)	11 (15.5)	14 (19.4)
→ IV	64 (44.8)	27 (38.0)	37 (51.4)
Not Staged	2 (1.3)	1 (1.4)	1 (1.4)



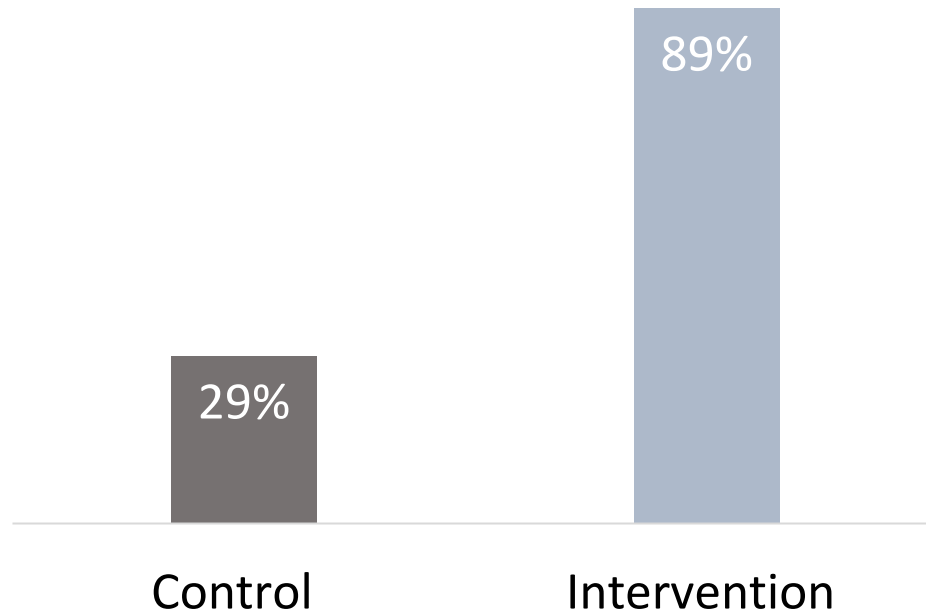
# Results: Health Related Quality of Life (Primary)

## Health-Related Quality of Life Mean Scores

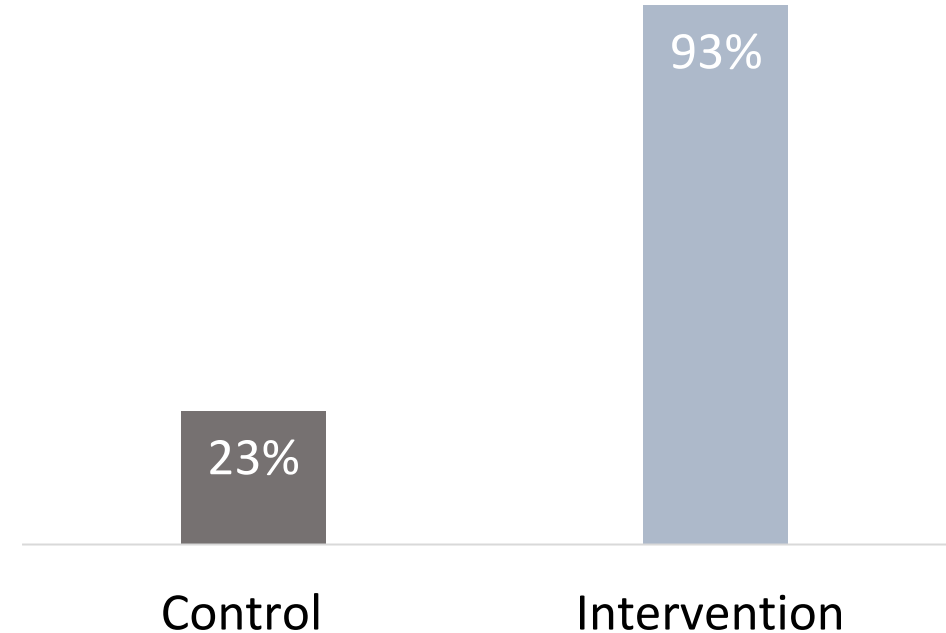


# Results: Goals of Care (Secondary)

**Goals of Care Documentation**

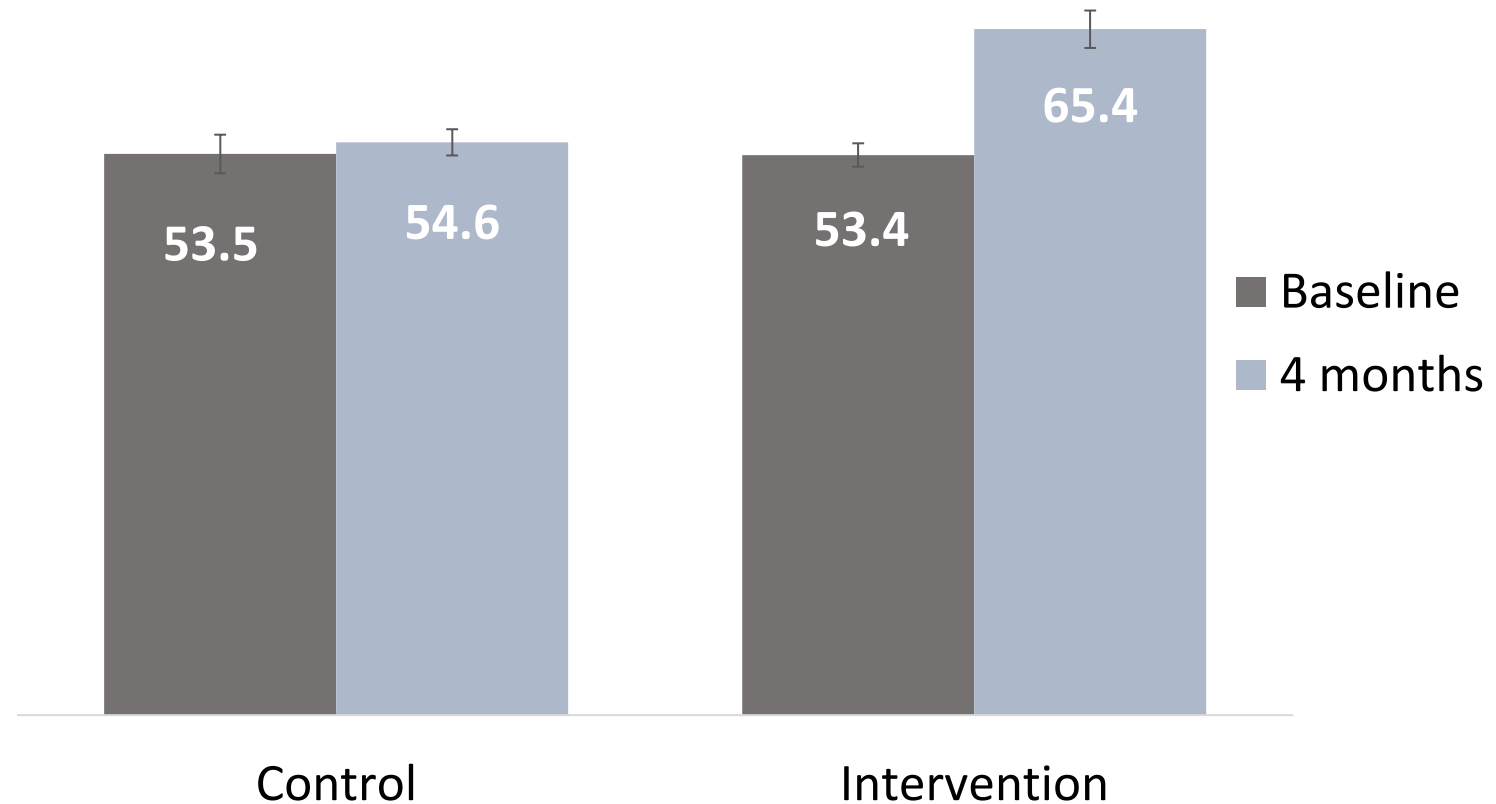


**Advance Directive Documentation**



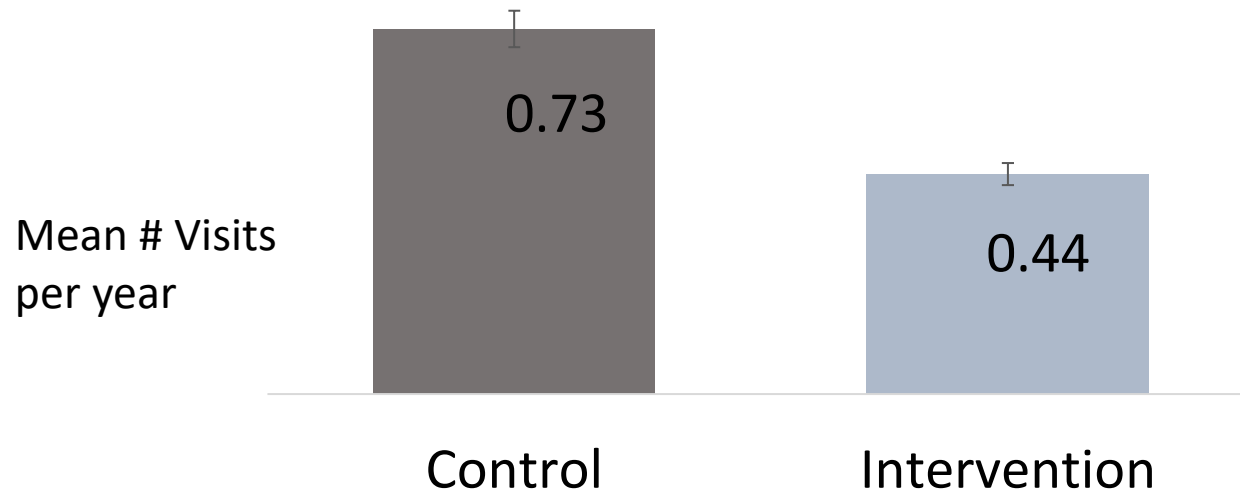
# Results: Patient Activation (Secondary)

**Patient Activation  
Measure  
Mean Scores**

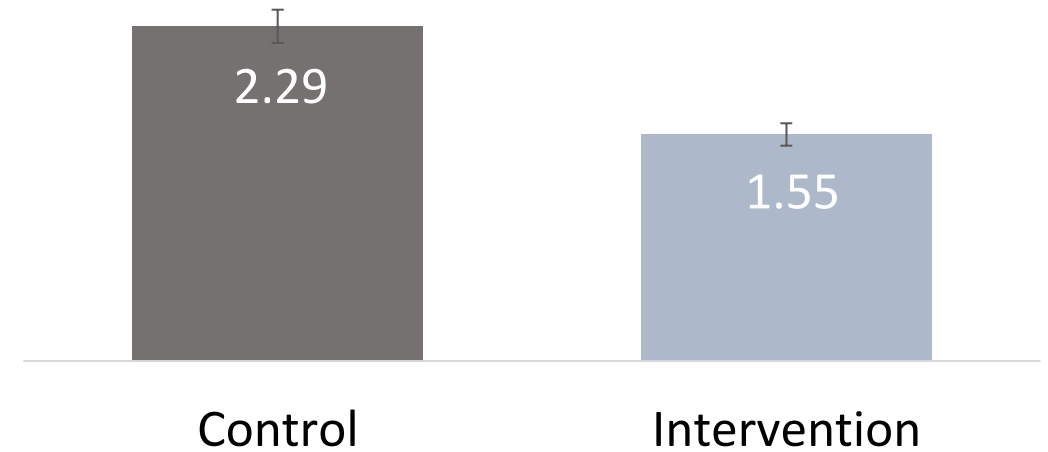


# Results: Health Care Use (Secondary)

## Emergency Department Use

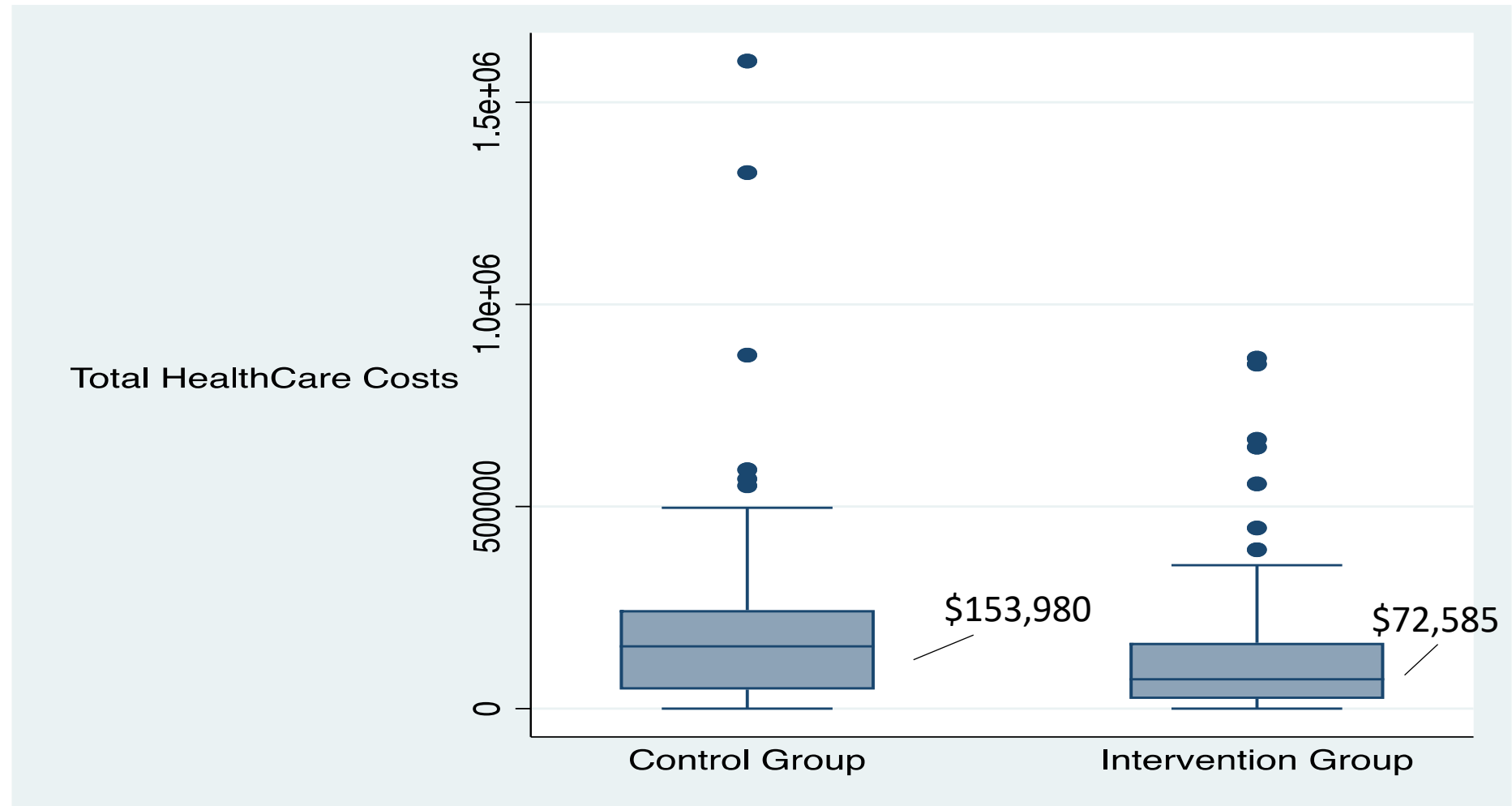


## Hospital Use





# Results: Total Cost Data (Secondary)



# Translation to Practice and Policy



Our critical services include:

Cancer treatment  
and infusion  
centers

In-house  
dispensary

Comprehensive  
lab testing

Outpatient stem  
cell transplant

Outpatient blood  
transfusion

Financial  
counseling

End-of-life  
counseling

Numerous  
clinical trials



## Community Health Workers

### DHCS Proposal to add Community Health Workers

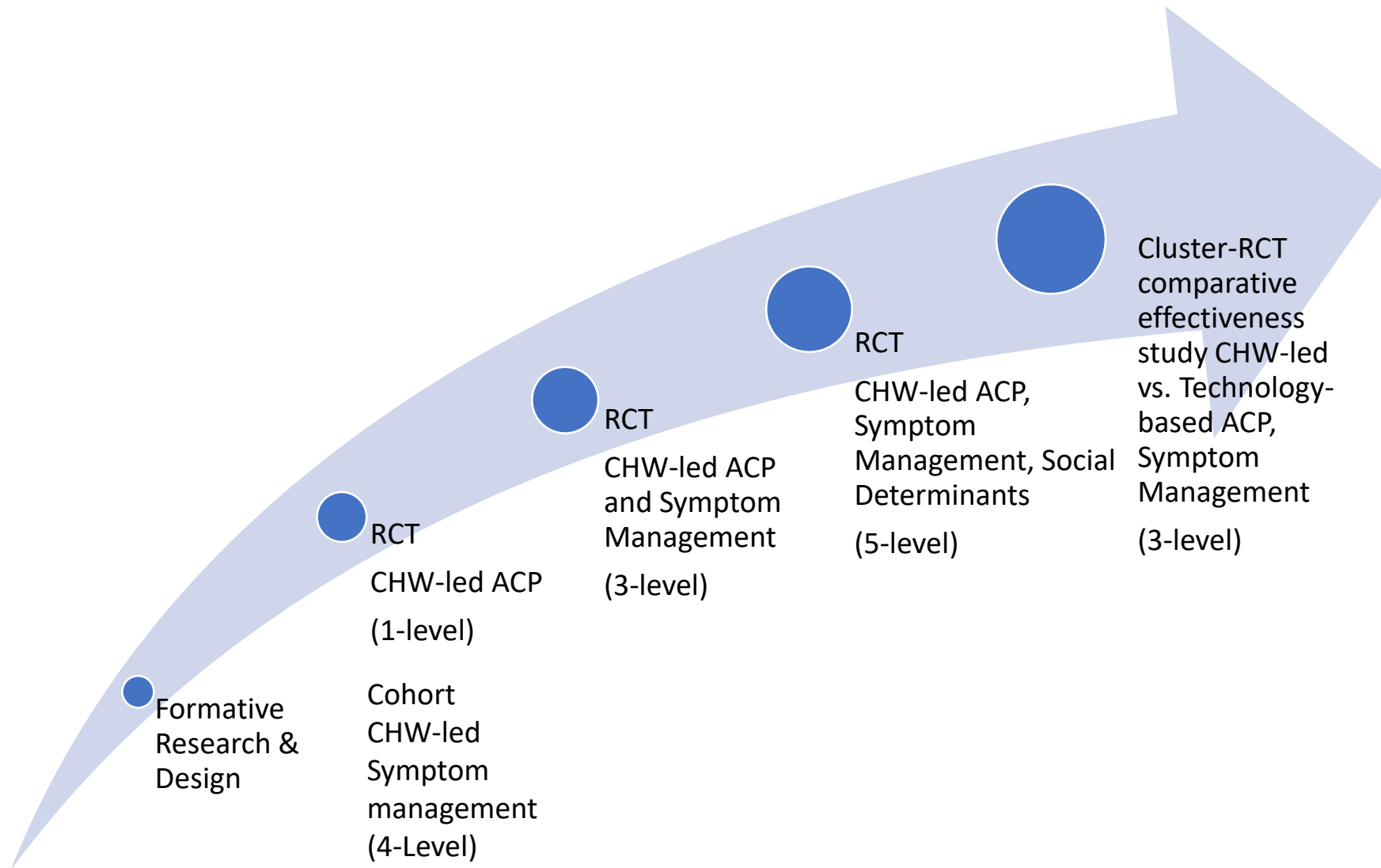
The Department of Health Care Services (DHCS) is adding Community Health Worker (CHW) services as a Medi-Cal benefit starting July 1, 2022.

DHCS conducted four stakeholder meetings to receive input on how to meet federal requirements for the SPA to add CHW services. Based upon stakeholder input, DHCS formally submitted [SPA 22-0001](#) to the Centers for Medicare & Medicaid Services (CMS) on April 29, 2022. CMS has until July 30, 2022, to take action on the SPA.

DHCS expects to publish the Medi-Cal Provider Manual section for CHW services in July 2022, and will seek stakeholder input on the policy in fee-for-service in May.

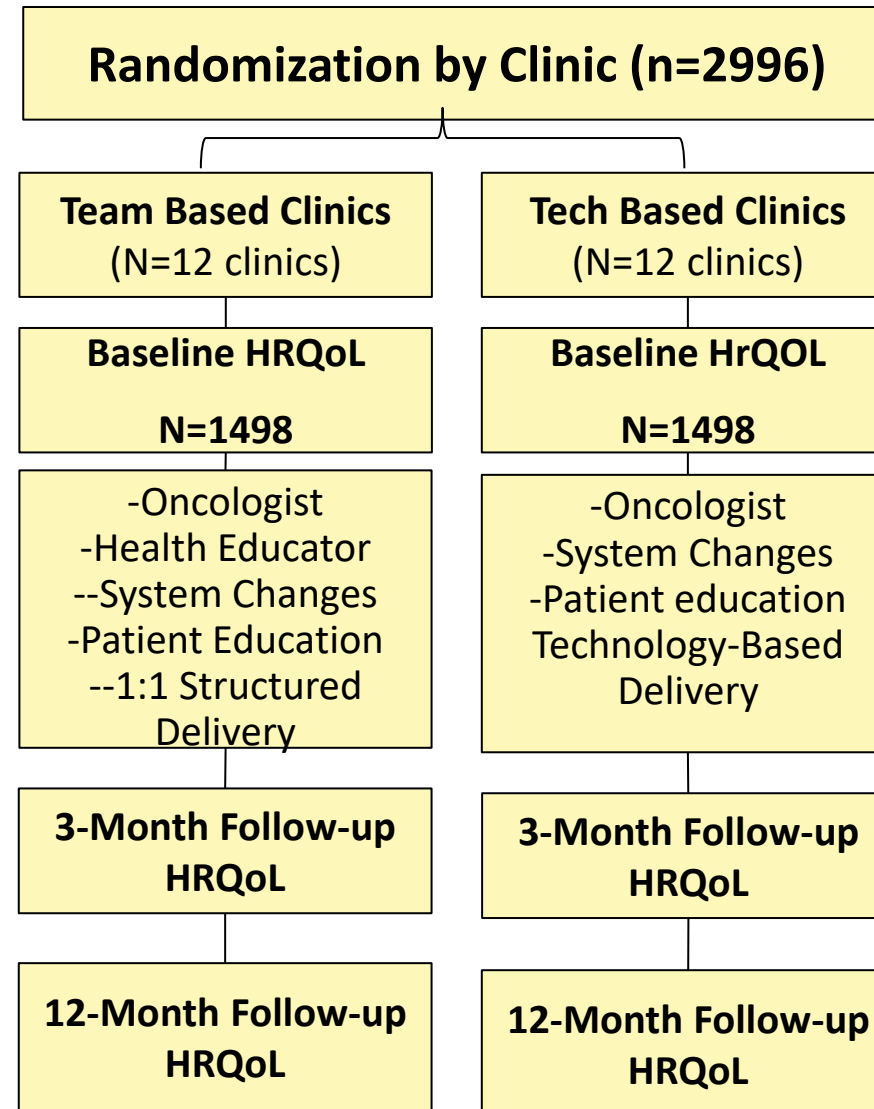
If you have any questions, please feel free to send them to [CHWBenefit@dhcs.ca.gov](mailto:CHWBenefit@dhcs.ca.gov). DHCS appreciates your collaboration and partnership on this important effort.

# Progression of Community-Based Research

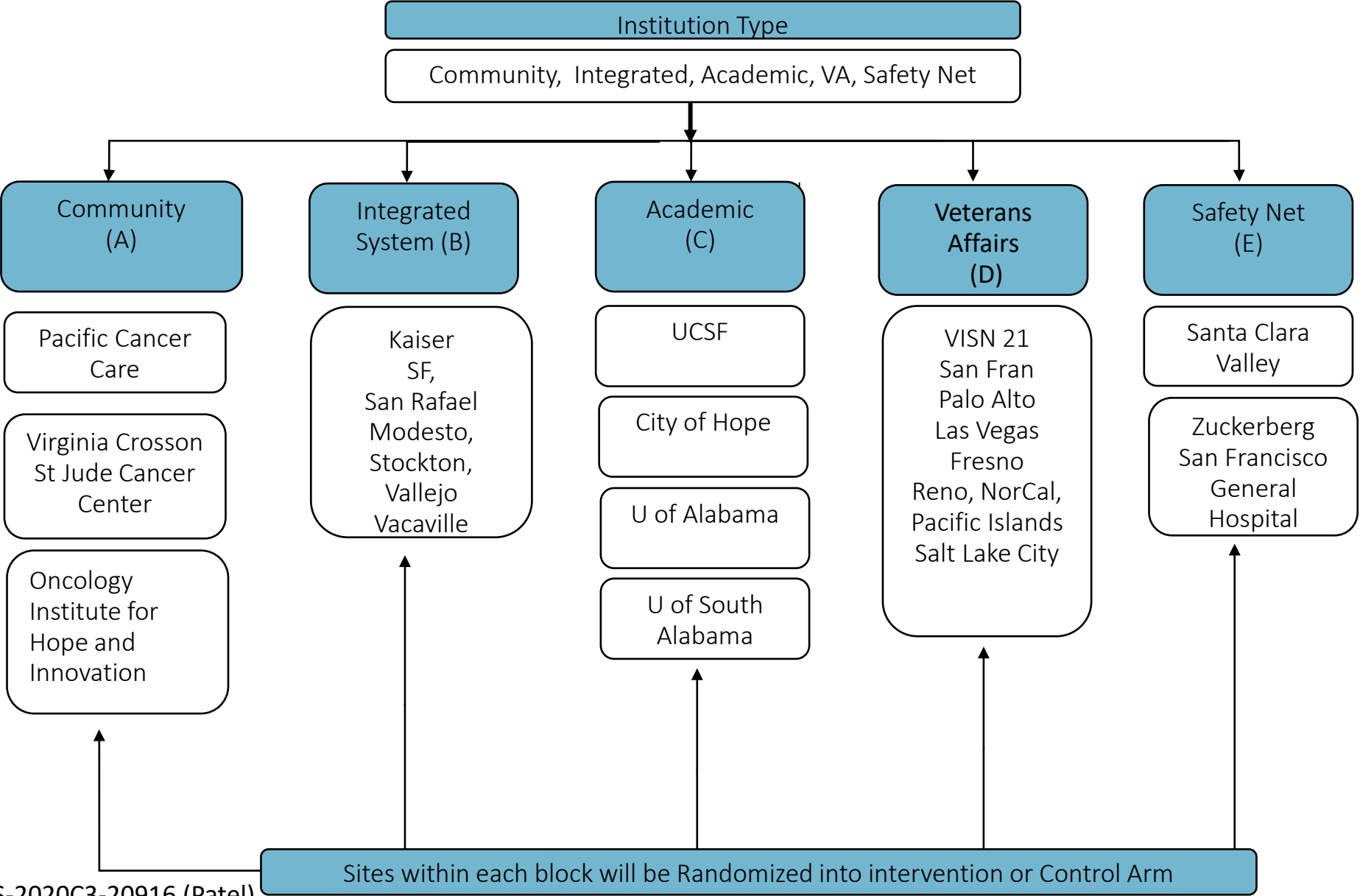


# Evaluating the Comparative Effectiveness of Multilevel Interventions For Supportive Cancer Care

- **Randomized 24 clinics to study**
- **Matching factors: Site-level**
- **Multilevel, multicomponent**
  - **Team Based**
  - **Technology Based**
- **Outcome: Health-related Quality of Life**



# Sites and Stratification



# Health Equity is a Choice



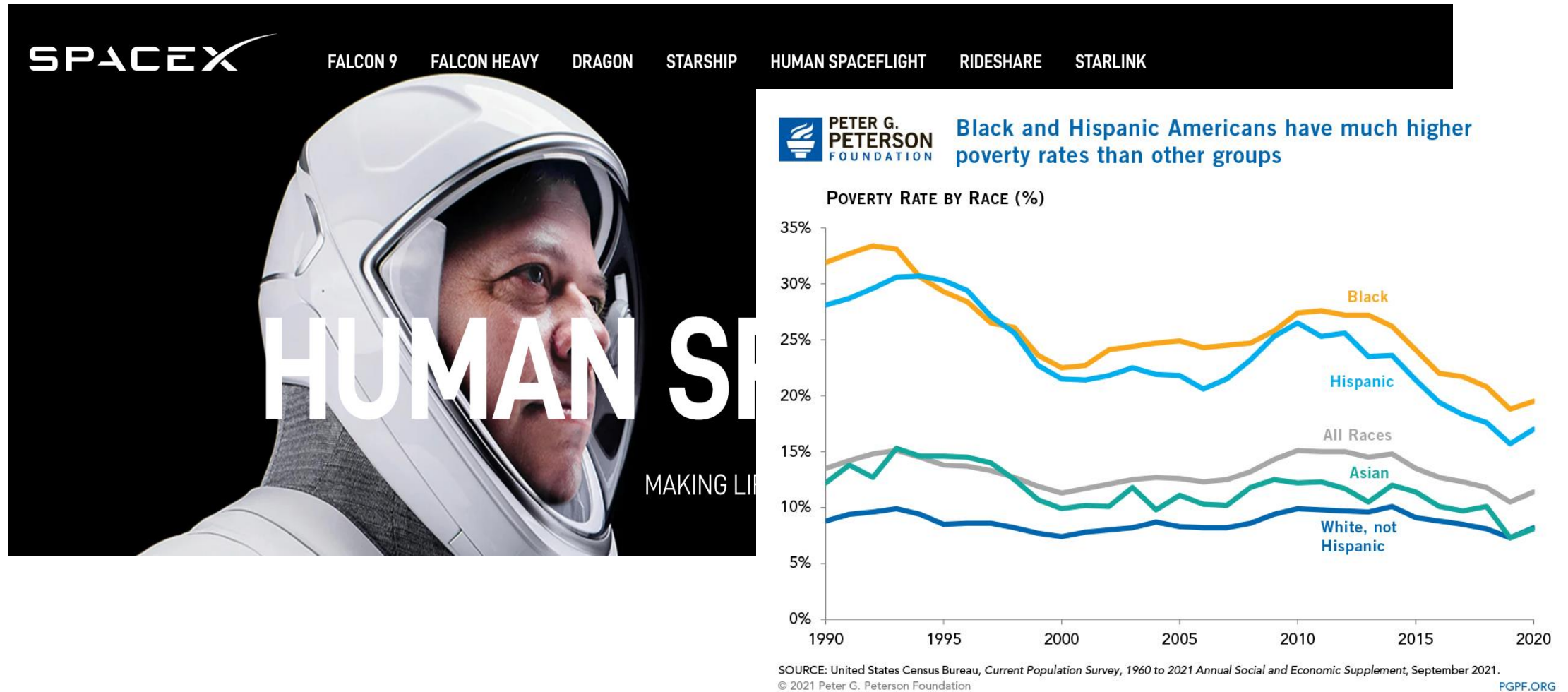
PAST TENSE

## For the Poor People's Campaign, the Moonshot Was Less Than a Triumph

"If we can spend \$100 a mile to send three men to the moon, can't we, for God's sake, feed our hungry?"



# Health Equity is a Choice



# Unity in our Quest for Health Equity



‘To be horrified by inequality and early death and not have any kind of plan for responding — that would not work for me’ - Paul Farmer




# Questions?

PACC PARTNERSHIPS TO ADVANCE CANCER CARE

PROGRAM RESEARCH KNOWLEDGE CENTER OUR TEAM / CONTACT

Some account services will not be available until you sign in again



All patients and their loved ones deserve care that is equitable.

At Partnerships to Advance Cancer Care (PACC) our research aims to improve patient experiences and the quality of care they receive.

LEARN MORE

<https://www.paccresearch.org>

Email: [manalip@Stanford.edu](mailto:manalip@Stanford.edu)

Twitter: @manalipatelmd