

ASSOCIATION OF  
COMMUNITY  
CANCER CENTERS

FINANCIAL  
ADVOCACY  
NETWORK

# Shared Decision Making for Financial Advocates

ACCC Financial Advocacy Network Summit

August 16, 2018

Downtown Washington DC



Association of Community Cancer Centers

# Cost Related Health Literacy and The Role of Navigation

**Nadine J. Barret, PhD., MA., MS**  
*Duke Cancer Institute*

# Financial Toxicity

## ***Financial Toxicity -***

Out-of-pocket expenses related to treatment are akin to physical toxicity, in that costs can diminish quality of life and impede delivery of the highest quality care. Existing data have identified both objective financial burden and subjective financial distress as key components of financial toxicity.

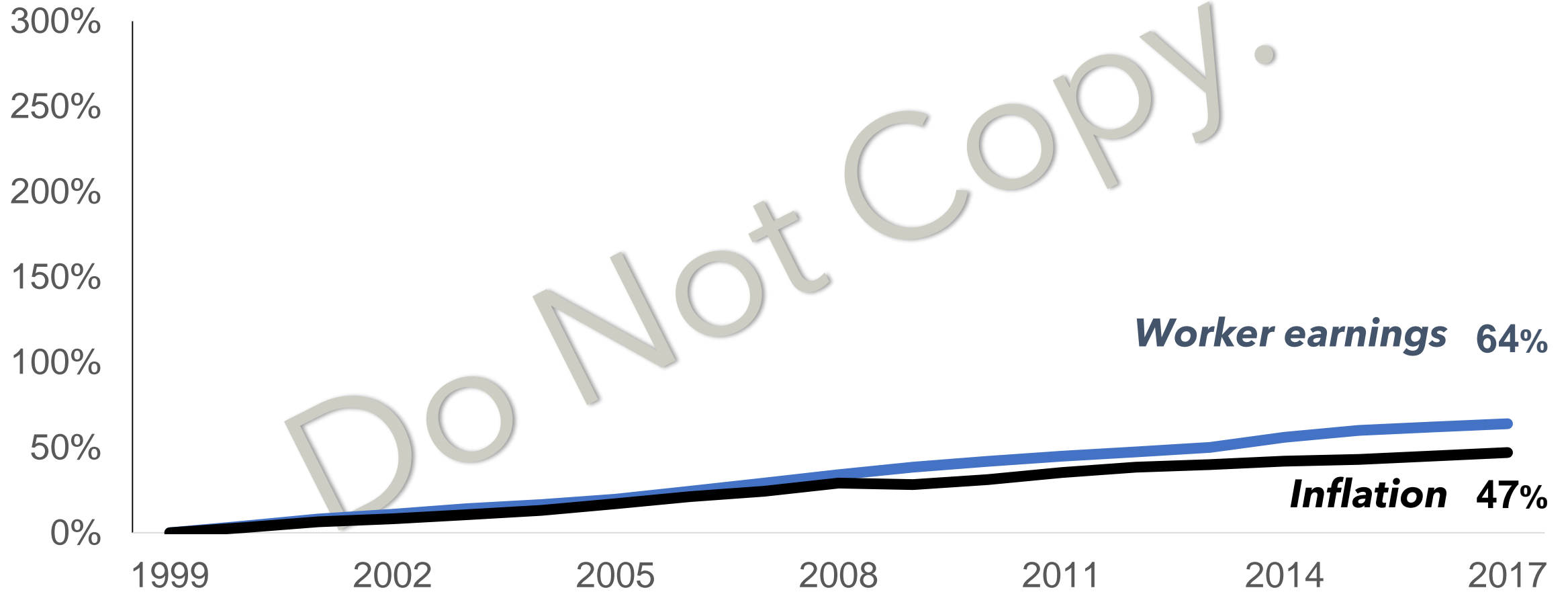
Zafar and Abernathy ***Financial Toxicity, Part I: A New Name for a Growing Problem*** Oncology 2013 Feb; 27(2): 80-149.

"..... current pricing models are **not rational** but simply reflect **what the market will bear.**"

# Why?

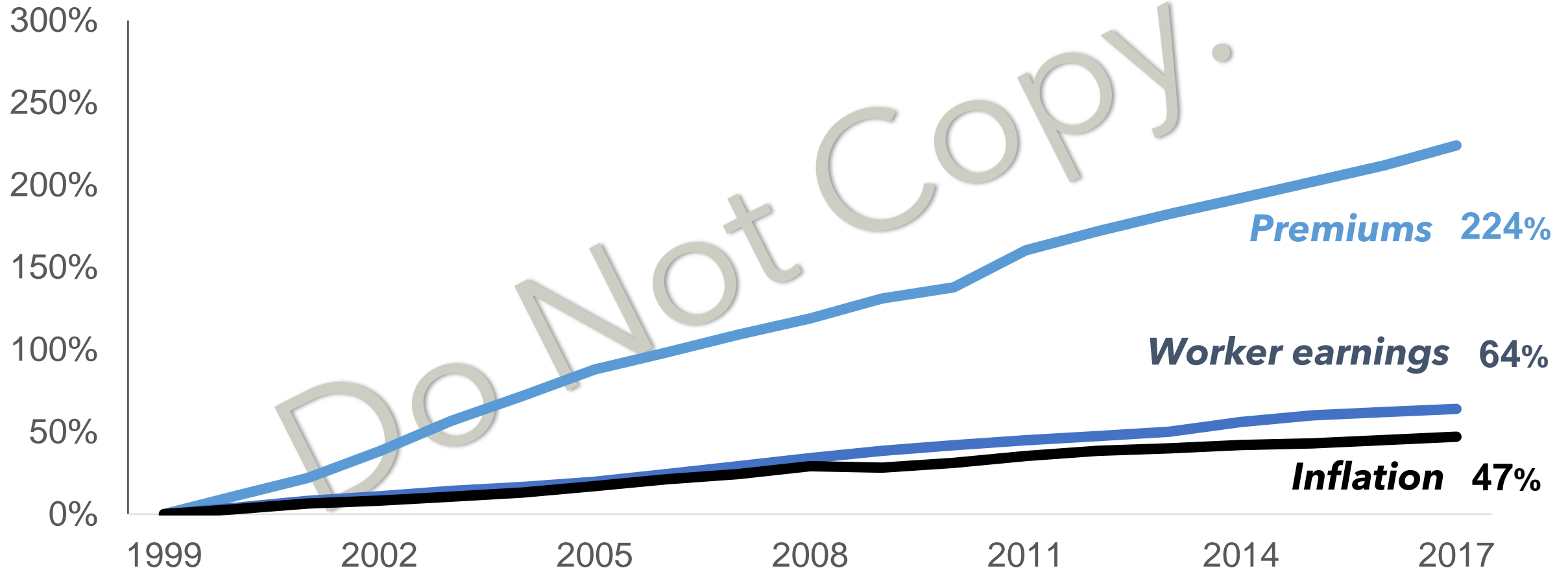
1. Treatment is expensive
2. Cost-sharing is increasing

# Increase in premiums over 18 years



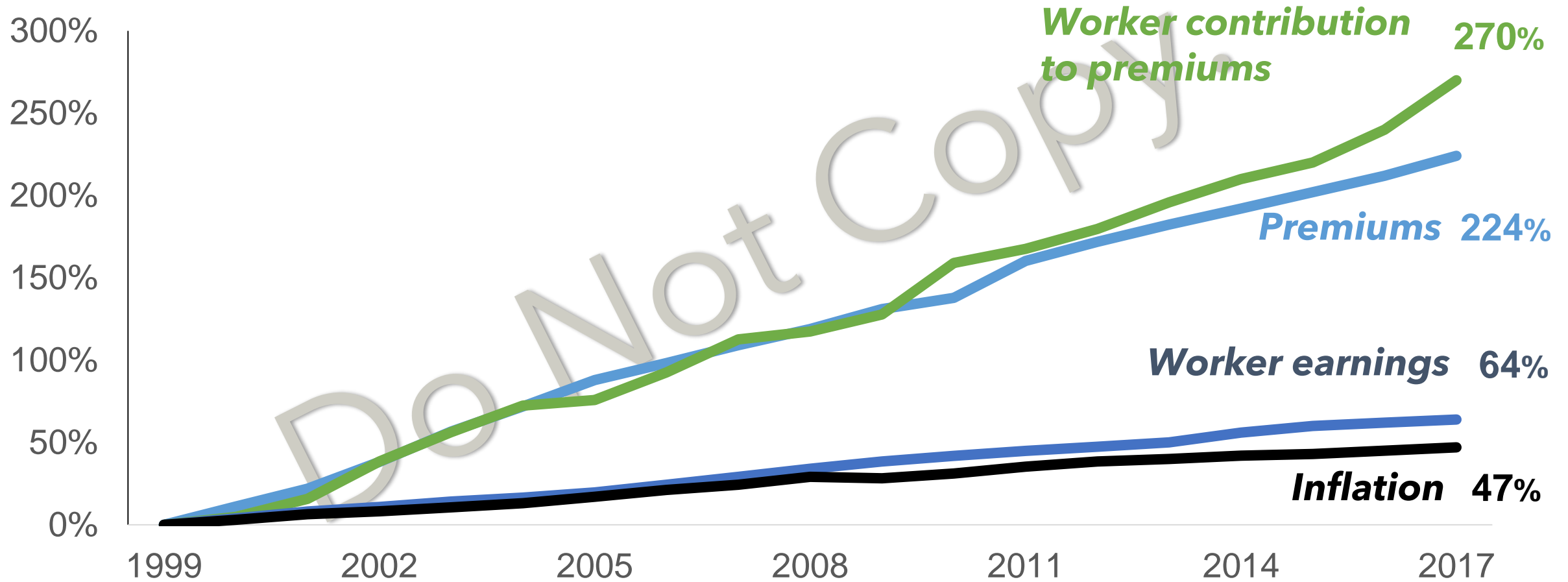
Kaiser Employer Health Benefits Survey, 2017

# Increase in premiums over 18 years



Kaiser Employer Health Benefits Survey, 2017

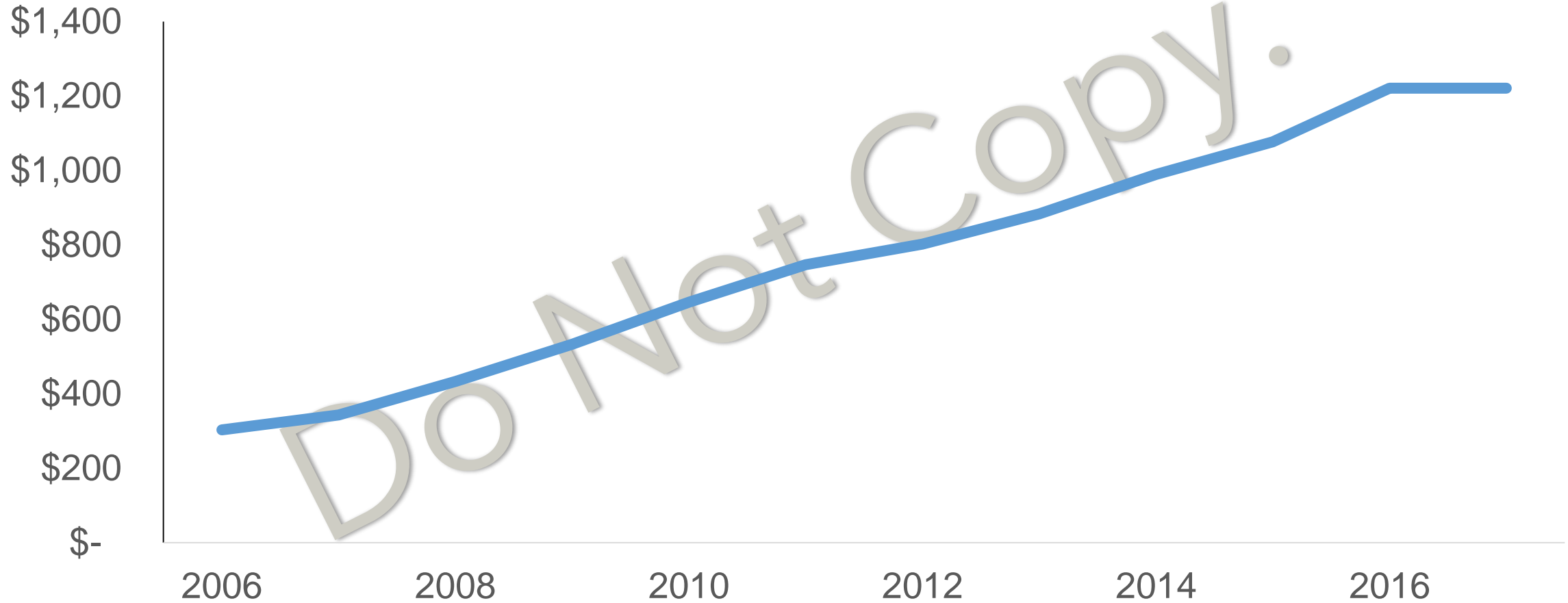
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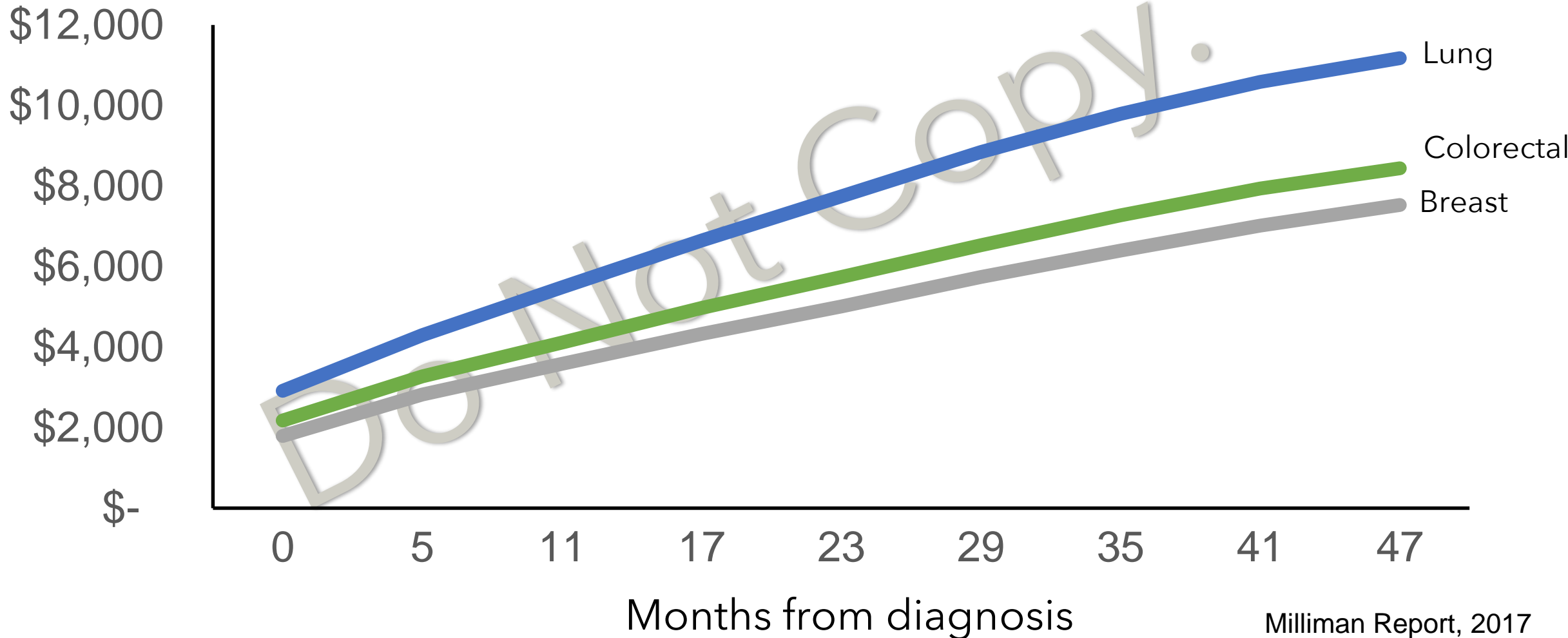


# Increase in deductibles over 12 years



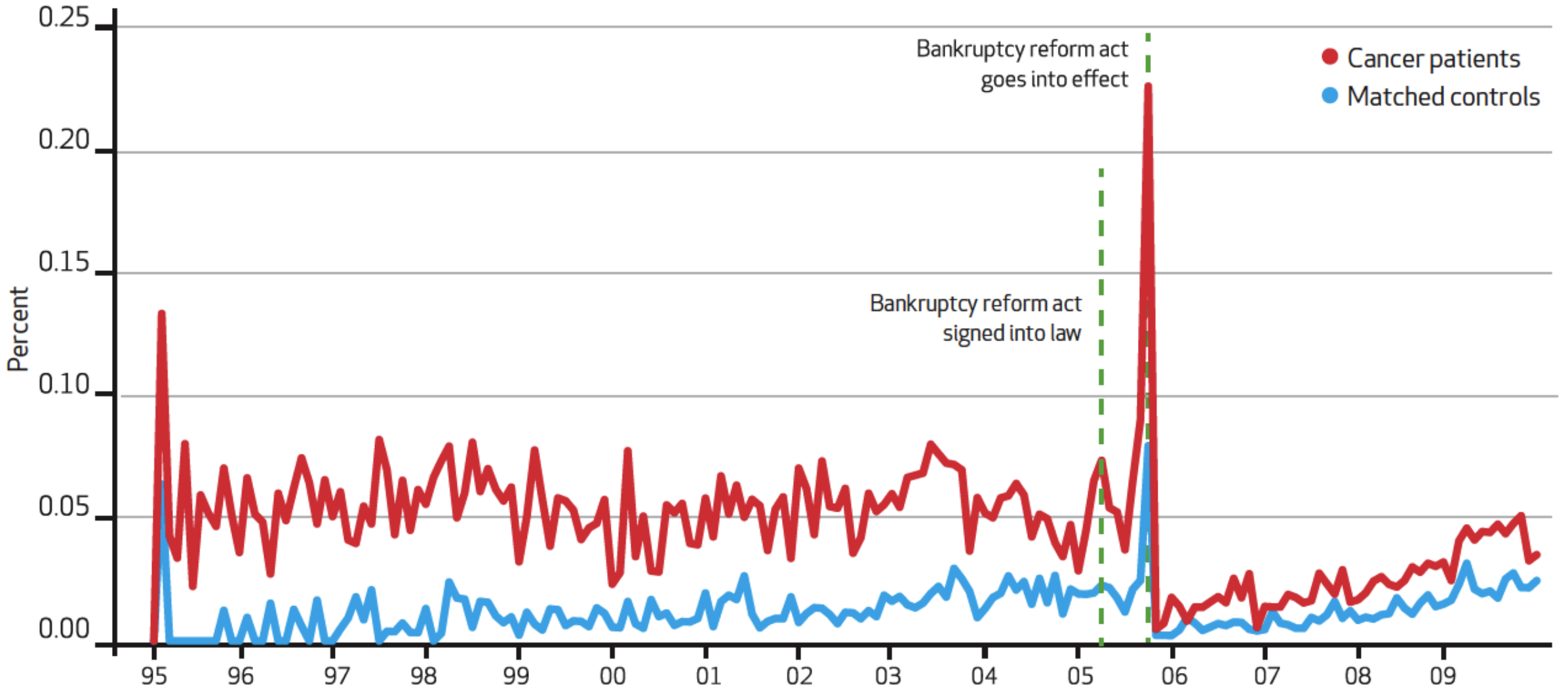
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# Average cumulative patient out-of-pocket costs from time of diagnosis

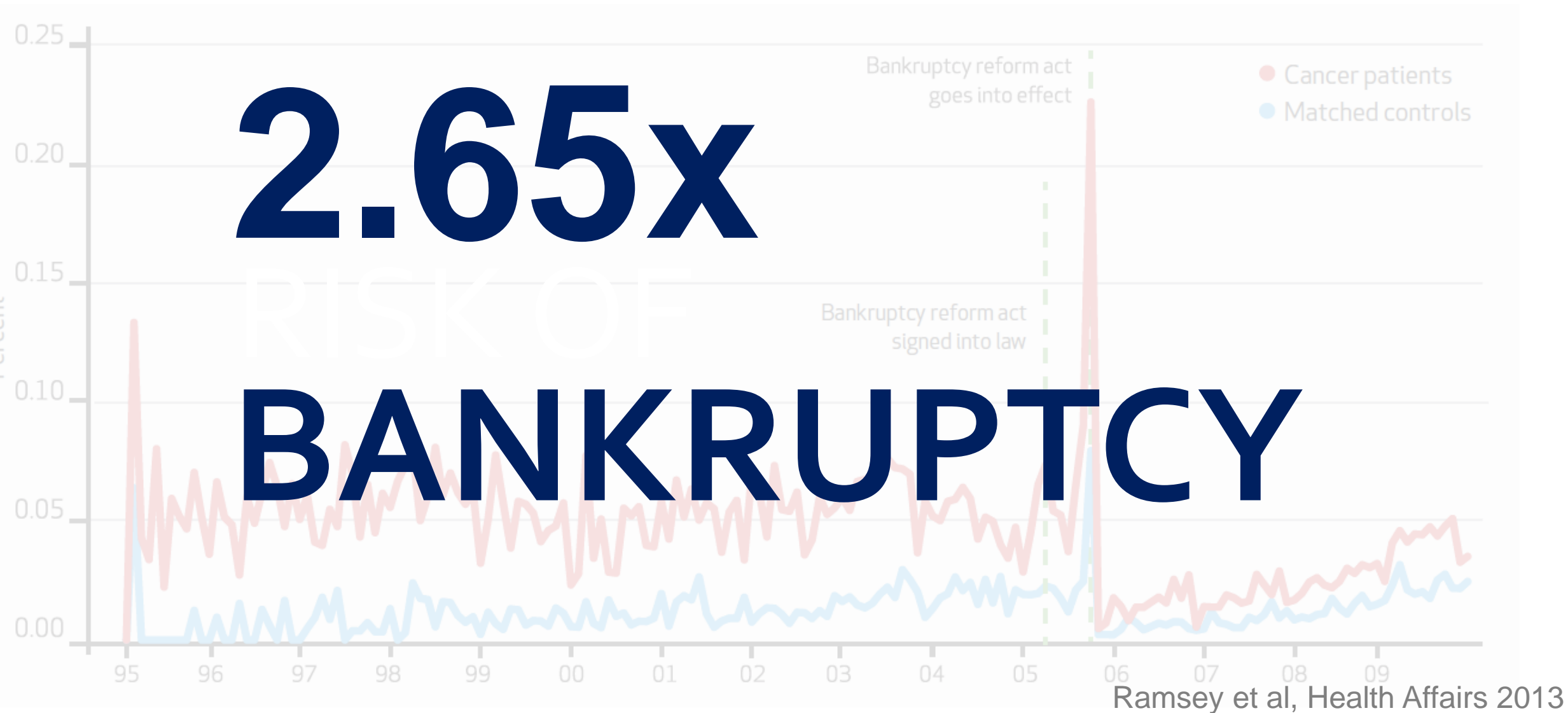


Milliman Report, 2017

# MONTHLY BANKRUPTCY RATES, WESTERN WASHINGTON STATE



# MONTHLY BANKRUPTCY RATES, WESTERN WASHINGTON STATE



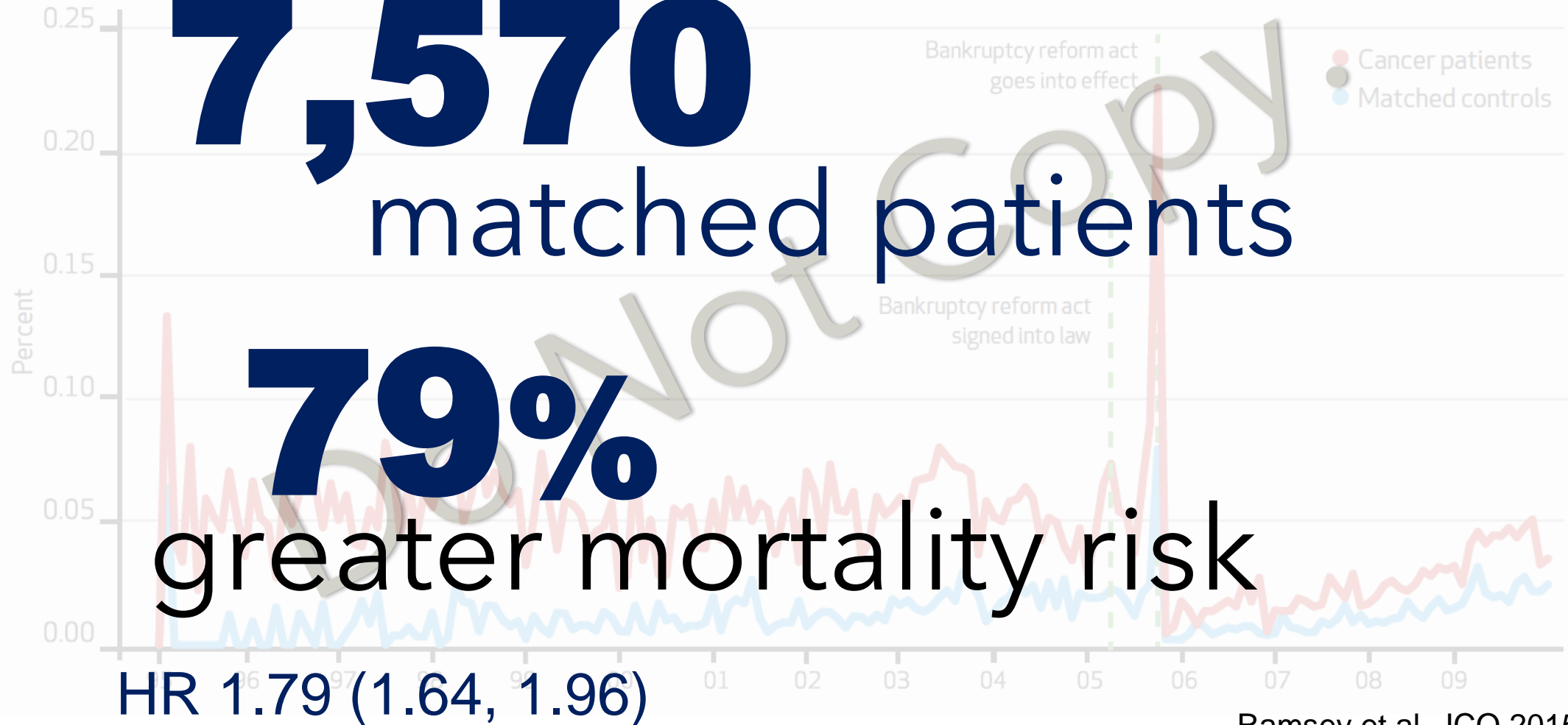
# MONTHLY BANKRUPTCY RATES, WESTERN WASHINGTON STATE

**7,570**

matched patients

**79%**

greater mortality risk



Ramsey et al, JCO 2015

**Extreme  
financial  
distress**

**?**

**Greater  
risk of  
mortality**



Foregone vacations

68%

Cut grocery expenses

46%

Depleted savings

46%

n=254

Zafar et al, Oncologist 2013



**50%** willing to declare bankruptcy

**39%** willing to sell their home

**73%** willing to spend less on  
food/clothing



# High financial burden:



Quality of life  
among patients with  
active cancer and  
survivors

adjusted beta 0.06 EQ-5D unit per financial burden category;  $p < .001$





# 70%

higher likelihood  
of non-adherence

Upper 75th percentile >\$53/month  
aRR, 1.70; 95% CI, 1.30 to 2.22

Dusetzina et al, JCO 2013



**45%**  
**WERE**  
**NON-ADHERENT**

n=254

Zullig et al, J Onc Pract 2013

**Extreme  
financial  
distress**

Well-being

Health-related  
quality of life

Quality of Care

?

**Greater  
risk of  
mortality**

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Buying less clothing

**Financial distress**

Buying less food Working longer hours

Spread out chemotherapy  
appointments

Cutting out vacations

**Missed appointments**

**Bankruptcy**

Using credit

Declining  
tests

**Spending savings**

Taking fewer medications

Using other people's medications

**Borrowing from  
friends or family**

**Selling property**

Replaced prescriptions with  
over the counter medications

Non-adherence

**Delaying care**





Buying less clothing

**Financial distress**

**Buying less food**

Working longer hours

Spread out chemotherapy appointments

Cutting out vacations

**Missed appointments**

**INTERVENE**

Bankruptcy

Borrowing credit

Declining tests

Spending savings

taking fewer medications

Using other people's medications

**Borrowing from friends or family**

**Selling property**

Replaced prescriptions with over the counter medications

Non-adherence

**Delaying care**

# Financial Navigation - Navigating Cost

- Cost-Related Health Literacy
- Navigation Programs address cost related barriers like cost/insurance literacy
- Benefit to the administration, and patient
- The Financial Advocate plays a unique role

# Financial Health Literacy

## Understanding Cost

- Institute of Medicine has issued a challenge to improve patients' understanding of cost of cancer care
- **Health literacy** - the degree to which an individual has the capacity to obtain, communicate, process and understand basic health information and services in order to make appropriate health decisions and follow instructions for treatment
- This challenge includes choosing the best insurance program for healthcare needs.

# Cost Related Health Literacy

***The degree to which an individual has the ability to understand:***

- The cost related to cancer care, medical treatments, medications, insurance costs and other contributing costs,
- The available financial assistance resources, allowing the patient to make the appropriate health decisions based on the cost

# Thank You!

## ***Nadine J. Barrett, PhD MA MS***

Duke Cancer Institute

Assistant Professor in Community and Family Medicine

*Director of the Office of Health Equity*

*Disparities Director of the Community Connections and Collaborations Core within the Duke CTSA*

*Director of the Center for Community and Population Health Improvement*

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# Addressing Cost Across the Continuum of Care

## Panel

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# Key Elements of Navigation Programs Panelists



Nadine J. Barrett, PhD, MA, MS  
Assistant Professor  
Duke University



Clara Lambert, BBA, OPN-CG  
Oncology Financial Navigator  
Advocate Good Samaritan  
Bhorade Cancer Center



Lori Schneider  
Business Office Manager  
Green Bay Oncology

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# Longitudinal Navigation Duke Cancer Institute

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# Example Navigation Programs

- ***Duke Cancer Institute (North Carolina)***
- Green Bay Oncology (Wisconsin)
- Advocate Good Samaritan Bhorade Cancer Center (Illinois)
- Cowell Family Cancer Center (Michigan)

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# Disparities Across the Cancer Spectrum



- Traditionally underrepresented groups fare worse in most cancer outcomes
- Disparities remain
  - In cancer screening, through treatment and survivorship.
  - From large academic institutions to small rural communities
  - Clinical trial participation, where underrepresented populations are grossly underrepresented.
  - Lack of diversity in the research and clinical workforce



# Health Equality and Health Equity



- Race and Ethnic
- Gender
- Rural/ Urban
- Socioeconomic
- Sexual Identity and Gender Expression (LGBTQA)

Equality



Equity



Justice



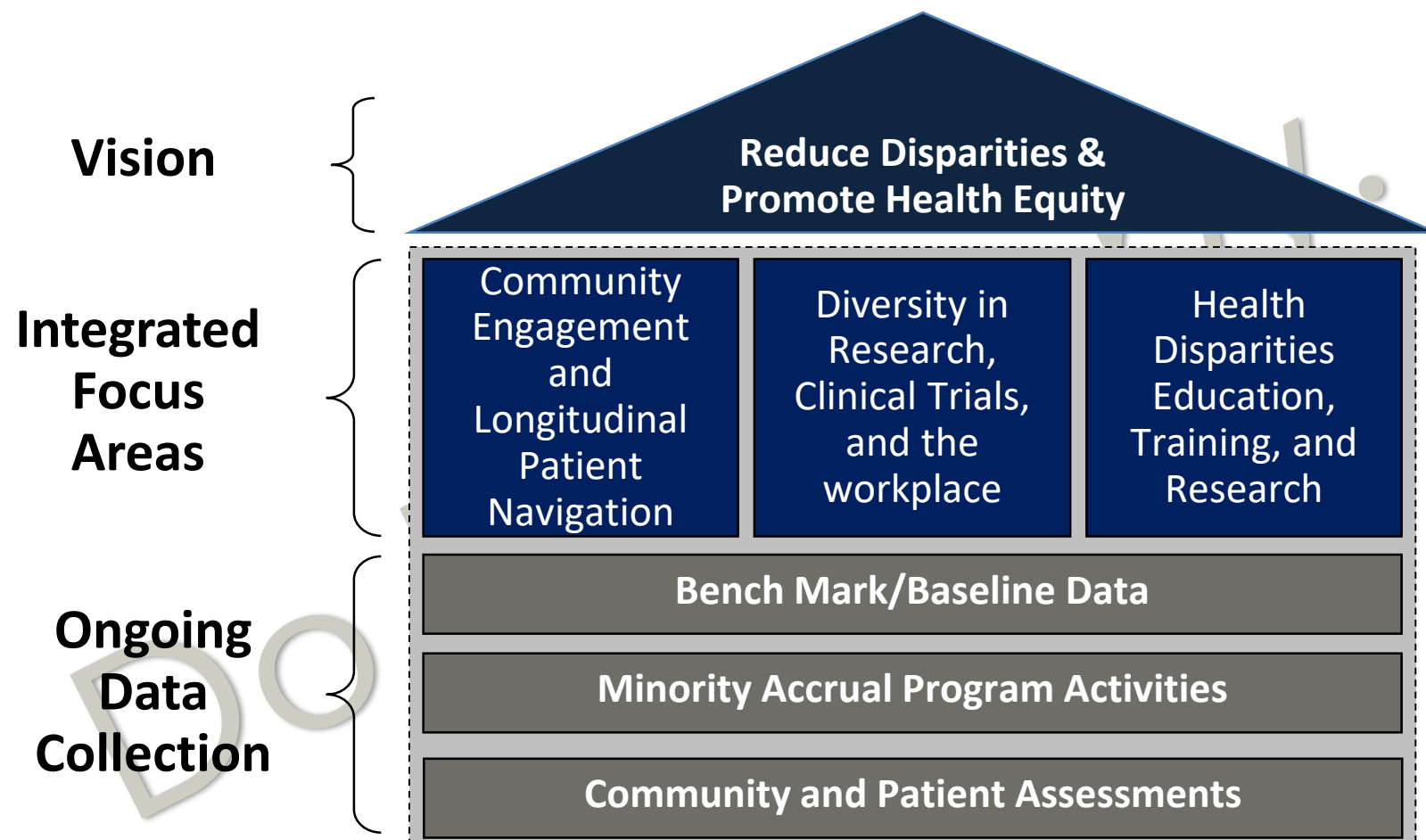
# Bi-Directional Communication



- **Diverse Community Advisory Council**
- **Focus groups – diverse populations**
- Community and patient town-hall sessions
- Health system and community listening sessions
- Individual and collective group meetings
- Outreach programs and evaluation surveys
- County Health Assessments, State Cancer Program, deliberate partnerships with organizations to share and learn.
- **ONGOING.....**

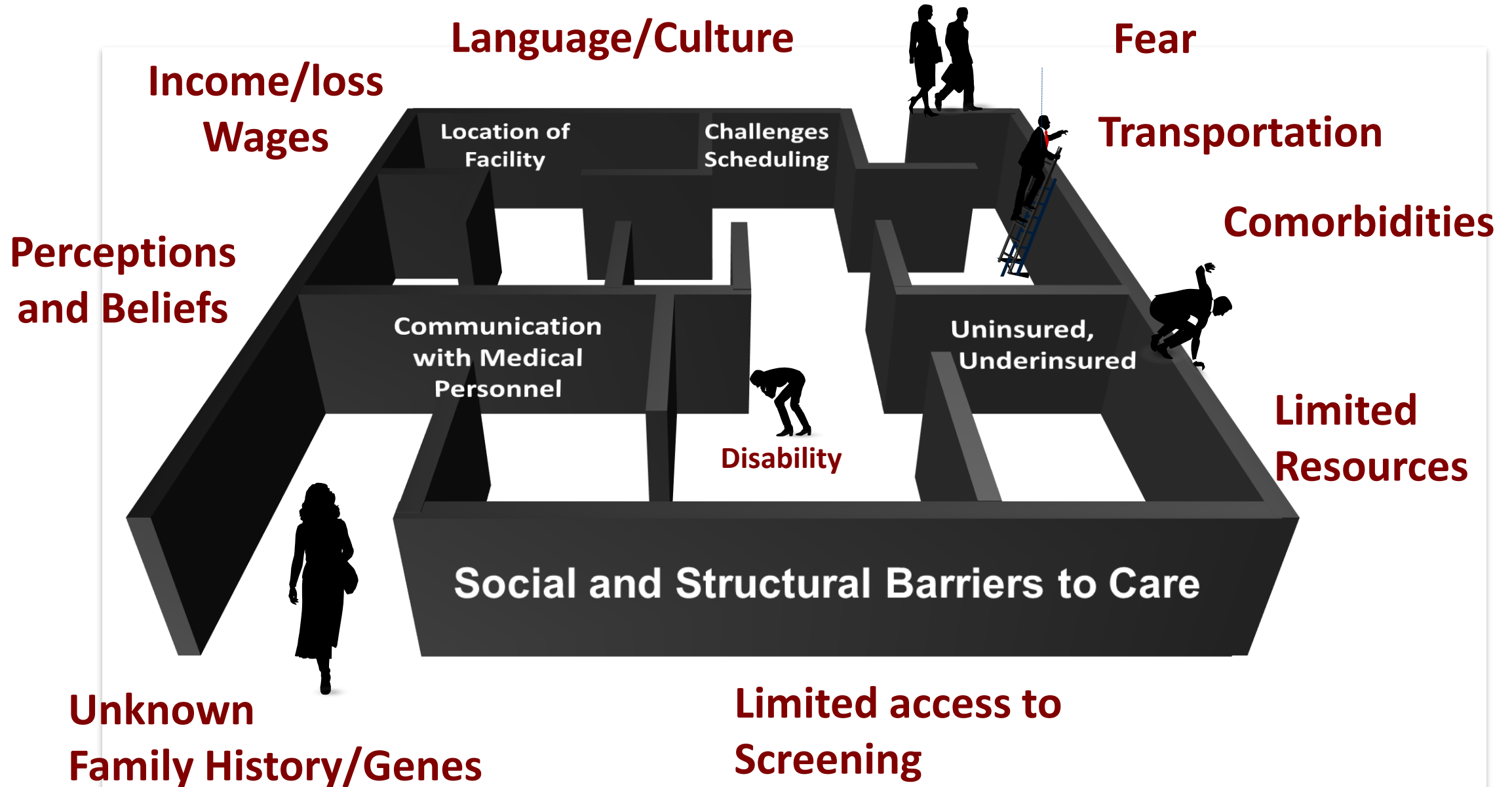


# The Office of Health Equity



Citation: Barrett, et.al, Implementation of a Health Disparities and Equity Agenda at the Duke Cancer Institute. *Journal of Oncology Issues: September/October Issue: 4:47-57*

# Barriers To Care: Navigating the System – Longitudinal







# Community Facing Navigation Program



## Initial Contact

- Outreach Activities
- Referral
- No shows
- Faith Partners
- Other

## Barriers

- Healthcare Access
- Service Availability
- Cultural Needs
- Transportation
- Childcare
- Work schedule
- Other

## Financial

- Undocumented
- No Insurance
- Under Insured
- Public Insurance
- Private Insurance
- Other

## Service/Payment

- Private Provider
- Project Access
- DCI Pilots
- LATCH
- BCCCP
- Komen
- Charity Care
- Other



In 2 years the Community Navigators with our partners:

- Educated 5,043 people on cancer risks, symptoms, screenings, and clinical research.
- Screened 1,523 people through partnered community outreach
  - Undocumented: 34.3%
  - Uninsured: 57.9%
  - No PCP: 12.9%
  - Follow-up care for 52 screened: (Includes biopsies, diagnostics mammograms, and thyroid cancer follow-up)

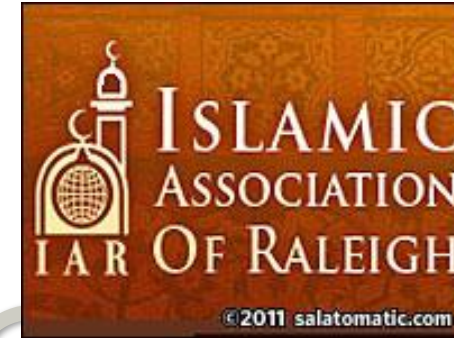


# Partners - Address Patient and Community Needs



MARIA PARHAM  
HEALTH

Duke LifePoint Healthcare



GRANVILLE VANCE  
public health



Public Health





## **DCI Support Services – Dr. Cheyenne Corbett**

- Community Facing Navigators provide a warm hand off to diversely trained treatment navigators
- Work in collaboratively with patients to identify and address needs
- Utilize ongoing distress screening and other needs assessments
- Build a comprehensive, holistic and partnered approach to patient care and needs.
- Identify financial barriers, challenges, and choices
  - Legal Clinical – paying rent, losing mortgage, bankruptcy



## **Onco-Primary Care Center – Dr. Kevin Oeffinger**

- Survivorship – to integrated patient back into the community and Primary Care
- Navigate patient back into community with connections to resources
- Non-clinical navigators play a key role here

# Example Navigation Programs

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