Behavioral and Social Science in Cancer Control Research

August 10, 2017

William Klein, Ph.D., National Cancer Institute
Catherine Alfano, Ph.D., American Cancer Society

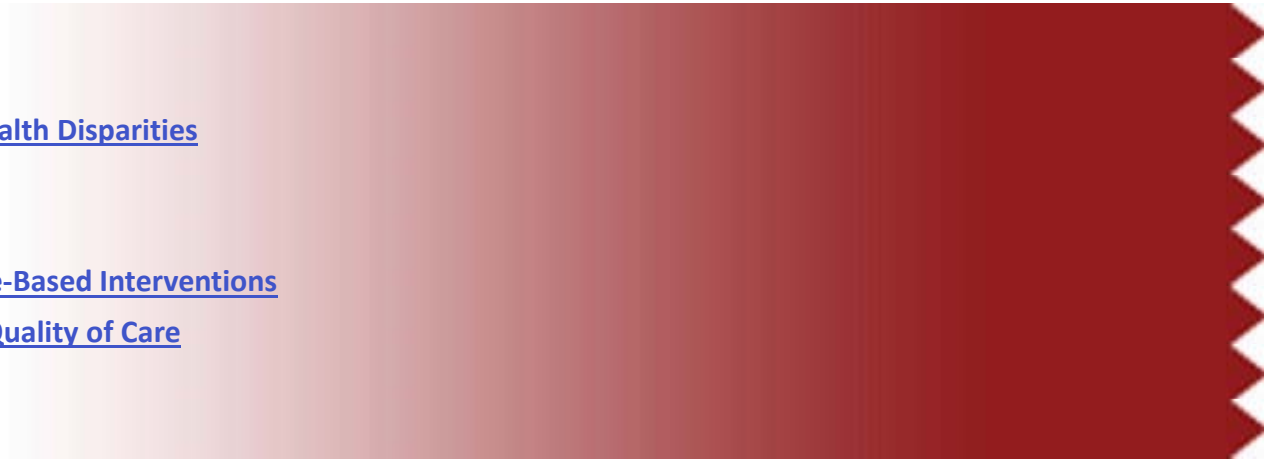
The Cancer Control Continuum

Focus

PREVENTION	DETECTION	DIAGNOSIS	TREATMENT	SURVIVORSHIP
Tobacco control Diet Physical activity Sun protection HPV vaccine Limited alcohol use Chemoprevention	Pap/HPV testing Mammography Fecal occult blood test Colonoscopy Lung cancer screening	Shared and informed decision making	Health care delivery and outcomes research	Coping Health promotion for survivors

Crosscutting Issues

- Communications
- Surveillance
- Social Determinants of Health Disparities
- Genetic Testing
- Decision-Making
- Dissemination of Evidence-Based Interventions
- Heath Care Delivery and Quality of Care
- Epidemiology
- Measurement



Adapted from David B. Abrams, Brown University School of Medicine

Overview

- Behavior
- Levels of Analysis
- Methods
- Survivorship

Behavioral Research in Cancer Prevention and Control

A Look to the Future

William M.P. Klein, PhD, Michele Bloch, MD, PhD, Bradford W. Hesse, PhD, Paige G. McDonald, PhD, MPH, Linda Nebeling, PhD, MPH, RD, Mary E. O'Connell, MA, William T. Riley, PhD, Stephen H. Taplin, MD, MPH, Gina Tesauro, MSW

Abstract: Human behavior is central to the etiology and management of cancer outcomes and presents several avenues for targeted and sustained intervention. Psychosocial experiences such as stress and health behaviors including tobacco use, sun exposure, poor diet, and a sedentary lifestyle increase the risk of some cancers yet are often quite resistant to change. Cancer screening and other health services are misunderstood and over-utilized, and vaccination underutilized, in part because of the avalanche of information about cancer prevention. Coordination of cancer care is suboptimal, and only a small fraction of cancer patients enroll in clinical trials essential to the development of new cancer treatments. A growing population of cancer survivors has necessitated a fresh view of cancer as a chronic rather than acute disease. Fortunately, behavioral research can address a wide variety of key processes and outcomes across the cancer control continuum from prevention to end-of-life care. Here we consider effects at the biobehavioral and psychological, social and organizational, and environmental levels. We challenge the research community to address key behavioral targets across all levels of influence, while taking into account the many new methodological tools that can facilitate this important work.

(Am J Prev Med 2014;46(3):303–311) Published by Elsevier Inc. on behalf of American Journal of Preventive Medicine

Introduction

Although rates of some cancers have decreased during the past 40 years, others have grown.[1,2] Cancer remains a leading cause of mortality, with an estimated U.S. economic impact of $263.8 billion in 2010.[3] It is estimated that in 2013, about 580,350 Americans will die of cancer, accounting for approximately 25% of all deaths.[4]

The more general health landscape has also evolved dramatically in that time. In 2010, Congress passed the U.S. Patient Protection and Affordable Care Act, which spotlights prevention and patient-reported outcomes and established the Patient-Centered Outcomes Research Institute (PCORI).[5] The 2009 Family Smoking Prevention and Tobacco Control Act provides the Food and Drug Administration (FDA) with broad authority to regulate the manufacturing, marketing, and distribution of tobacco products. The U.S. Preventive Services Task Force has revised guidelines for mammography, cervical, lung, and prostate screening. The guidelines call for more shared decisions between physicians and patients given the importance of weighing costs and benefits of different screening modalities.[6,7] Social media and crowd-sourcing platforms have altered the decision-making process and patient-provider dynamic,[8,9] and the platform for health messages has evolved from print media to websites and mobile applications. Individuals can now obtain access to their genetic profiles (outside of the healthcare system), access personal health records, and share concerns and symptoms with thousands of online acquaintances.

At least three IOM reports[10–12] recognize the need to embrace multi-disciplinary, multilevel, and multiple-method approaches to quality health care and communication directly applicable to cancer control research. National Cancer Institute Director Dr. Harold Varmus observed in a 2006 *Science* editorial that

> concerted national efforts to ensure the vitality of all of the components of modern oncology—academic

From the Behavioral Research Program, National Cancer Institute, Rockville, Maryland

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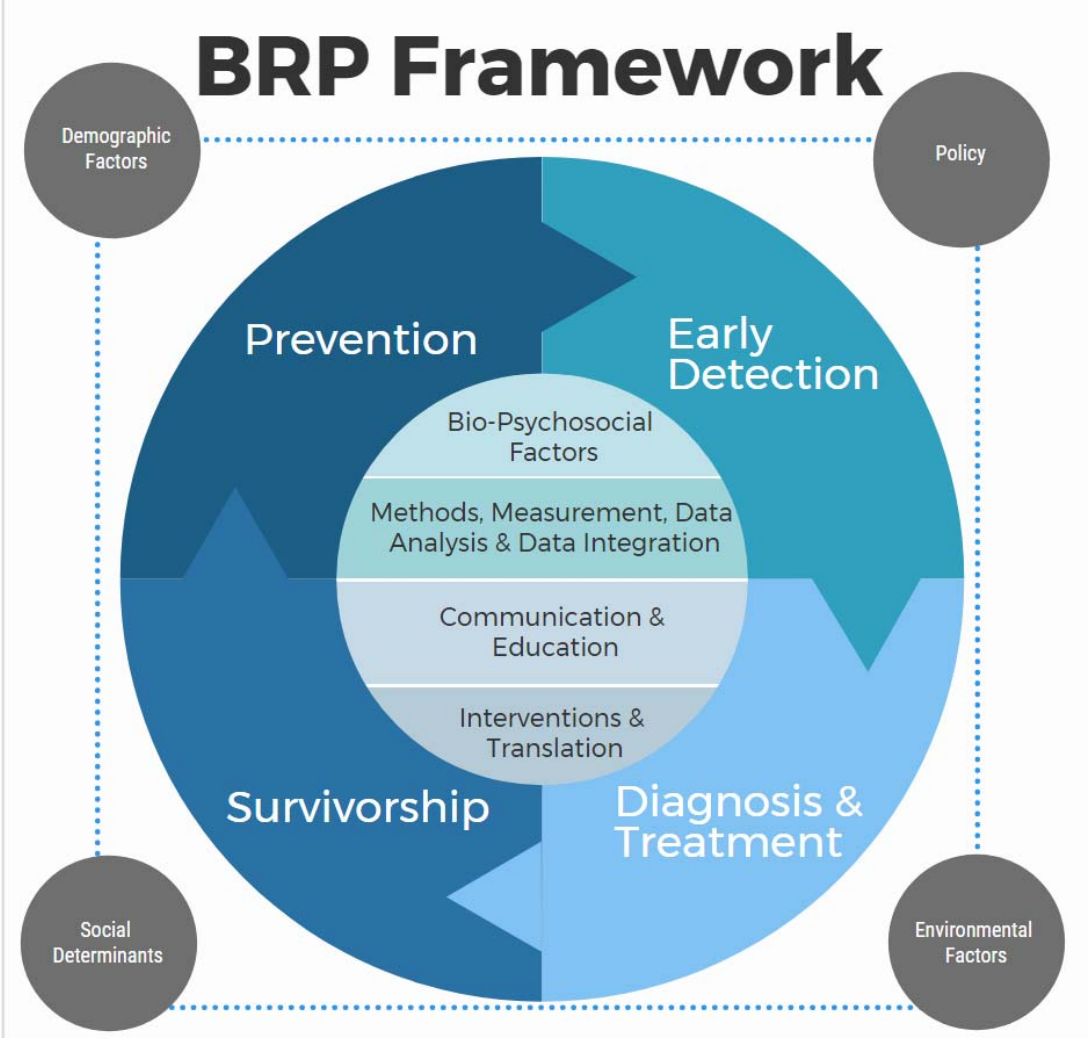
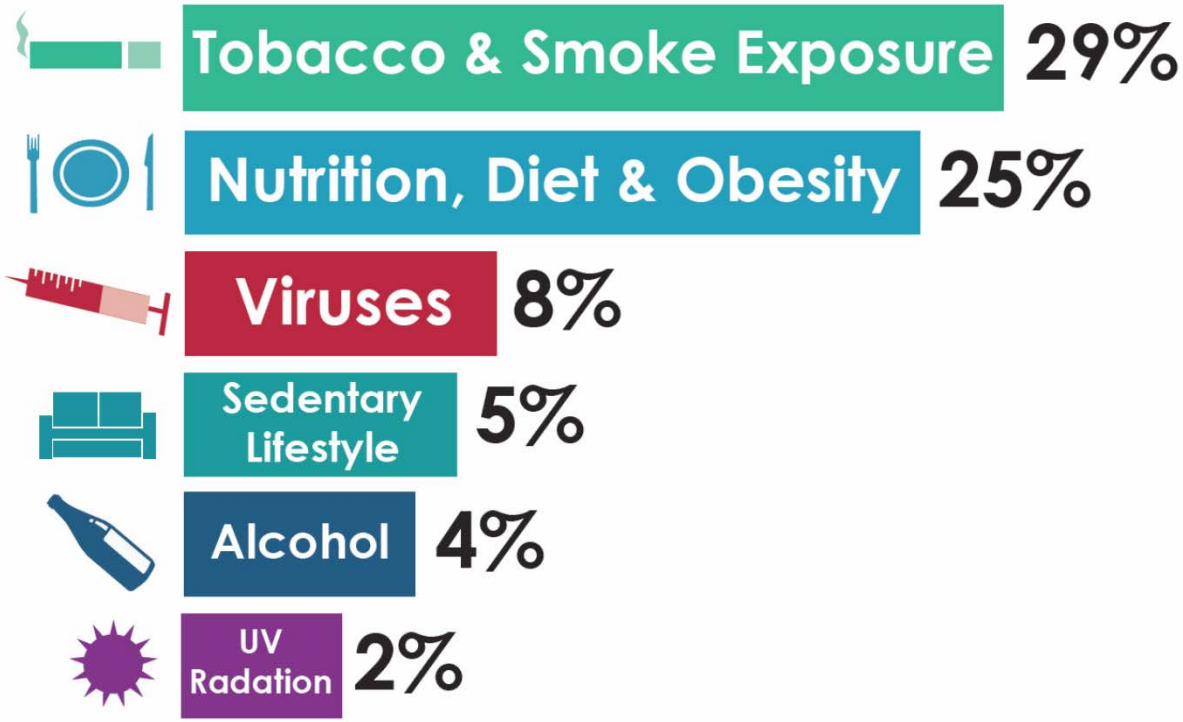
0749-3797/$36.00
http://dx.doi.org/10.1016/j.amepre.2013.10.004


BRP Framework
Demographic Factors
Policy
Prevention
Early Detection
Bio-Psychosocial Factors
Methods, Measurement, Data Analysis & Data Integration
Communication & Education
Interventions & Translation
Survivorship
Diagnosis & Treatment
Social Determinants
Environmental Factors

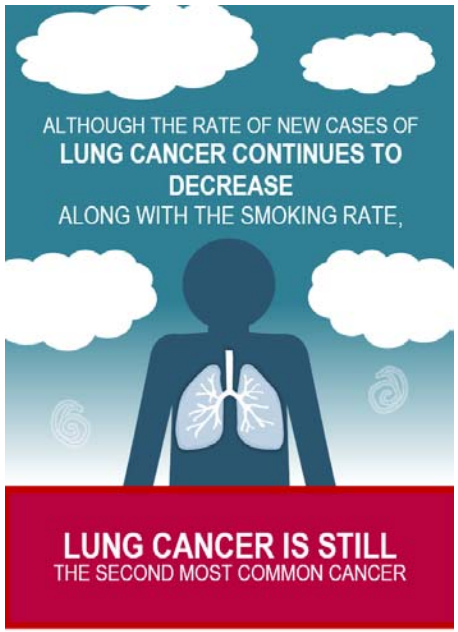
Some of the most intractable behaviors significantly contribute to cancer risk.



Adapted from Wolin, Carson, and Colditz, 2010

Smoking and tobacco

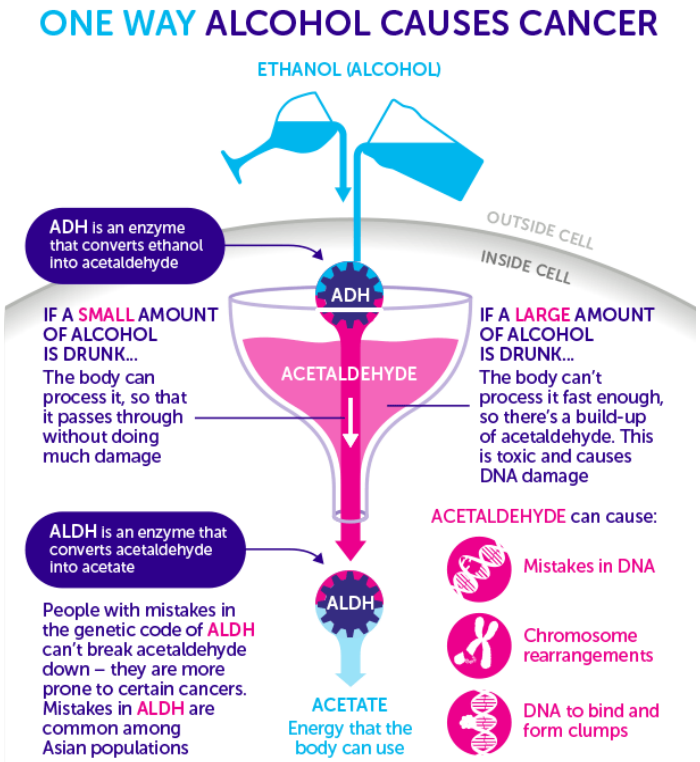
- Lung cancer is the number one cause of cancer death for both men and women
- State cigarette excise tax rates vary dramatically
  - MO - $0.17/20-pack
  - NY - $4.35/20-pack
- Geography matters, with the greatest tobacco burden in the South
- Veterans are among the sub-populations with a higher prevalence of smoking
- Approximately 13% young adults use cigarettes



Diet, weight and alcohol use

- Considerable evidence indicates maintaining a healthy lifestyle can potentially reduce cancer-related morbidity

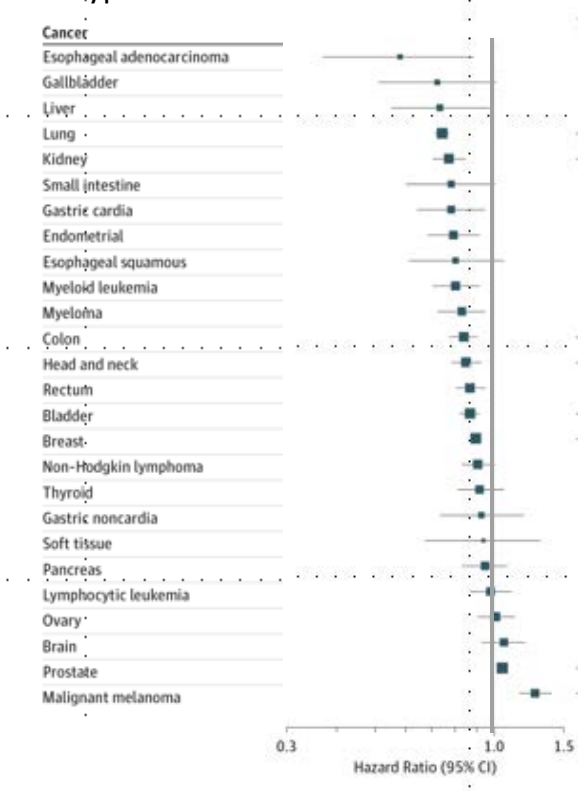
- Alcohol-related cancer is responsible for 3.5 percent of all cancer deaths



Physical activity

- Increasing levels of physical activity associated with lower risk of 13 cancers, including colon, breast and endometrial cancer, but higher risk of malignant melanoma
- Higher levels of physical activity associated with a 7 percent lower risk of total cancer

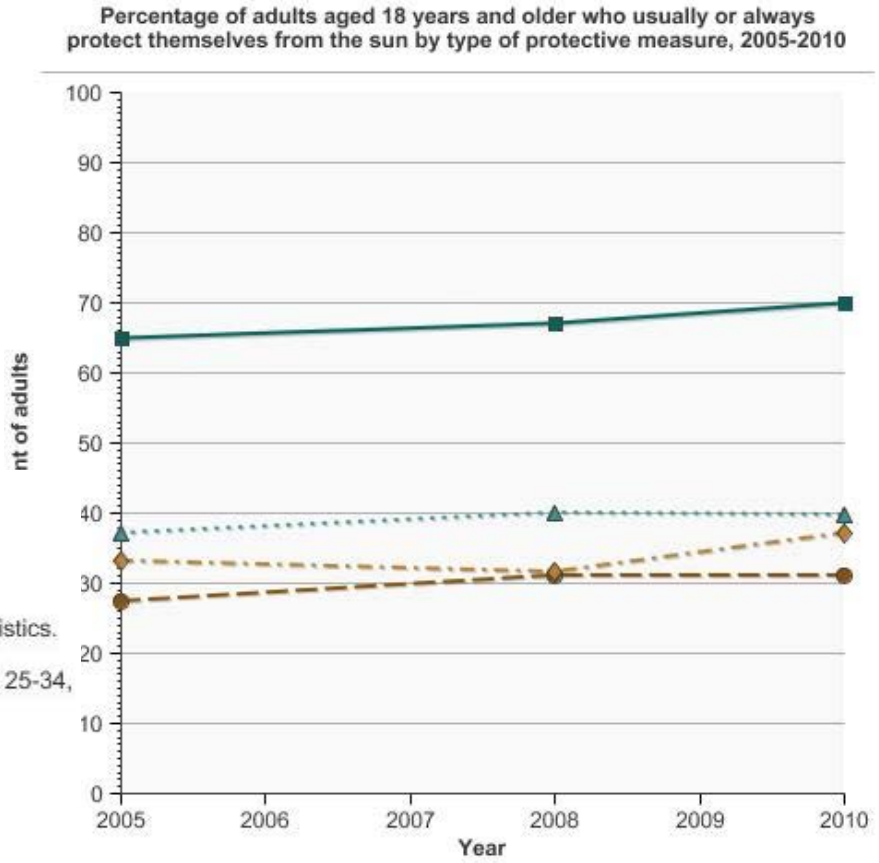
Association of Leisure-Time Physical Activity with Risk of 26 Types of Cancer in 1.44 Million Adults



Moore SC, et al., JAMA Intern Med. 2016

UV exposure and sun protective practices

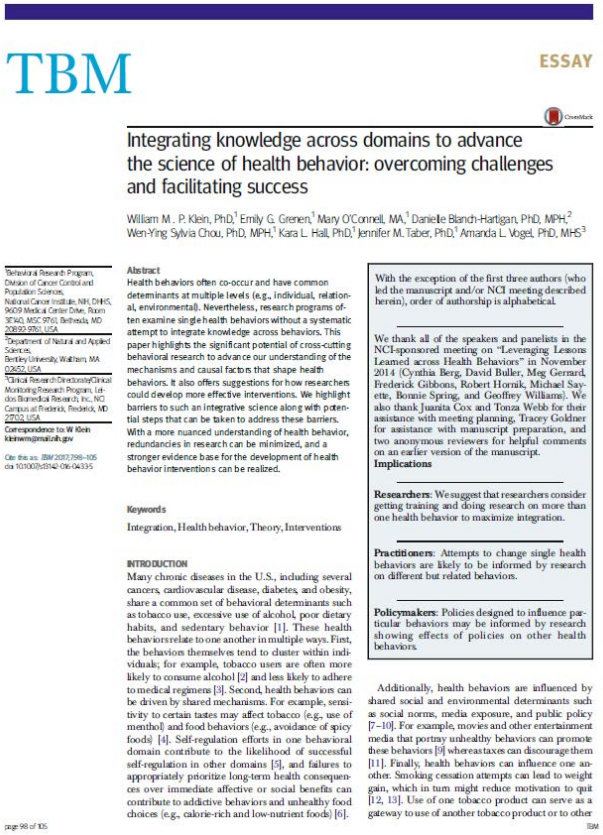
- Reducing unprotected exposure to the sun and avoiding artificial ultraviolet (UV) light from indoor tanning beds, tanning booths, and sun lamps can lower the risk of skin cancer



Source: Centers for Disease Control and Prevention, National Center for Health Statistics. National Health Interview Survey.
Data are age-adjusted to the 2000 US standard population using age groups: 18-24, 25-34, 35-44, 45-64, 65+.

Crosstalk – a unique approach to behavioral medicine

- Repurpose evidence-based approaches
- Apply basic disciplinary principles
- Apply common behavioral theory and identify common mechanisms
- Optimize study design and harmonize data



TBM ESSAY

Integrating knowledge across domains to advance the science of health behavior: overcoming challenges and facilitating success

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Abstract
Health behaviors often co-occur and have common determinants at multiple levels (e.g., individual, relational, environmental). Nevertheless, research programs often examine single health behaviors without a systematic attempt to integrate knowledge across behaviors. This paper highlights the significant potential of cross-cutting behavioral research to advance our understanding of the mechanisms and causal factors that shape health behaviors. It also offers suggestions for how researchers could develop more effective interventions. We highlight barriers to such an integrative science along with potential steps that can be taken to address these barriers. With a more nuanced understanding of health behavior, redundancies in research can be minimized, and a stronger evidence base for the development of health behavior interventions can be realized.

Keywords
Integration, Health behavior, Theory, Interventions

INTRODUCTION
Many chronic diseases in the U.S., including several cancers, cardiovascular disease, diabetes, and obesity, share a common set of behavioral determinants such as tobacco use, excessive use of alcohol, poor dietary habits, and sedentary behavior [1]. These health behaviors relate to one another in multiple ways. First, the behaviors themselves tend to cluster within individuals; for example, tobacco users are often more likely to consume alcohol [2] and less likely to adhere to medical regimens [3]. Second, health behaviors can be driven by shared mechanisms. For example, sensitivity to certain tastes may affect tobacco (e.g., use of menthol) and food behaviors (e.g., avoidance of spicy foods) [4]. Self-regulation efforts in one behavioral domain contribute to the likelihood of successful self-regulation in other domains [5], and failures to appropriately prioritize long-term health consequences over immediate affective or social benefits can contribute to addictive behaviors and unhealthy food choices (e.g., calorie-rich and low-nutrient foods) [6].

With the exception of the first three authors (who led the manuscript and/or NCI meeting described herein), order of authorship is alphabetical.

We thank all of the speakers and panelists in the NCI-sponsored meeting on "Leveraging Lessons Learned across Health Behaviors" in November 2014 (Cynthia Berg, David Buller, Meg Gerrard, Frederick Gibbons, Robert Hornik, Michael Sayette, Bonnie Spring, and Geoffrey Wilkams). We also thank Juanita Cox and Tonza Webb for their assistance with meeting planning, Tracey Goldner for assistance with manuscript preparation, and two anonymous reviewers for helpful comments on an earlier version of the manuscript.

Implications

Researchers: We suggest that researchers consider getting training and doing research on more than one health behavior to maximize integration.

Practitioners: Attempts to change single health behaviors are likely to be informed by research on different but related behaviors.

Policymakers: Policies designed to influence particular behaviors may be informed by research showing effects of policies on other health behaviors.

Additionally, health behaviors are influenced by shared social and environmental determinants such as social norms, media exposure, and public policy [7–10]. For example, movies and other entertainment media that portray unhealthy behaviors can promote these behaviors [9] whereas taxes can discourage them [11]. Finally, health behaviors can influence one another. Smoking cessation attempts can lead to weight gain, which in turn might reduce motivation to quit [12, 13]. Use of one tobacco product can serve as a gateway to use of another tobacco product or to other

Examples of bio-psychosocial factors relevant to cancer control

- Emotion
- Cognition
- Decision-making
- Stress/distress
- Attention
- Motivation
- Genetic predisposition
- Sensory processes

Examples of social & environmental factors in cancer control

- SES/Social determinants
- Discrimination
- Individual/social factors
- Relationships/social support
- Physical/built environment
- Health provider recommendations
- Social and conventional media
- Local, state, Federal policy
- Product availability

Health communication

- Individual level
  - Patient-provider communication
- Mass media
  - Social media
  - Warning labels
  - Campaigns

REUTERS

Many hold mistaken beliefs about reducing risks of cigarette smoking

Will Boggs MD 4 MIN READ

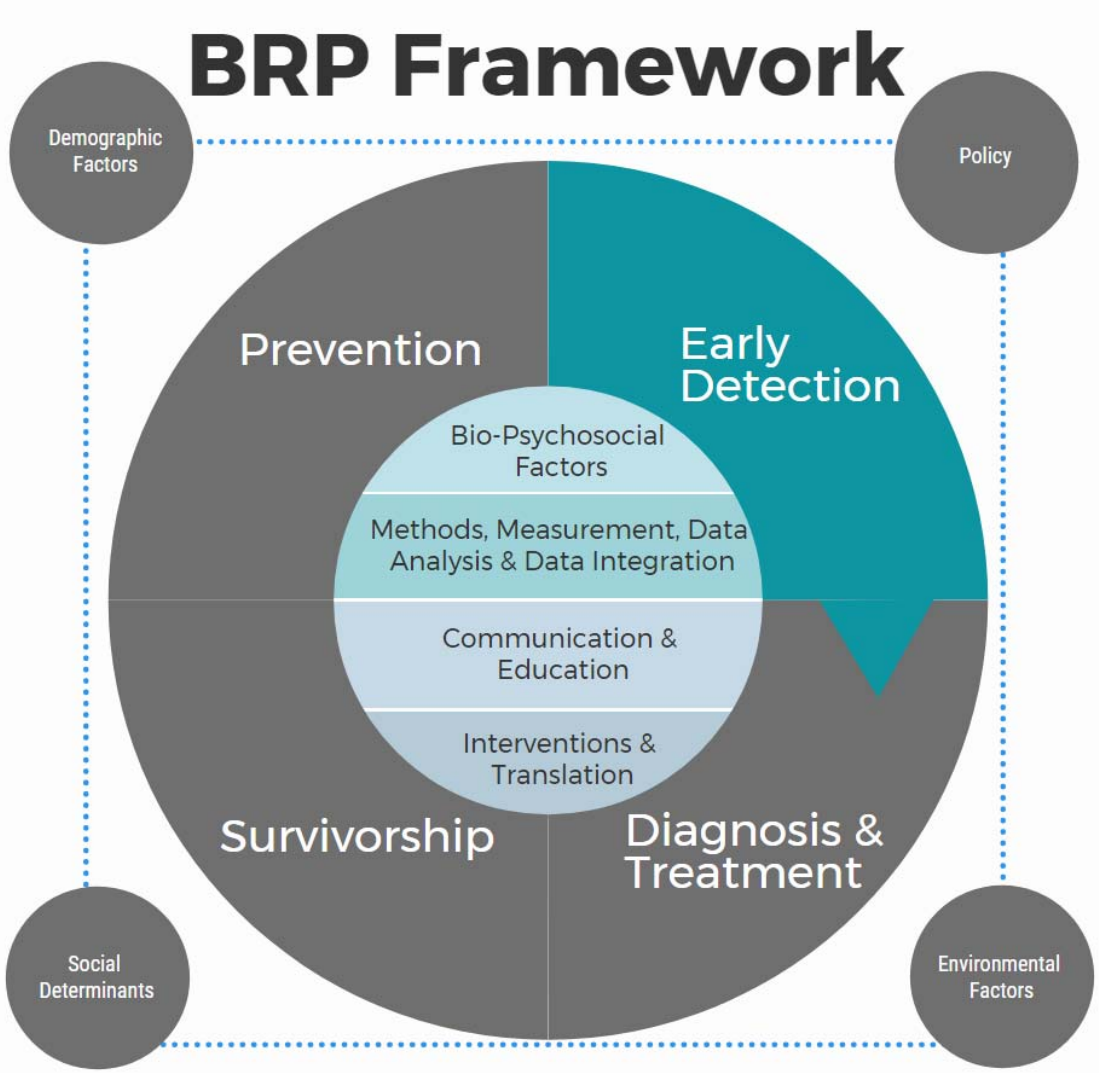
Mistaken beliefs about behaviors that could reduce the risks of cigarette smoking are most common among those most vulnerable to the harmful effects of smoking, U.S. researchers say.

"It is important for the public to understand that the harms of smoking cannot be reduced except by quitting," Annette R. Kaufman from the National Cancer

"It is important for the public to understand that the harms of smoking cannot be reduced except by quitting."
-- Annette Kaufman, Ph.D.

The researchers used information from the Health Information National Trends Survey to find out what people believe about risk-reducing behaviors and whether these beliefs differ between people who smoke, or have smoked in the past and those who have not. They also looked at whether income

Source: Pew Research Center Survey conducted March 7-April 4, 2016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Environmental Factors

Behaviors in a health care context

- HPV vaccination
- Cancer screening
- Genetic testing

HPV vaccines prevent cancer

- Human Papilloma Virus (HPV) is a major cause of cervical cancer
- Two safe and effective vaccines are available to protect against infection with the two most prevalent cancer-causing HPV types
- The Advisory Committee on Immunization Practices (ACIP) recommends routine vaccination for HPV at age 11 or 12

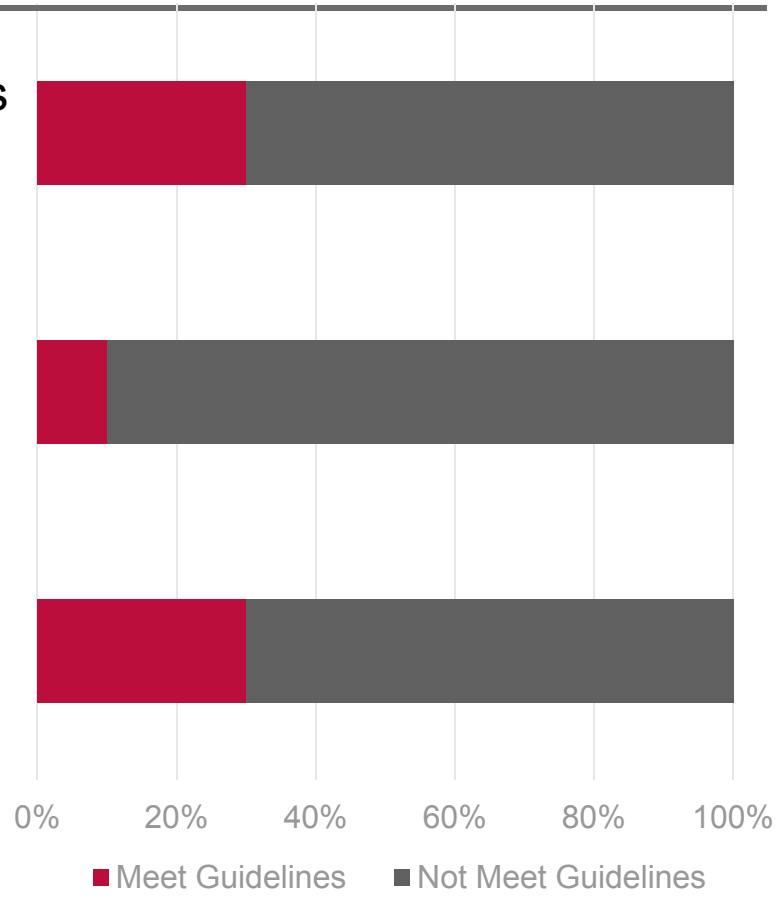
Cancer screening

- Colorectal cancer screening
- Lung cancer screening
- Prostate Specific Antigen (PSA) screening
- Melanoma screening

NLST
National Lung Screening Trial
NATIONAL CANCER INSTITUTE

BRCA 1/2 Referral/Testing

- ~30% of eligible breast cancer patients received guideline concordant testing
- ~10 percent of women meeting guideline criteria reported discussion about BRCA 1/2 testing with a provider
- ~30% of women who were BRCA 1/2 tested did not meet NCCN guideline criteria



Levy, 2011, Chun, 2017; Levy, 2009; Roberts, in preparation

The Cancer Control Continuum

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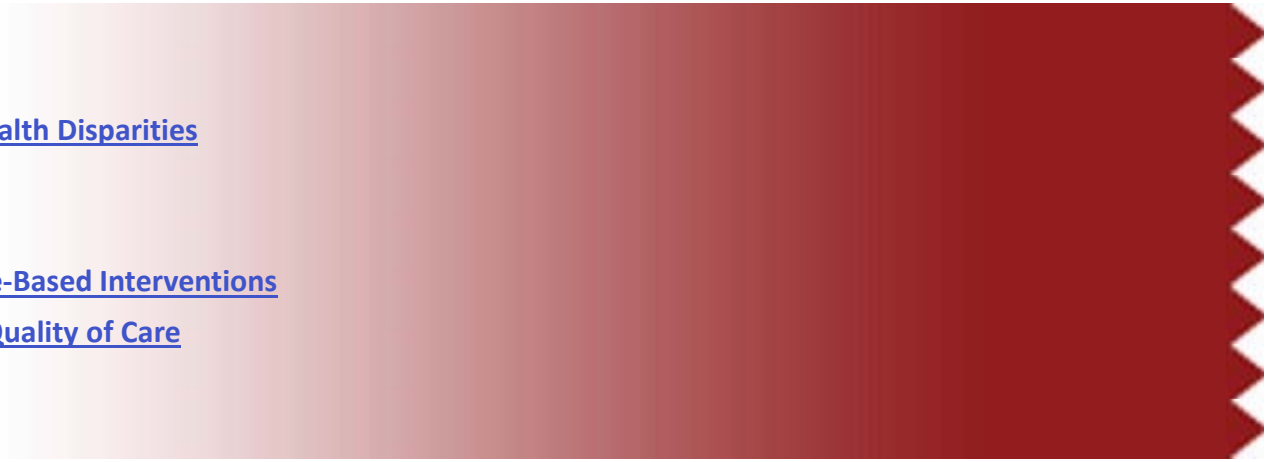


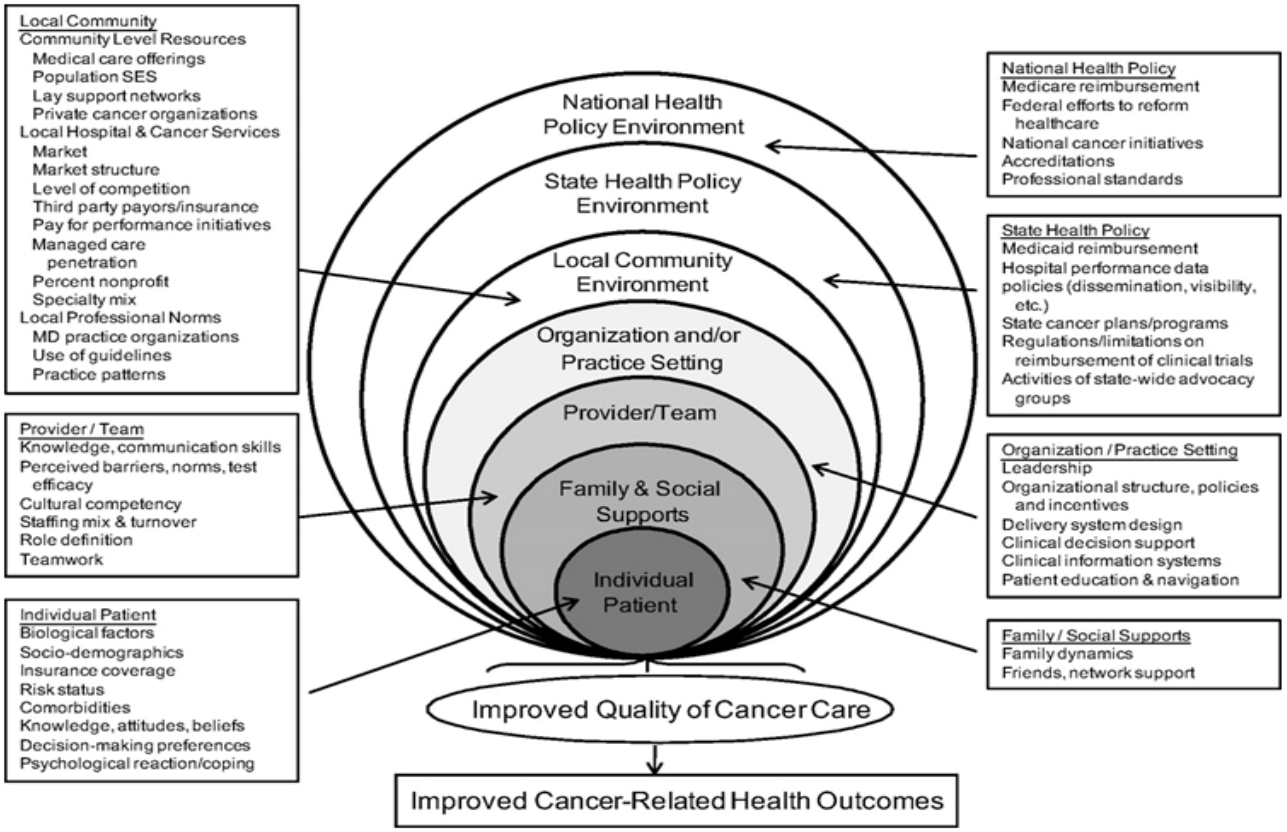
Adapted from David B. Abrams, Brown University School of Medicine


The Perfect Storm
Skyrocketing Costs of Cancer Care & Survivorship
15.5 Million Survivors +1.7M each year
Provider Knowledge Deficits
Chronic & Late Effects of Cancer (Physical, Psychosocial, Financial, Ability to Work)
Provider Shortages (ONC, PCP, Nursing)

Improve Care for Smooth Sailing

- Effective, Efficient Care
- Risk-based, personalized
- Patient-centered
- Toxicity prevention or early management
- Optimize function, QOL, longevity

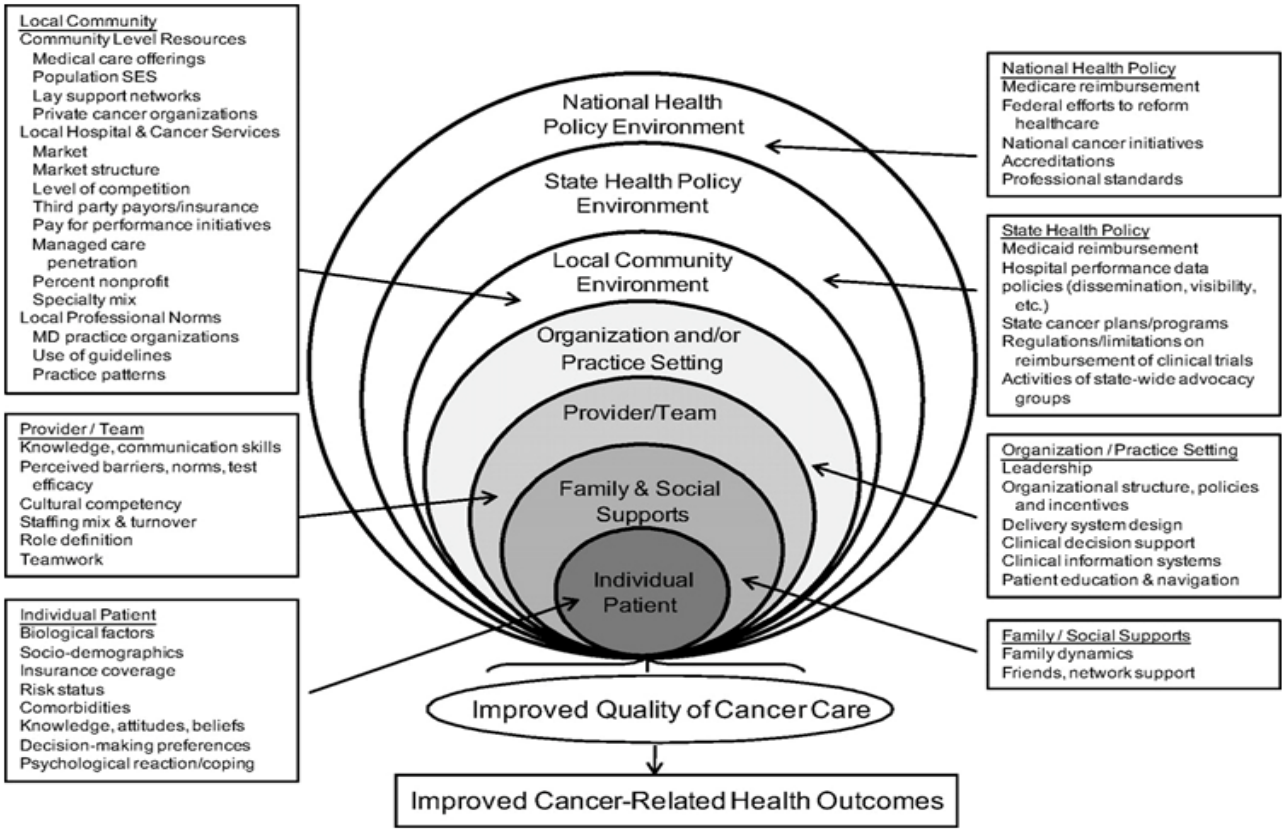
Multilevel influences on Health and Healthcare (Cancer Example)



Taplin S H et al. J Natl Cancer Inst Monogr 2012;2012:2-10

Multilevel influences on Health and Healthcare (Cancer Example)

∧ Of Behavioral & Social Science



Taplin S H et al. J Natl Cancer Inst Monogr 2012;2012:2-10

Rose

Behavioral & Social Science: Rose's Trajectory

Diagnosis
- Decision making
- Pt-provider communication

Treatment
- Toxicity risk
- Toxicity mechanisms
- Assessment/ management
- Adherence
- Caregiver

Follow-up
- Risk-stratified care
- LT adherence
- Prevention

Behavioral & Social Science: Rose's Trajectory

Dx: HF

EOL decision making

Diagnosis
- Decision making
- Pt-provider communication

Treatment
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- Caregiver

Follow-up
- Risk-stratified care
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- Prevention

Diagnosis of 2nd breast cancer

CANCER CARE CHANGES (1)…
Precision Medicine


NEJM — 2/24/16, 8:59 AM

The NEW ENGLAND JOURNAL of MEDICINE

Perspective

A New Initiative on Precision Medicine

Francis S. Collins, M.D., Ph.D., and Harold Varmus, M.D.
N Engl J Med 2015; 372:793-795 | February 26, 2015 | DOI: 10.1056/NEJMp1500523

Comments open through March 4, 2015

Share

Article

"Tonight, I'm launching a new Precision Medicine Initiative to bring us closer to cures for diseases like cancer and diabetes — and to give all of us access to the personalized information we need to keep ourselves and our families healthier."

— President Barack Obama, State of the Union Address, January 20, 2015

President Obama has long expressed a strong conviction that science offers great potential for improving health. Now, the President has announced a research initiative that aims to accelerate progress toward a new era of precision medicine (www.whitehouse.gov/precisionmedicine). We believe that the time is right for this visionary initiative, and the National Institutes of Health (NIH) and other partners will work to achieve this vision.

The concept of precision medicine — prevention and treatment strategies that take individual variability into account — is not new.[1] Blood typing, for instance, has been used to guide blood transfusions for more than a century. But the prospect of applying this concept broadly has been dramatically improved by the recent development of large-scale biologic databases (such as the human genome sequence), powerful methods for characterizing patients (such as proteomics, metabolomics, genomics, diverse cellular assays, and even mobile health technology), and computational tools for analyzing large sets of data. What is needed now is a broad research program to encourage creative approaches to precision medicine, test them rigorously, and ultimately use them to build the evidence base needed to guide clinical practice.

The proposed initiative has two main components: a near-term focus on cancers and a longer-term aim to generate knowledge applicable to the whole range of health and disease. Both components are now within our reach because of advances in basic research, including molecular biology, genomics, and bioinformatics. Furthermore, the initiative taps into converging trends of increased connectivity, through social media and mobile devices, and Americans' growing willingness to participate in research.

Oncology is the clear choice for enhancing the near-term impact of precision medicine. Although cancers, in aggregate, they are among the leading causes of death nationally and worldwide, and they affect a substantial population ages. They are also especially feared, because of their lethality, their symptoms, and the therapies used to treat them. Research has already revealed many of the molecular features of cancer cells. Each cancer has its own genomic signature, with some tumor-specific features and some shared among cancers. Although cancers are largely a consequence of accumulating genomic damage during a person's lifetime, sometimes profoundly. This new understanding of oncogenic mechanisms has

http://www.nejm.org/doi/full/10.1056/NEJMp1500523?view Type=Print&viewClass=Print

Integrate molecular, genomic, cellular, clinical, behavioral, physiological, and environmental data to:

"…enable better assessment of disease risk, understanding of disease mechanisms, and the prediction of optimal therapy for many more diseases…"

THE JOURNAL OF PRECISION MEDICINE
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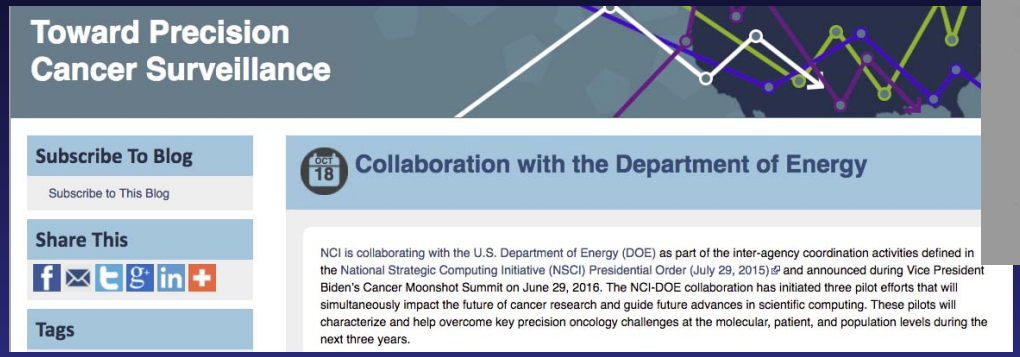
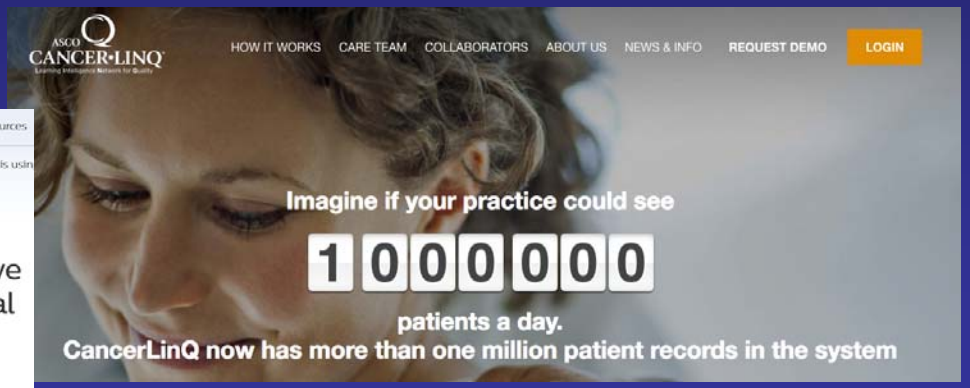
National Cancer Institute

CANCER CARE CHANGES (2)…
BIG DATA & AI





BIAS IN AI

PostEverything • Perspective

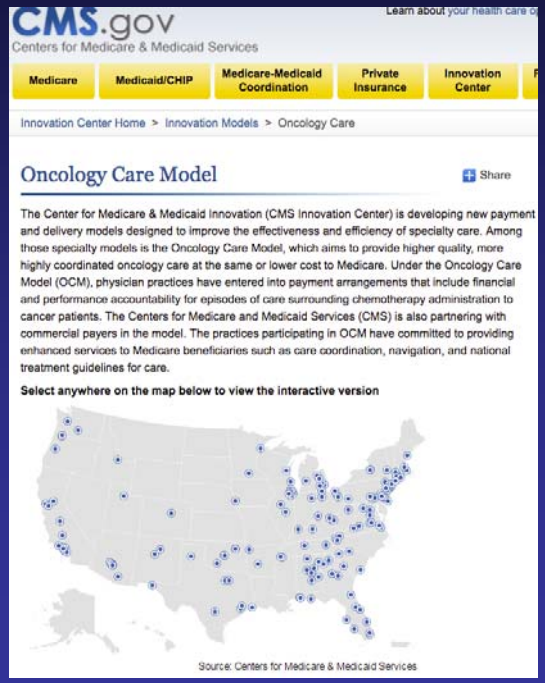
Tech's sexism doesn't stay in Silicon Valley. It's in the products you use.

By Sara Wachter-Boettcher August 8 at 12:44 PM Follow @sara_ann_marie

Sara Wachter-Boettcher is a web consultant and author of the forthcoming book "Technically Wrong: Sexist Apps, Biased Algorithms, and Other Threats of Toxic Tech."

"The TIME WARP of AI: Study after study has shown that biased machine-learning systems result in everything from job-search ads that show women in lower-paying positions than men to predictive-policing software that perpetuates disparities in communities of color."

CANCER CARE CHANGES (3)…Transition from Fee-for-Service to *Value-based reimbursement*



- Testing of novel, bundled payment models
- Search for interventions with
  - "bang for buck" for multiple chronic diseases
- Change practice patterns

CANCER CARE CHANGES (4)…
IMMUNOTHERAPY !!!

ASCO CONNECTION

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ASCO Names Immunotherapy 2.0 as Cancer Advance of the Year In Latest Clinical Cancer Advances Report

Feb 01, 2017

VOLUME 35 · NUMBER 12 · APRIL 20, 2017

JOURNAL OF CLINICAL ONCOLOGY | ASCO SPECIAL ARTICLE

Clinical Cancer Advances 2017: Annual Report on Progress Against Cancer From the American Society of Clinical Oncology

Harold J. Burstein, Lada Krilov, Jeanny B. Aragon-Ching,† Nancy N. Baxter,† E. Gabriela Chiorean,† Warren Allen Chow,† John Frederick De Groot,† Steven Michael Devine,† Steven G. DuBois,† Wafik S. El-Deiry,† Andrew S. Epstein,† John Heymach,† Joshua Adam Jones,† Deborah K. Mayer,† Rebecca A. Miksad,† Nathan A. Pennell,† Michael S. Sabel,† Richard L. Schilsky,‡ Lynn Mara Schuchter,† Nadine Tung,† Karen Marie Winkfield,† Lori J. Wirth,† and Don S. Dizon**

Author affiliations and support information (if applicable) appear at the end of this

A MESSAGE FROM ASCO'S PRESIDENT

Toxicity from Cancer Immunotherapy

"...hyperactivated T-cell response with reactivity directed against normal tissue"

Checkpoint inhibitors induce autoinflammatory response

Adoptive cell therapy (T cells) induces Cytokine Release Syndrome resembling sepsis

IFN-alpha, IL-2 induce fatigue, fever, autoimmunity, neurotoxicity, and myocarditis

Long-term toxicities???

Weber et al, J Clin Oncol. 2015 Jun 20;33(18):2092-9

Sections

The Washington Post
Democracy Dies in Darkness

Health & Science

This 8-year-old is free of cancer — for now — after a 'breakthrough' treatment

CAR T cells

- Remission
- Brain swelling, death

Precision Medicine, Risk-based Comprehensive Care

Better predict: recurrence, 2nd cancers, chronic & late effects

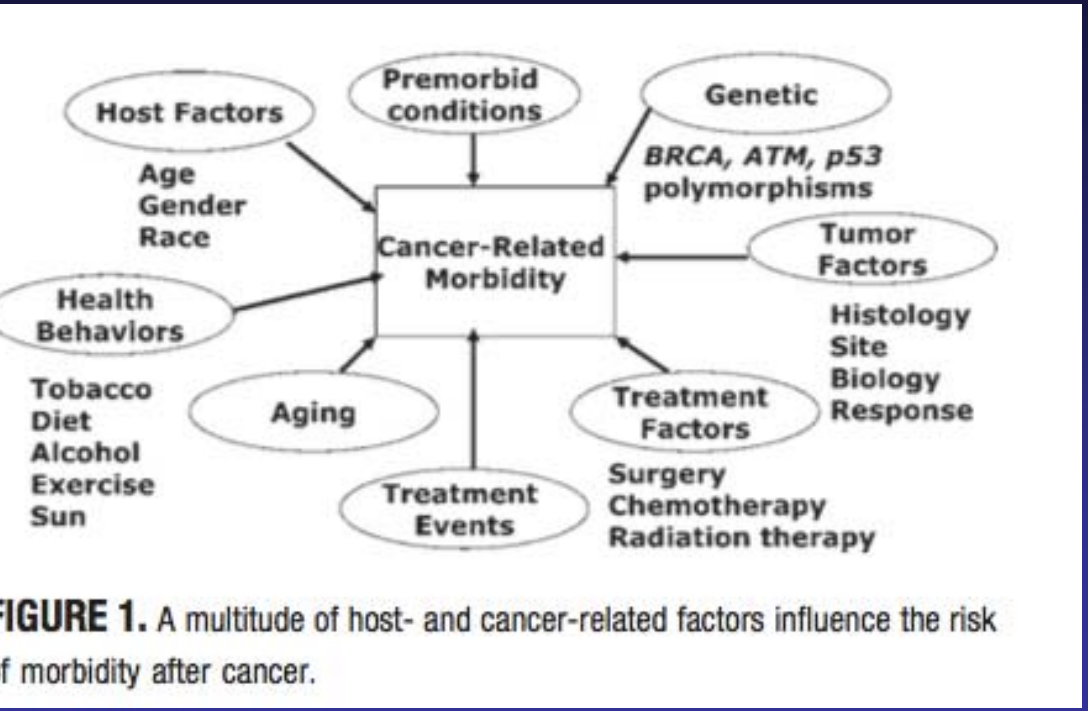

FIGURE 1. A multitude of host- and cancer-related factors influence the risk of morbidity after cancer.

Hudson, 2005, *Cancer*

THANK YOU !

CATHERINE.ALFANO@CANCER.ORG

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