

Risky translation: The promise and pitfalls of discussing health risks with the public

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SCHOOL OF MEDICINE

Translation is critical but difficult



What is risk?



Objective

RR

RRR

odds

OR

HR

NNT

NNH

AR

ARR

Attributable
risk

What is risk?



Subjective
Danger
Hazard
Uncertainty
Certainty
All-or-nothing
Frightening
Severe

Han et al, *Health Expectations*, 2009
Holmberg, *Health, Risk & Society*, 2010
Reyna, *Medical Decision Making*, 2008
Slovic, *The Perception of Risk*, 2000

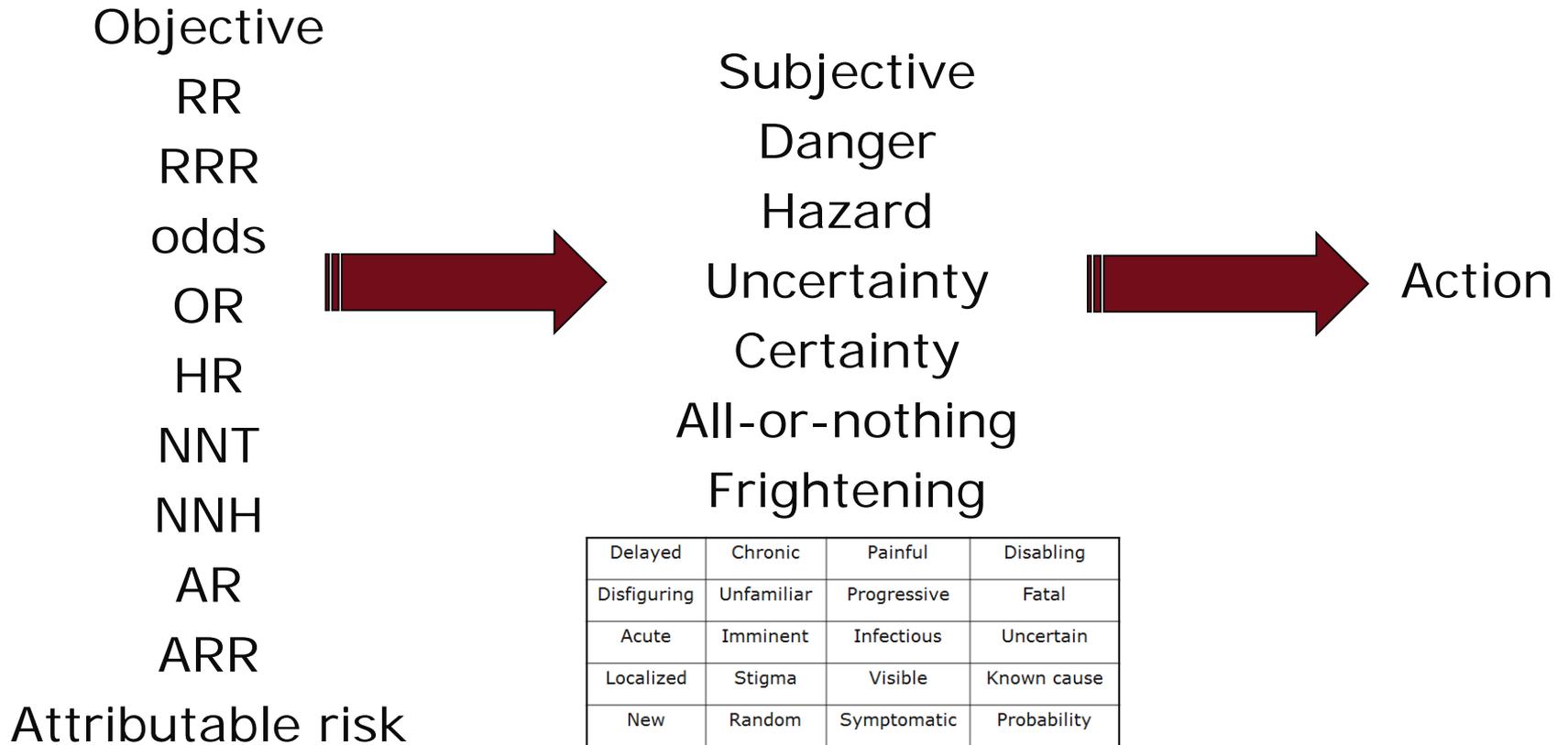
What is risk?

Delayed	Chronic	Painful	Disabling
Disfiguring	Unfamiliar	Progressive	Fatal
Acute	Imminent	Infectious	Uncertain
Localized	Stigma	Visible	Known cause
New	Random	Symptomatic	Probability

Slovic, *The Perception of Risk*, 2000

Weinstein, *Society of Behavioral Medicine*, 2003

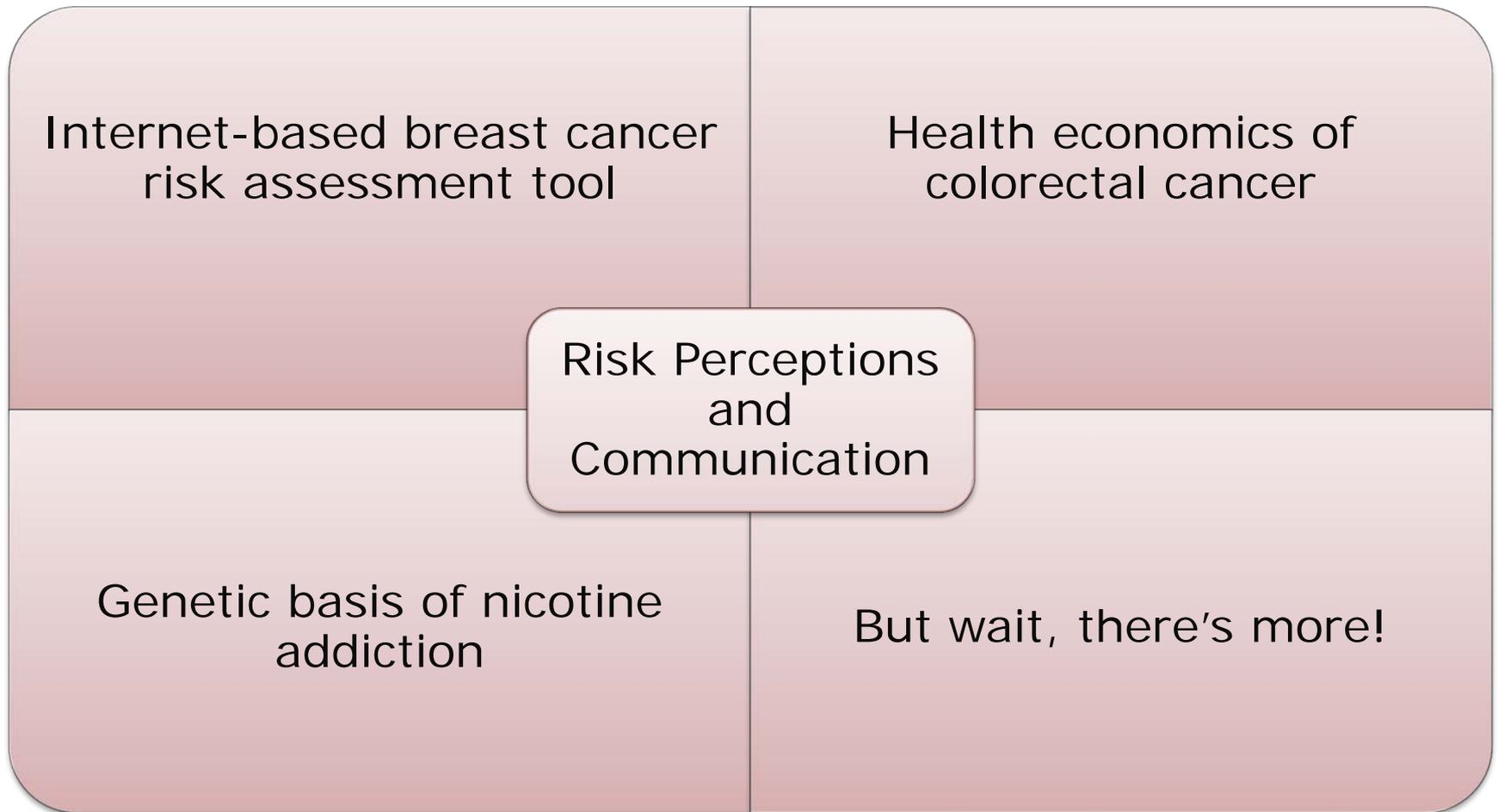
The challenge



What does it mean and what should I do?



Applicability across multiple domains



Applicability across multiple domains

Internet-based breast cancer
risk assessment tool

NIH NCATS #UL1TR000448 and
the Barnes Jewish Hospital Foundation

Health economics of
colorectal cancer

Risk Perceptions
and
Communication

Genetic basis of nicotine
addiction

But wait, there's more!

Internet-based cancer risk assessment

Detailed Breast Cancer Risk Calculator

Estimate your risk of breast cancer by answering these questions.

1. How many of your sisters, daughters or mother had breast cancer? Risk increases with number of first degree relatives affected.

2. How many benign breast biopsies have you had? "Benign" means: no cancer. Have you ever had a biopsy result showing "atypical hyperplasia"?

NATIONAL CANCER INSTITUTE U.S. National Institutes of Health | www.cancer.gov

Breast Cancer Risk Assessment Tool

An Interactive Tool For Measuring the Risk of Invasive Breast Cancer

> Risk Calculator

About the Tool

Breast Cancer Risk

The Breast Cancer Risk Assessment Tool is an interactive tool designed by scientists at the National Cancer Institute (NCI) and the [National Surgical Adjuvant Breast and Bowel Project \(NSABP\)](#) to estimate a woman's risk of developing [invasive breast cancer](#). The tool has been updated for African American women based on the Contraceptive and Reproductive Experiences (CARE) Study. See [About the Tool](#) for more information.

Before using the tool, please note the following:

What is your risk?		
	Cancer: There's much more to it than just smoking and lung cancer.	What's your cancer risk?
	Diabetes: Over 18 million in the U.S. suffer from it. Take steps now to lower your risk.	What's your diabetes risk?
	Heart disease: The #1 killer in the U.S. is also one of the most preventable.	What's your heart disease risk?
	Osteoporosis: Calcium isn't the only way (or even the best way) to protect yourself.	What's your osteoporosis risk?
	Stroke: Most cases of this feared disease can be avoided by lifestyle changes.	What's your stroke risk?

Waters et al., *Journal of Medical Internet Research*, 2009
www.yourdiseaserisk.wustl.edu
www.cancer.gov/bcrisktool/
<http://www.chiprehab.com/CVD/index.php>
www.halls.md/breast/risk.htm

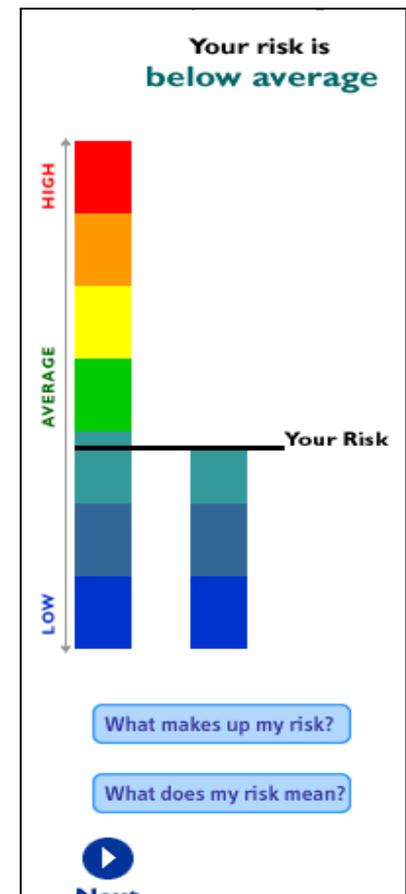
...but their output varies...

5 Year Risk

- > This woman (age 52) 3.7%
- > Average woman (age 52): 1.4%

Explanation

Based on the information provided (see below), the woman's estimated risk for developing invasive breast cancer over the next 5 years is 3.7% compared to a risk of 1.4% for a woman of the same age and race/ethnicity from the general U.S. population. This calculation also means that the woman's risk of NOT getting breast cancer over the next 5 years is 96.3%.



Calculate Results

using

NSABP model 2

[click for Gail Model and NSABP formula info.](#)

Your chance of being diagnosed with breast cancer is estimated to be: **22.5%** within lifetime (to age 90).

4.8% within 5 years,

15.4% within 20 years,

8.4% within 10 years,

22.5% within 30 years,

Your true risk could be somewhere within a range around these estimates.

Study aim and design

What is the effect of an internet-based breast cancer risk assessment tool on key social cognitive precursors of behavior change, when optimal risk communication strategies are used?

- Experimental design with 1 month follow-up
- 132 women with no prior cancer history (target N=200)

Breast Cancer Risk Factors Table

The table below shows the relative risk of breast cancer for many factors. The relative risk compares the risk of breast cancer for people who have the factor to those who do not. Factors are grouped based on the strength of the scientific evidence for each risk.

- Established and probable have the strongest evidence behind them and are recognized as linked (or not linked in some cases) to breast cancer.

Risk Categories

Strong increase	Moderate increase	Weak increase	No increase or decrease	Weak decrease	Moderate decrease	Strong decrease
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Established and Probable Factors

Generally recognized as linked (or not linked in some cases) to breast cancer.

Factor	Risk of breast cancer for people with the factor compared to those without the factor
Age	Strong increase in risk
Being female	Strong increase in risk
BRCA1 or BRCA2 gene mutation	Strong increase in risk
Family history of breast cancer	
• More than one immediate family member	Strong increase in risk
• One immediate family member	Moderate increase in risk
Hyperplasia (benign breast condition)	
• Atypical	Strong increase in risk
• Usual	Moderate increase in risk
Personal history of cancer (including invasive breast cancer, DCIS, Hodgkin's disease and other cancers)	Strong increase in risk
Childbearing	
• Not having children	Moderate increase in risk
• Having a first child after age 35	Moderate increase in risk
Age at first period < 12 years	Weak increase in risk
Age at menopause > 55 years	Weak increase in risk
Alcohol consumption (one or more drinks/day)	
• No daily multivitamin with folate	Weak increase in risk
• With daily multivitamin with folate	No increase in risk
Ashkenazi Jewish heritage	Weak increase in risk
Birth control pills (current or recent use only)	Weak increase in risk
Being tall	Weak increase in risk
Postmenopausal hormone use (current or recent use only)	
• Estrogen only	Weak increase in risk
• Estrogen + progestin	Moderate increase in risk
Breastfeeding	Weak decrease in risk
Tamoxifen and raloxifene daily for 5 years or more (prescription drugs for those at higher risk)	Strong decrease in risk
Weight gain	
• Premenopausal	No increase or decrease in risk
• Postmenopausal	Moderate increase in risk
Physical activity	
• Premenopausal	No increase or decrease in risk
• Postmenopausal	Weak decrease in risk

Results: Breast Cancer



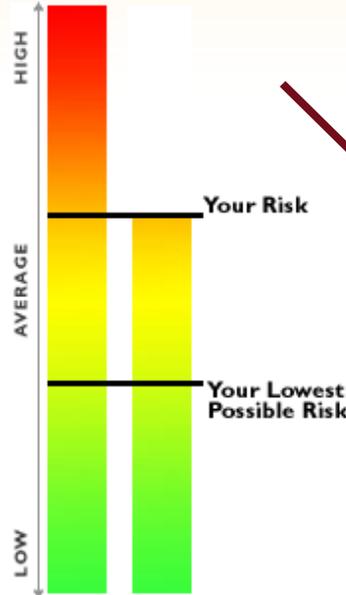
Your risk is Above Average compared to a typical woman your age.

Above average risk doesn't mean you'll definitely get breast cancer. It's just an estimate based on your risk factors, some of which you may not be able to change. If you have any concerns, talk to a doctor.

Screening Tip

Beginning at age 20, get screened regularly. [More >>](#)

Lower Your Risk



You have 3 things you can do to lower your risk.

To see what your risk could be, click on a box and watch your risk drop.

- Avoid birth control pills. Ask a doctor about the risks and benefits.
- Drink less than 1 serving of alcohol a day.
- Increase your physical activity. Work towards at least 30 minutes a day.

Watch your weight. While your weight gain doesn't increase your risk right now, it's still important to keep your weight in check.

Breast cancer has few controllable risk factors. But it's still important to know your risk and how these factors relate to it. Choose a healthy lifestyle to protect against breast cancer as well as other diseases. And don't forget to follow the screening recommendations.

[What makes up my risk?](#)

[What does my risk mean?](#)

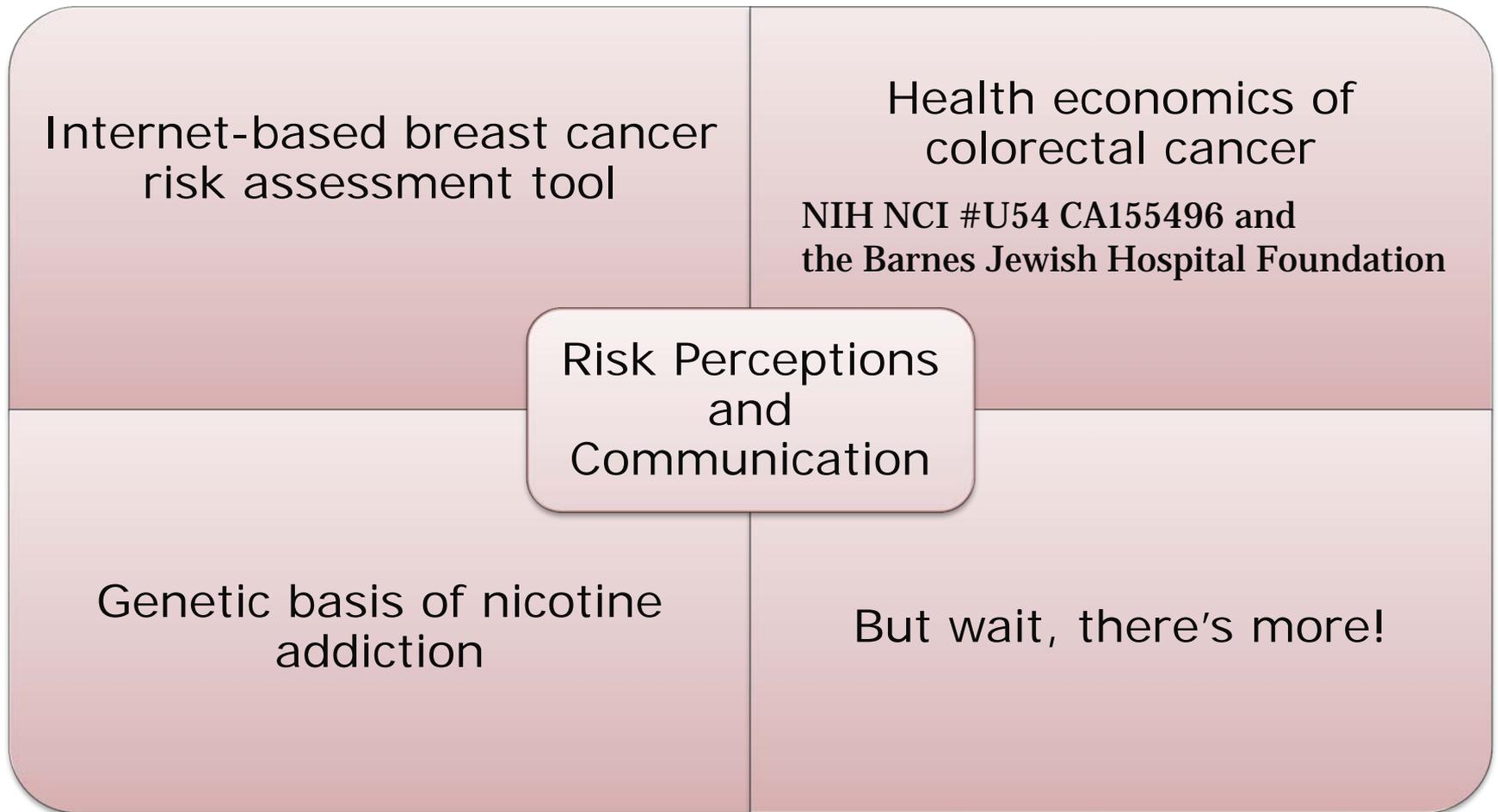
Results



But...



Applicability across multiple domains



The solution

Capitalize on what we already know

Delayed	Chronic	Painful	Disabling
Disfiguring	Unfamiliar	Progressive	Fatal
Acute	Imminent	Infectious	Uncertain
Localized	Stigma	Visible	Known cause
New	Random	Symptomatic	Probability

The solution: Health economics?

Quality of life (QALYs, DALYs)

Delayed	Chronic	Painful	Disabling
Disfiguring	Unfamiliar	Progressive	Fatal
Acute	Imminent	Infectious	Uncertain
Localized	Stigma	Visible	Known cause
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The solution: Health economics?

Years of life lost (YLLs)

Delayed	Chronic	Painful	Disabling
Disfiguring	Unfamiliar	Progressive	Fatal
Acute	Imminent	Infectious	Uncertain
Localized	Stigma	Visible	Known cause
New	Random	Symptomatic	Probability

The solution: Health economics?

Cost

Delayed	Chronic	Painful	Disabling
Disfiguring	Unfamiliar	Progressive	Fatal
Acute	Imminent	Infectious	Uncertain
Localized	Stigma	Visible	Known cause
New	Random	Symptomatic	Probability

Study aim and design

Compare economic health indicators (Cost, Quality of Life, Life Years) to usual care (probability of developing CRC) in increasing social-cognitive precursors of physical activity.

- Experimental design
- General population (N=816, Survey Sampling International)

Mallory Leung calculations

National Health Interview Survey (NHIS), including mortality linked files

Medical Expenditure Panel Survey Household Component (MEPS-HC)

Usual care

What does colon cancer mean to you?



The average person has a 5% CHANCE of getting colon cancer at some point in their lifetime.

This means that 5 out of 100 people will get colon cancer.

30 minutes of physical activity, 5 days a week, can LOWER YOUR CHANCES of getting colon cancer!

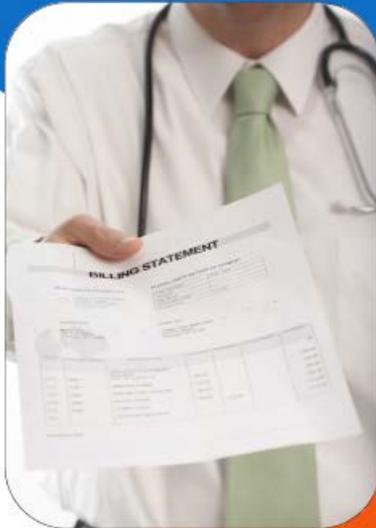
Get active. Prevent colon cancer!

Learn what you can do: www.cdc.gov/physicalactivity/strategies



Cost—Negative frame

What does \$10,000
mean to you?



People who get colon cancer SPEND OVER \$10,000
in out-of-pocket medical costs.

30 minutes of physical activity, 5 days a week,
can lower your chances of getting colon cancer
and help you AVOID SPENDING OVER \$10,000!

Get active. Prevent colon cancer. Avoid spending money!

Learn what you can do: www.cdc.gov/physicalactivity/strategies



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Years of life—Negative frame

What does losing 10 years of life mean to you?



People who get colon cancer LIVE 10 FEWER YEARS than people who do not get colon cancer.

30 minutes of physical activity, 5 days a week, can lower your chances of getting colon cancer and help you AVOID LOSING 10 YEARS OF LIFE!

Get active. Prevent colon cancer. Avoid losing years of your life!
Learn what you can do: www.cdc.gov/physicalactivity/strategies



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Quality of life—Negative frame

What does 7 years of
bad health mean to you?



People who get colon cancer live 7 MORE YEARS
IN BAD HEALTH than people who do not get colon cancer.

30 minutes of physical activity, 5 days a week,
can lower your chances of getting colon cancer and
help you AVOID LIVING 7 YEARS IN BAD HEALTH!

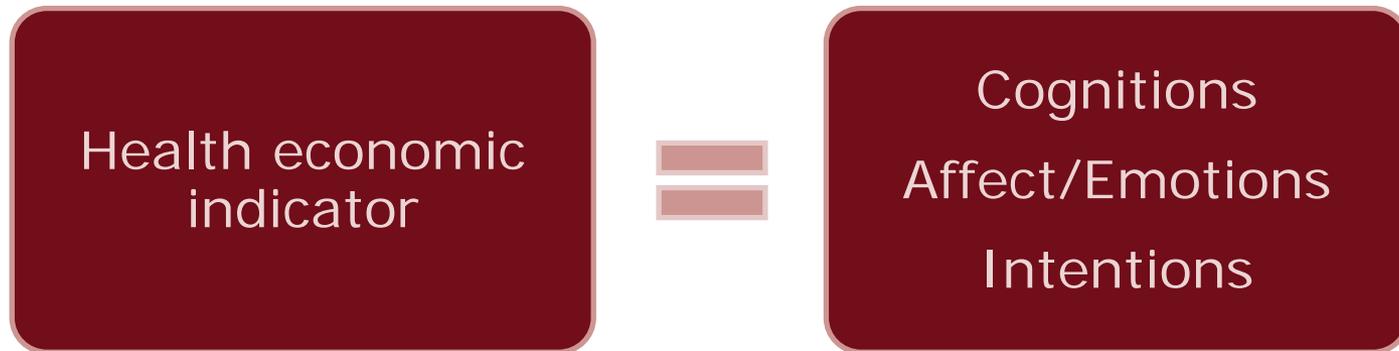
Get active. Prevent colon cancer. Avoid living in bad health!

Learn what you can do: www.cdc.gov/physicalactivity/strategies

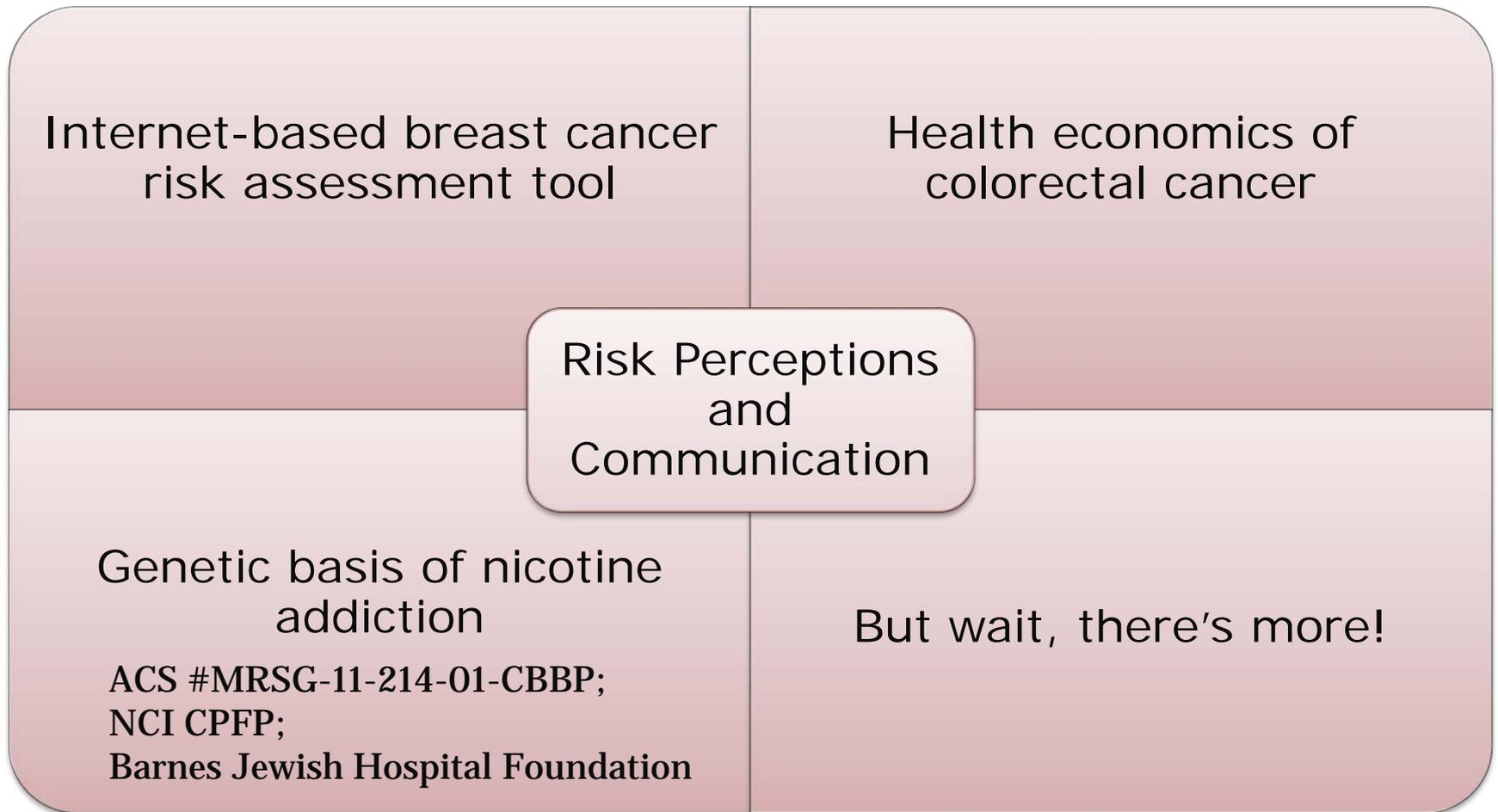


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Results



Applicability across multiple domains



msn Outlook More ▾ bing TODAY Nightly News Meet the Press Dateline

Home US World Politics Business Sports Entertainment Health

Addictions on  NBCNEWS.com

Can't quit smoking? Blame your genes

New studies show 'double whammy' link to addiction and cancer

www.nbcnews.com/id/23919596/ns/health-addictions/t/cant-quit-smoking-blame-your-genes/

Several quantitative and qualitative studies

Experiment with college-aged smokers

Revealing genetic etiology did not change beliefs.

Focus groups with socio-demographically diverse adult smokers

“Is this true?”... “Sounds like some B.S.”

Smoking and Genetics

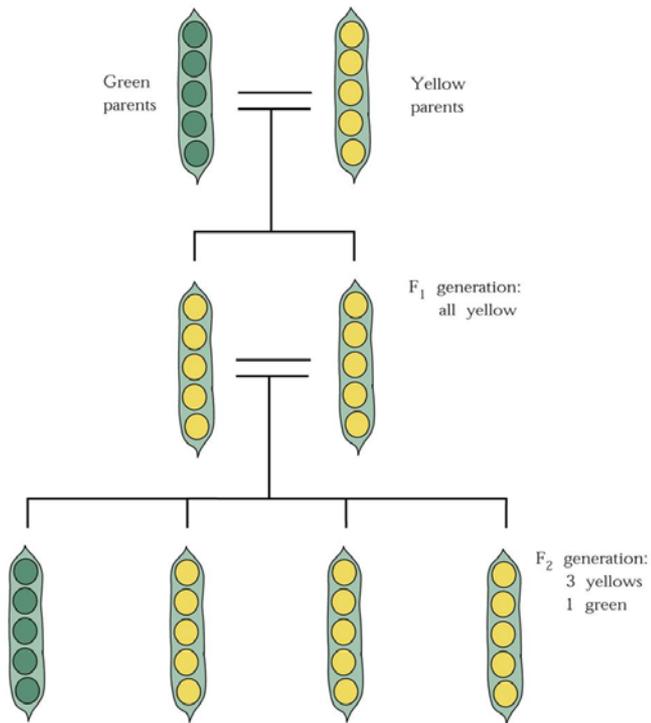
Intervention with socio-demographically diverse adult smokers

Intervening on causes of skepticism was ineffective.

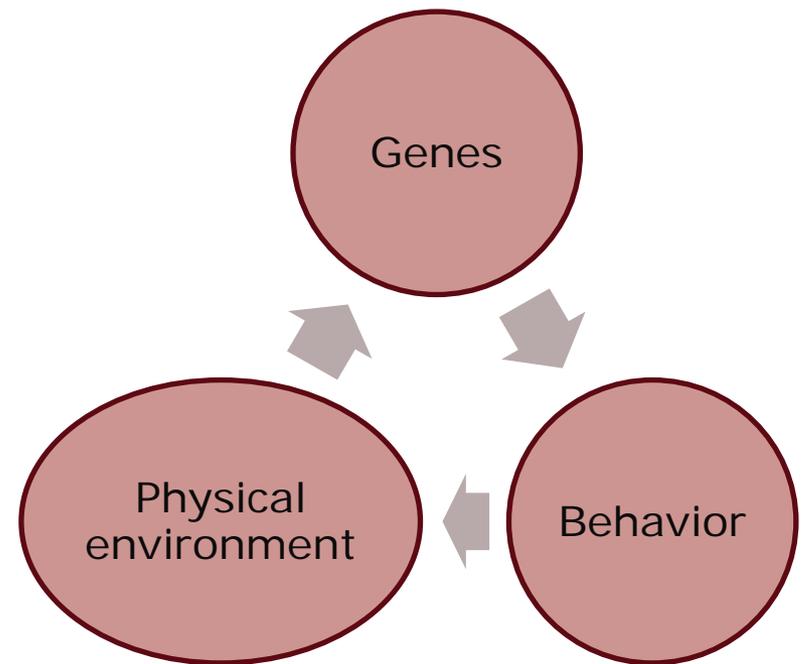
Population-based survey of the correlates of multifactorial beliefs

MF beliefs associated with cancer screening.

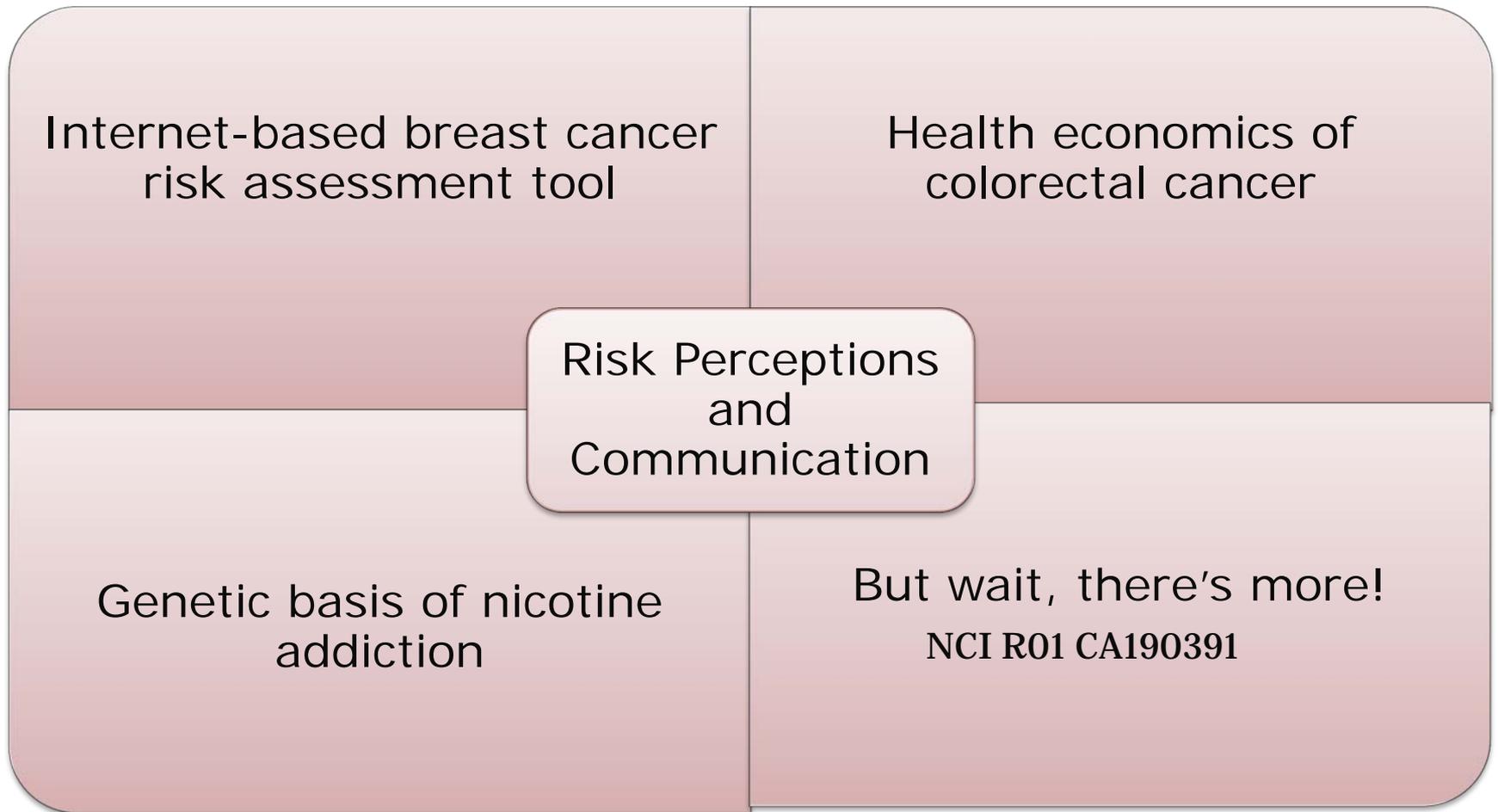
Lay and expert beliefs are not concordant



≠

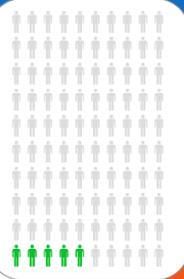


Applicability across multiple domains



Traditional disease-focused communication

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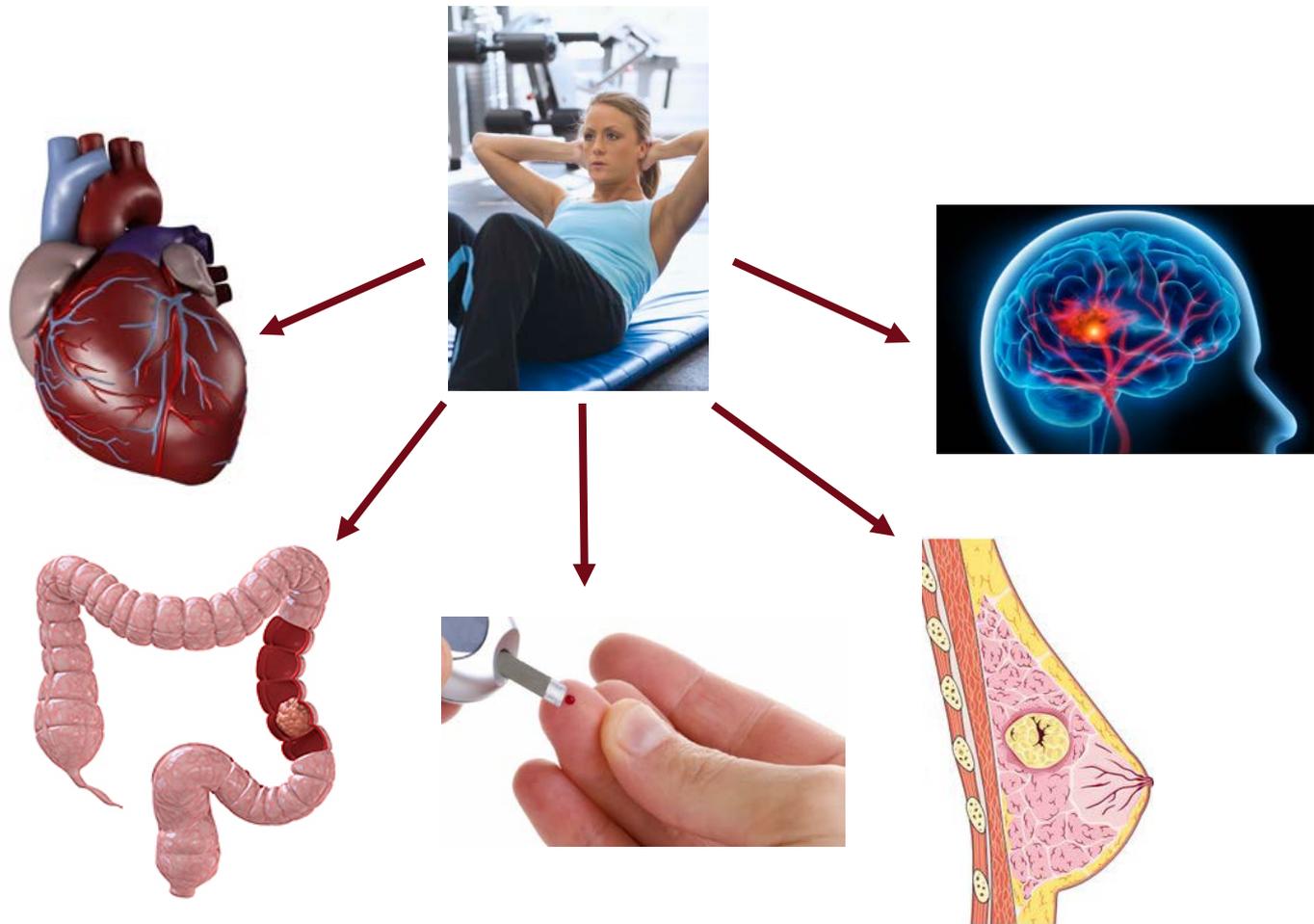
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Wellness-focused communication



Promise in the Pitfalls



Thank you!

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Acknowledgements

Collaborators

Stephanie Fowler
Annette Kaufman
Eva Janssen
Mallory Leung
Ying Liu
Michelle Stock
Helen Sullivan

Staff and Students

Linda Ball
Avissek Datta
Carrie Kincaid
Jaclyn McGuire
Courtney Wheeler

Mentors

Graham Colditz
Sarah Gehlert
Brad Hesse
Neil Weinstein