

# Your Disease Risk: The Culmination of 17 Years of Transdisciplinary Research

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Washington University in St. Louis

SCHOOL OF MEDICINE

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**Your Disease Risk**  
 THE SOURCE ON PREVENTION

- Cancer
- Diabetes**
- Heart disease
- Osteoporosis
- Stroke

8 ways  
to prevent  
disease

What is...?

- Prevention
- Risk
- A Screening Test

How to...

- Estimate Risk

Community Action

my results: **No Results Yet** ▼

[About the Move to Siteman](#)

Welcome to *Your Disease Risk*, the source on prevention. Here, you can find out your risk of developing five of the most important diseases in the United States and get personalized tips for preventing them.

Developed over the past ten years by world-renowned experts, *Your Disease Risk* collects the latest scientific evidence on disease risk factors into one easy-to-use tool.

To get started, choose one of the diseases below.

| What is your risk?  |   |                                   |
|---|---|-----------------------------------|
|   | <b>Cancer: There's much more to it than just smoking and lung cancer.</b>                       | What's your cancer risk? →        |
|  | <b>Diabetes: Over 18 million in the U.S. suffer from it. Take steps now to lower your risk.</b> | What's your diabetes risk? →      |
|  | <b>Heart disease: The #1 killer in the U.S. is also one of the most preventable.</b>            | What's your heart disease risk? → |
|  | <b>Osteoporosis: Calcium isn't the only way (or even the best way) to protect yourself.</b>     | What's your osteoporosis risk? →  |

[www.yourdiseaserisk.wustl.edu](http://www.yourdiseaserisk.wustl.edu)

# Origins in 1994

Creation of the Harvard Center for Cancer Prevention (Harvey Fineberg)

Goal: To bring additional focus to cancer prevention, drawing on Harvard's strengths in public health, medicine, molecular biology, statistics, and social and behavioral sciences.

*“Through communication, behavior change, and cutting-edge research, the Center is enhancing society's capacity to stop cancer.”*

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# Initial priorities and next steps

To review and summarize evidence for **both** academic **and** lay audiences.

| Etiology   | Prevention  |
|--|---|
| Harvard Report on Cancer Prevention. Volume 1: Causes of human cancer, summary. Cancer Causes Control. 1996;7 Suppl 1 (3):S55-8. | Harvard Report on Cancer Prevention. Volume 2: Prevention of human cancer. Cancer Causes Control. 1997;8 Suppl 1:S1-50. |

To develop tools to help *the public* understand that cancer can be prevented

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# Inherently transdisciplinary

A wide range of knowledge, perspectives,  
and experiences

Competing standards of evidence and  
practice, including benefits and drawbacks  
to each approach

*Successful resolution required a unified  
goal, compromise, accommodation,  
and excellent communication skills*



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# Inherently transdisciplinary

Biostatistics

Epidemiology

Communication science

Computer science

Human factors

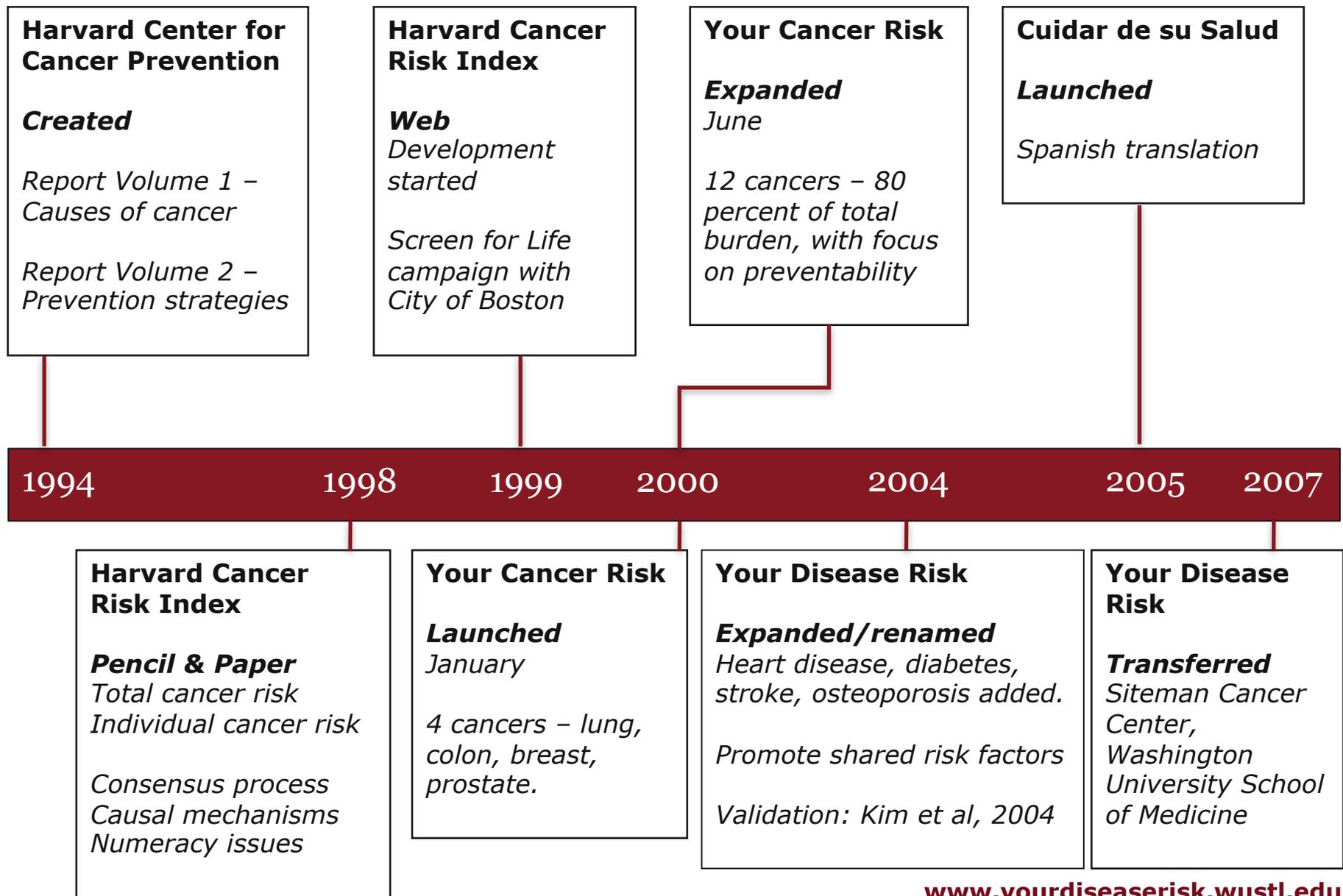
Web design

Decision science

Psychology



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# Usage

Heavy usage, varies over time

Conservatively we can estimate  
1000 visitors per day,  
365 days a year,  
for 12 years

***4,000,000 visitors***



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February 03, 2000

the HARVARD UNIVERSITY **Gazette**

HARVARD GAZETTE ARCHIVES

**New Cancer Risk Website Logs Record-breaking Launch**

More than 13,000 visits were logged on to a new Website of the Harvard Center for Cancer Prevention within the first week

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Online

**www. quitsmokingandstartexercisingbeforeitstoolate.com**

Harvard can now assess your health risks via the internet

Jo Revill, health editor  
Sunday July 4, 2004

Recent articles

The New York Times  
Wednesday, May 27, 2009

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**Well**

Tara Parker-Pope on Health

March 27, 2009, 9:48 AM

**A Better Health Quiz**

By TARA PARKER-POPE

More than 27 mil which asks quest young or old you

| Date | Number of Visits |
|------|------------------|
| 3/1  | 1,500            |
| 3/6  | 1,500            |
| 3/11 | 1,500            |
| 3/16 | 1,500            |
| 3/21 | 1,500            |
| 3/26 | 1,500            |
| 3/31 | 6,800            |
| 4/5  | 4,000            |
| 4/10 | 1,500            |
| 4/15 | 1,500            |
| 4/20 | 1,500            |
| 4/25 | 1,500            |
| 4/30 | 1,500            |
| 5/5  | 1,500            |



WSJ.com **THE WALL STREET JOURNAL.**  
ONLINE

October 31, 2006

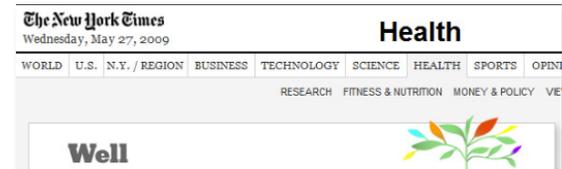
**HEALTH JOURNAL**  
By TARA PARKER-POPE

**Web Site Tallies Your Risk Of Disease And Tells You What You Can Do About It**

October 31, 2006; Page D1

Everybody worries about cancer, heart disease and other illnesses, but



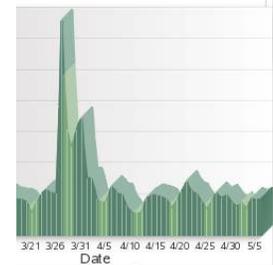


February 03, 2000

HARVARD GAZETTE ARCHIVES

## New Cancer Risk Website Logs Record-breaking Launch

More than 13,000 visits were logged on to a new Website of the Harvard Center for Cancer Prevention within the first week of its launch in mid-January, making it the most successful site launched at the Harvard School of Public Health.



8 2009



October 31, 2006; Page D1  
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- ▶ Harvard News Office
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The New York Times  
Wednesday, May 27, 2009

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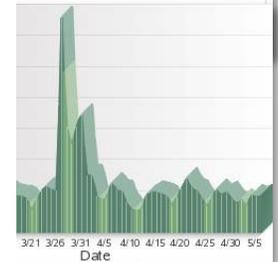
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Harvard can now assess your health risks via the internet

**Recent articles**  
[Students marked on writing in Wikipedia](#)

**Jo Revill, health editor**  
**Sunday July 4, 2004**  
[The Observer](#)

It is a hypochondriac's dream come true. Harvard, the Ivy League



October 31, 2006; Page D1

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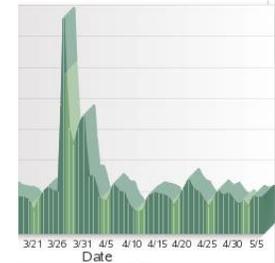
The New York Times  
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October 31, 2006

**HEALTH JOURNAL**  
By TARA PARKER-POPE



## Web Site Tallies Your Risk Of Disease And Tells You What You Can Do About It

October 31, 2006; Page D1

Everybody worries about cancer, heart disease and other illnesses, but most people don't have any idea what their long-term risk for developing a serious health problem really is.

8 2009



October 31, 2006; Page D1

Everybody worries about cancer, heart disease and other illnesses, but

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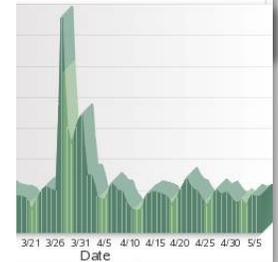
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## Well

### Tara Parker-Pope on Health

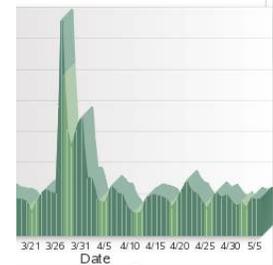
March 27, 2009, 9:48 AM

## A Better Health Quiz

By TARA PARKER-POPE, Editor

More than 27 million people reportedly have taken the RealAge health quiz, which asks questions about lifestyle and family history to determine how young or old your habits make you. But [a recent story in The New York Times notes that RealAge](#) often targets its members with health information that may be sponsored by drug marketers.

My problem with the RealAge quiz is its lack of scientific validity. The notion that health behaviors can translate into a meaningful “biological age” is just marketing hype, not real science.



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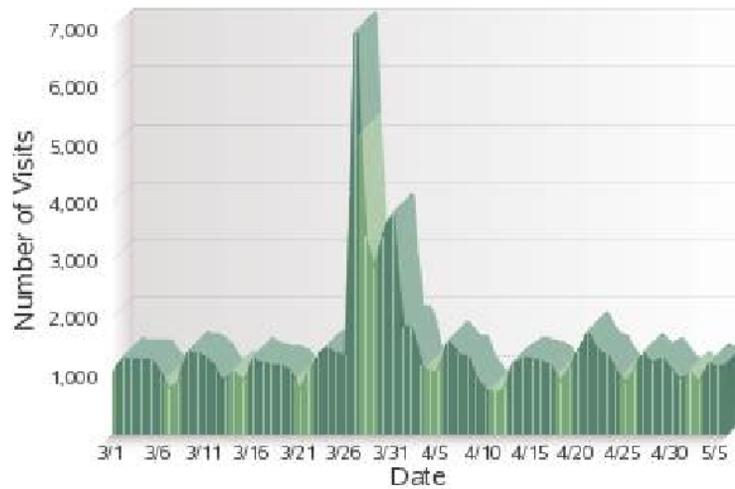
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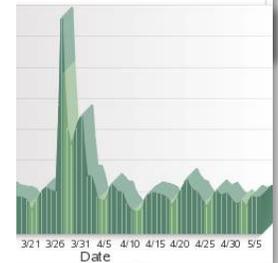
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October 31, 2006; Page D1

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# Site development – General

Multiple components, working together and separately in a continual iterative process

Epidemiology/biostatistics  
Computer science/programming

Website design/usability  
Psychology/communication

What does this mean?

*Changes in biostatistical calculations are implemented in the website by programmers, and any implications for communication are addressed by psychologists and/or communication scientists*

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# Site development – Communication and usability

Research conducted by Neil D. Weinstein, Karen M. Emmons, Mike Atkinson, Hank Dart, and others

Communication strategies based on principles of risk perception, risk communication, and health behavior change

*Help people recognize that they can change their risk (i.e., specific behavioral recommendations)*

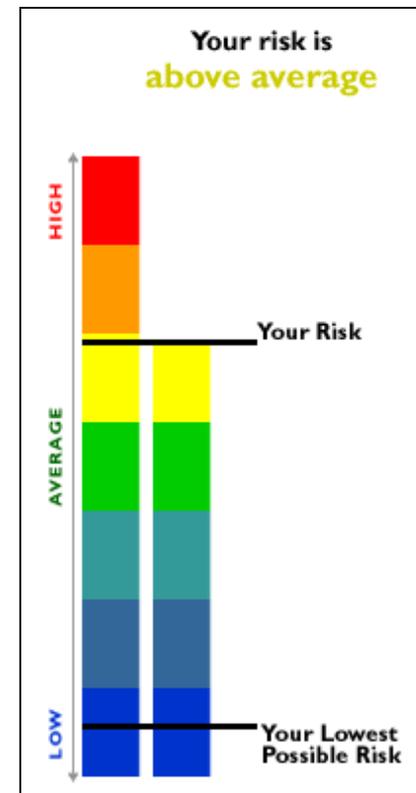


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# Site development – Communication and usability

## Issues considered

- Principles of risk communication
  - Number of risk levels (5 vs 7)
  - What types of words as descriptors
  - What type of visual display (thermometer, speedometer, bar)
  - Conveying an approximation of personal absolute risk



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# Site development – Communication and usability

## Issues considered

- Principles of risk communication
- Principles of health behavior change
- Need to provide personalized risk reduction strategies and tips for complex behaviors

- Take a single aspirin (325 mg tablet) 4 to 6 times a week. But check with your doctor first! [\[Tips\]](#)
- Eat less than 3 servings of red meat a week. [\[Tips\]](#)
- Increase your physical activity: work towards at least 30 minutes a day. [\[Tips\]](#)
- Achieve and maintain a healthy weight. [\[Tips\]](#)
- Get screened for colon cancer regularly. [\[Tips\]](#)
- Drink less than 2 servings of alcohol a day. [\[Tips\]](#)
- Take a multivitamin every day or nearly every day. [\[Tips\]](#)

**Keep up the good work!**  
You're already doing these things to lower your risk:

- You eat enough dairy foods every day or nearly every day. [\[More\]](#)
- You take a vitamin D supplement. [\[More\]](#)

### Tips

[Close window](#)

#### Weight

**Try to achieve and maintain a healthy weight. It's one of the best things you can do for your health.**

The best way to lose weight is to be physically active. A lot of things count as physical activity, like walking, jogging, or dancing – whatever you enjoy! Try to get at least 30 minutes a day. Make it a fun part of your normal routine.

To see where you fall on the weight range, click [here](#)

Don't feel like you have to tackle losing weight alone. Losing weight and maintaining a healthy weight can be difficult. Talk to a doctor or other health care provider for advice. And remember: small changes can make a big difference over time.

Maintaining a healthy weight lowers your risk of several cancers like colon, breast, kidney, uterine, pancreatic, and esophageal cancer. It also lowers your risk of heart disease, diabetes, and stroke.

To learn more about eating well and exercising visit these web sites:

[Fitness Center](#)  
[American Heart Association](#)

[Fit Forever](#)  
[American Heart Association](#)

[Healthy Eating Tips](#)  
[Centers for Disease Control and Prevention](#)

[Community Action](#)

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# Site development – Communication and usability

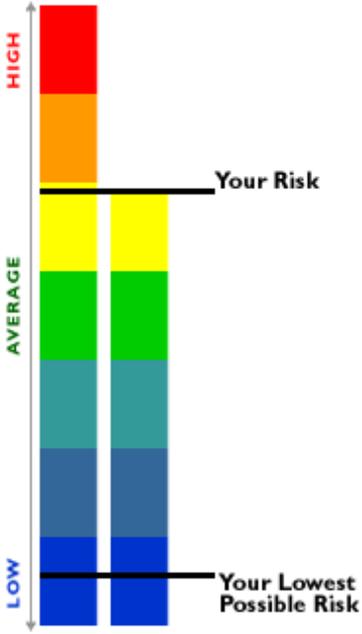
## Issues considered

- Principles of risk communication
- Principles of health behavior change
- Principles of persuasion and adult learning

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# Site development – Communication and usability

**Your risk is above average**



**Watch Your Risk Drop**  
You have 7 things you can do to lower your risk. To see what your risk could be, click on a box and watch your risk drop:

- Take a single aspirin (325 mg tablet) 4 to 6 times a week. But check with your doctor first! [\[Tips\]](#)
- Eat less than 3 servings of red meat a week. [\[Tips\]](#)
- Increase your physical activity: work towards at least 30 minutes a day. [\[Tips\]](#)
- Achieve and maintain a healthy weight. [\[Tips\]](#)
- Get screened for colon cancer regularly. [\[Tips\]](#)
- Drink less than 2 servings of alcohol a day. [\[Tips\]](#)
- Take a multivitamin every day or nearly every day. [\[Tips\]](#)

**Keep up the good work!**  
You're already doing these things to lower your risk:

- You eat enough dairy foods every day or nearly every day. [\[More\]](#)
- You take a vitamin D supplement. [\[More\]](#)

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# Site development – Communication and usability

## Key points

- “Watch Your Risk Drop” function provides “active involvement” in learning about risk.
- “What makes up my risk?” and “What does my risk mean?” buttons provide options for examining more detailed information.

**Your risk could be below average**

**Watch Your Risk Drop**  
You have 7 things you can do to lower your risk. To see what your risk could be, click on a box and watch your risk drop:

- Take a single aspirin (325 mg tablet) 4 to 6 times a week. But check with your doctor first! [\[Tips\]](#)
- Eat less than 3 servings of red meat a week. [\[Tips\]](#)
- Increase your physical activity: work towards at least 30 minutes a day. [\[Tips\]](#)
- Achieve and maintain a healthy weight. [\[Tips\]](#)
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**Keep up the good work!**  
You're already doing these things to lower your risk:

- You eat enough dairy foods every day or nearly every day. [\[More\]](#)
- You take a vitamin D supplement. [\[More\]](#)

[What makes up my risk?](#)

[What does my risk mean?](#)

# Site development – Communication and usability

## Issues considered

- Principles of risk communication
- Principles of health behavior change
- Principles of persuasion and adult learning
- User ability/facility
  - Access to and familiarity with computers
  - Numeracy
- Website interaction and navigation
  - Colors
  - Location of buttons
  - Branding

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# Site development – Communication and usability

Where are the  
publications?



*Sometimes the questions that most need answers  
are of little theoretical interest*

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# Going live

Go live when the science, communication, and technical aspects are solid

1. Is the science in line with the latest consensus review?
2. Are the messages and communication strategies scientifically sound?
3. Do the changes impede the website's usability?
4. Have the bugs/errors in programming been resolved?
5. Does the website follow good e-health practices (e.g., privacy policy)



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# Practical considerations – Research

Significant barriers to conducting research on the live site

1. Privacy and tracking
2. Consent process as barrier
3. Attrition
4. Programming challenges

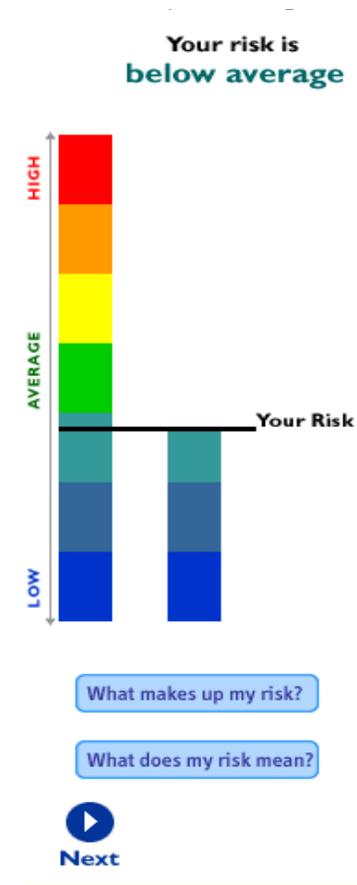
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# Practical considerations – Research

Alternatives to research on the live site

1. Recruit after people obtain their risk results (precludes obtaining risk scores)
2. Pull out module (considerable technical challenges)

Early developmental work (2000) was performed on paper due to concerns about familiarity with computers among low-literacy populations



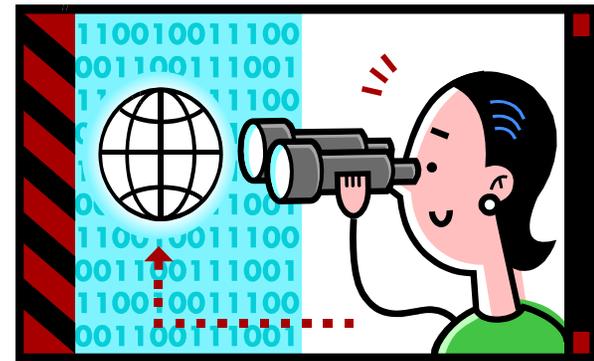
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# Practical considerations – Technical

There are multiple levels of computer programming involved, from basic website design to the complex processes underlying the calculation of the risk score.

Languages change over time, including programming.

Maintaining website and enhancing flexibility needs constant attention from experts.



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# Conclusions

Essentially transdisciplinary, cooperative, and dynamic arrangements can grow, support, and enhance a risk assessment website.

Despite growth, fundamental principles remain the same

1. Scientific rigor
2. Source transparency
3. Bug-free and highly usable website
4. Message consistency
5. Avoid financial conflicts of interest
6. Good e-health practices

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# Resources

[www.yourdiseaserisk.wustl.edu](http://www.yourdiseaserisk.wustl.edu)

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- Weinstein ND et al. Colon cancer: risk perceptions and risk communication. *J Health Commun.* 2004 Jan-Feb;9(1):53-65.

# Resources

Health on the Net Foundation - <http://www.hon.ch>

New Cancer Risk Website Logs Record-Breaking Launch - Feb 2000  
Harvard Gazette  
[http://news.harvard.edu/gazette/2000/02.03/cancer\\_risk.html](http://news.harvard.edu/gazette/2000/02.03/cancer_risk.html)

Website Tallies Your Risk of Disease and Tells You What You Can Do About IT - Oct 2006  
Wall Street Journal  
<http://online.wsj.com/article/SB116225793407508406.html>

Best of the Web - Health: Finding a Digital Diagnosis - Nov 2006  
US News & World Report  
<http://www.usnews.com/usnews/biztech/articles/061112/20sites.health.htm>

A Better Health Quiz - Mar 2009  
New York Times  
<http://well.blogs.nytimes.com/2009/03/27/a-better-health-quiz/>

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