HEALTH INFORMATICS AND DECISION SUPPORT FOR HUMAN USERS

Holly Witteman, Ph.D.
My background
Reality-based design

- Designing for the way people are
  - rather than the way we wish they were.
Reality-based design
Health Communication, Decisions

- Health-related decisions:
  - Frequently involve risks and benefits
  - Require:
    - Understanding proportions
    - Dealing with uncertainty
    - Making tradeoffs
Research focus

- Objectives: Help people
  - Understand risk and benefit tradeoffs
  - Make choices that appropriately reflect individual and system priorities and values

- Health informatics (web, mobile, social media) for:
  - Risk communication
  - Decision making
Research focus

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- Health informatics (web, mobile, social media) for:
  - Risk communication
  - Decision making designed for the way people are, rather than the way we wish they were
RISK COMMUNICATION

Cognitive abilities, Cognitive and affective biases
AVATARS AND ANIMATION OF RANDOMNESS IN RISK GRAPHICS HELP PEOPLE BETTER UNDERSTAND THEIR RISK OF CARDIOVASCULAR DISEASE
Investigators

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Background: Proportions

- People have trouble with proportions. E.g., many people:
  - prefer a lottery that offers 5, 6, 7, 8, or 9 winning draws in 100 (5-9%) over a lottery that offers 1 winning draw in 10 (10%) (Denes-Raj & Epstein, 1994)
  - respond differently to percentages (25%), natural frequencies (25 in 100) and '1 in n' formats (1 in 4) (Lipkus, 2007; Cuite et al., 2008)
  - think cancer is riskier when it ‘kills 1286 out of 10000 people’ (13%) than when it ‘kills 24.14 out of 100 people’ (24%) (Yamagishi, 1997)
Background: Numeracy

- Facility with numbers
- Nearly half of US adults have trouble with very simple number tasks (National Adult Literacy Survey, 3rd ed.)
- Related to education, but even well-educated have trouble
  - E.g., in tests of highly educated samples (Lipkus et al., 2001)
    - 16% unable to identify biggest risk: 1%, 5%, or 10%
    - 22% unable to identify biggest risk: 1 in 10, 1 in 100 or 1 in 1000
    - 30% cannot translate 20 in 100 to 20%
- Relevant for care providers, too
  - E.g., Doctors with lower numeracy less likely to tell patients numeric results of screening tests (Anderson et al., 2011)
Ancker & Kaufman 2007

Figure 3. Systolic and diastolic blood pressure displayed in a computer-generated table as part of the IDEATel telehealth program, and (inset) on the blood pressure meter. Some elderly participants who had no difficulty reading the values on the meter were unable to understand the same information displayed in the table.
Background: Risk Communication

- But numbers are important!
  - Difficult to communicate about health risks without them
  - Health informatics applications often involve interfaces with numbers
Background: Graphics

- Graphics can help (especially for people with low numeracy) but there is still room for improvement (Price et al. 2007; Hawley et al. 2008; Zikmund-Fisher et al. 2008)
Objectives

- Tackle 2 key issues:
  - Conveying randomness of events
  - Mapping population-based event statistics onto individual circumstances
    - Interval $[0,1]$ onto set $\{0,1\}$
    - Personal applicability ("This applies to me")
Background: Randomness

Schapira et al. 2001

Feldman-Stewart et al. 2007

Ancker et al. 2010
Design Goal #1

- Convey randomness without sacrificing sense of quantity
Games that help people map population-based statistics onto individual events or non-events have shown limited promise (Ancker et al. 2010)
Background: Personal applicability


- Avatar’s experiences and appearance influences self-perception
  - E.g., people assigned a taller avatar more confident in negotiation (Yee & Bailenson 2007, 2008)
Avatars
Design Goal #2

- Bring home the risk, make it “apply to me”
Methods

- Design of intervention:
  - Animation (used for signaling)

- Experimental factors:
  - Randomness
  - Avatar

- Context: **Actual** 10-year risk of cardiovascular disease (D’Agostino et al. 2008)
Demo

- Signaling quantity via animated temporal cues
  - Events added one at a time (takes longer for larger risks)
- Randomness shown, then events settle to show quantity
- Avatar used
Methods

- Online study (N = 3676)
  - Mean age 53 (SD 10)
  - 45.5% male, 54.5% female
  - 11% Hispanic
  - 78% White, 14% Black or African American, 4% Asian or Asian-American
  - 54% no college
Methods

- Online study (N = 3676)
  - 11% of participants not eligible (previous event)
  - Of eligible participants:
    - Median risk of cardiovascular disease 8% (IQR 11%)
    - Risk levels:
      - Low <5% (24% of eligible participants)
      - Moderate 5-9% (32%)
      - High 10% or higher (45%)
Methods

- Outcomes
  - Perceptions
    - How large or small does the risk feel to you?
    - How likely do you think you are to get heart disease or stroke in the next 10 years?
  - Behavioural intentions
    - In the next 30 days, how likely are you to ...
  - Recall
Results: Animated randomness

- **Low risk feels smaller and high risk feels bigger**  
  \( F_{2,3623} = 3.40, P = .03 \)
  
  * Same effect for perceived likelihood  
    \( F_{2,3669} = 4.28, P = .01 \)

- **Low risk less likely to see a doctor in next 30 days, high risk more likely**  
  \( F_{2,3648} = 3.95, P = .02 \)

- No effect on other behavioural intentions or recall
CVD perceived as more likely for those at moderate and high risk, but not those at low risk ($F_{1, 2792} = 8.45, P = .004$)

Low risk less likely to see a doctor in next 30 days, high risk more likely ($F_{2, 3648} = 6.03, P = .002$)

No effect on perceived magnitude, other behavioural intentions or recall
Conclusions

- Overall, intriguing results for a 3 minute intervention
- Animation and avatars show some promise in this context
- Future research: Personalized avatar
Personalized avatar

- Does a personalized avatar enhance:
  - Engagement?
    - Understanding of risk
  - Personal applicability ("this applies to me")?
    - Behavioural intentions
Personalized avatar
Personalized avatar
“Viral” flu game
INTEGERS ARE BETTER: ADDING DECIMALS TO RISK ESTIMATES MAKES THEM LESS BELIEVABLE AND HARDER TO REMEMBER
Investigators

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Based on my age, PSA, and DRE findings what is the likelihood that I have cancer, if a biopsy is performed?

In order to provide you with an estimate of your individual probability of prostate cancer on biopsy, please provide us with the following information:

(For definitions of terms, hover your mouse over the words or click for more detailed information)

* Age: 65
* DRE: Suspicious
* PSA: 1.7

* Required fields

Calculate

Your probability of having prostate cancer on needle biopsy is 41.9%. Please discuss this probability with your physician. This percentage needs to be interpreted in context of your age, general health and several other considerations!
Science Behind the Prostate Cancer Assessment Tools

PCATs are based on nomograms published in the Journal of Urology to ensure highly accurate assessments. Nomograms are paper-based decision-making statistical tools that are comprised of information from thousands of real-life observations from documented prostate cancer cases.

The tools assist patients and physicians in decision making by providing calculated predictions of the outcomes of various stages of treated prostate cancer.

The nomograms behind the 12 PCATs have an average accuracy rate of 80 per cent, and are of significant benefit to patients in that they eliminate bias and subjectivity that is inherent in the perspective of individual clinicians and caregivers.
Motivation
Background: Risk Calculators

- Online cancer risk calculators have poor adherence to known best practices in risk communication (Waters et al., 2009)
Your HIV Risk Change: 0.447836146272855%

You can have sex until you are infected with HIV 223.00 times

Feeling Lucky?

Have sex right now by clicking on one heart below.

The hearts symbolize all your sex partners you can have sex with right now.

There is 1 HIV+ heart within 223.00 hearts.
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, and for Asian and Pacific Islander women in the United States based on the Asian American Breast Cancer Study (AABCS). See About the Tool for more information.

**Results (Breast Cancer Risk)**

Remainder: The Breast Cancer Risk Assessment Tool was designed for use by health professionals. If you are not a health professional, you are encouraged to discuss these results and your personal risk of breast cancer with your doctor.

**Race/Ethnicity:**
White

**5 Year Risk**

- This woman (age 55) 2.6%
- Average woman (age 55): 1.5%
Heart disease risk calculator

Your results

Your risk score is 11 percent. That means about 1 of 10 people with this level of risk will have a heart attack or die of heart disease within the next 10 years.

Take action to reduce your risk

The good news is that you can improve your risk score. Depending on your specific risk factors, you may need to make lifestyle changes or in some cases take medication to help reduce your risk of having a heart attack or dying of heart disease within the next 10 years.

What you can do
Information about your risk score:
Age: 47
Gender: female
Total Cholesterol: 260 mg/dL
HDL Cholesterol: 45 mg/dL
Smoker: Yes
Systolic Blood Pressure: 125 mm/Hg
On medication for HBP: Yes
Risk Score* 9%

Means 9 of 100 people with this level of risk will have a heart attack in the next 10 years.

* Your risk score was calculated using an equation. Other NCEP products, such as printed ATP III materials, use a point system to determine a risk score that is close to the equation score.

To find out what your risk score means and how to lower your risk for a heart attack, go to "High Blood Cholesterol—What You Need to Know".

Your Guide to Lowering Cholesterol with Therapeutic Lifestyle Changes (TLC)
Prostate Cancer Nomograms: Post-Radical Prostatectomy

This nomogram can be used to predict the probability that a patient's cancer will recur after radical prostatectomy, that is, the probability at two, five, seven and 10 years that the patient's serum PSA level will become detectable and begin to rise steadily. The nomogram should only be used for patients when radical prostatectomy is the sole, primary treatment. To learn more, visit our frequently asked questions.

**Enter Your Information**

To gather the information required below, download our PDF worksheet.

**Pre-Treatment PSA**

PSA value from the laboratory report before the radical prostatectomy was performed or any other therapy for prostate cancer begun.

Pre-Treatment PSA: 5.2 ng/ml (0.1 to 100)

**Age**

Age: 65 years old (20 to 120)

**Gleason Grade**

Primary Gleason Grade at Surgery: Grade 4

Secondary Gleason Grade at Surgery: Grade 4

**Your Results**

Learn more about your results below.

<table>
<thead>
<tr>
<th>CURRENT MODEL</th>
<th>HISTORICAL MODEL</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 Year</td>
<td>Progression-Free Probability After Surgery</td>
</tr>
<tr>
<td>5 Year</td>
<td>97%</td>
</tr>
<tr>
<td>7 Year</td>
<td>90%</td>
</tr>
<tr>
<td>10 Year</td>
<td>87%</td>
</tr>
<tr>
<td></td>
<td>82%</td>
</tr>
</tbody>
</table>

Print These Results

Make An Appointment
Diabetes Basics

Diabetes Risk Test

TYPE 2 DIABETES RISK TEST

100% complete. You really are our hero.

Everyone Should Know Their Risk.

You can help. Tell your friends and family that you took the Diabetes Risk Test to assess your risk for type 2 diabetes and that they should too. And don't worry, your results won't be mentioned.

That was pretty painless right?

Based on the answers that you provided, you're at high risk for having type 2 diabetes. The good news is, now that you know what's putting you at risk, you can do something about it. Use our resources below and definitely talk to your doctor to see if additional testing is needed.

Your Risk Factors
- Age over 45 years
- Race or ethnic background
- Family history of diabetes
- Low physical activity level
- High blood pressure

Tips to lower risk

Stay in touch with ADA

Sign up for the latest news on diabetes research, food and fitness, and opportunities to support the American Diabetes Association.

Email Address
Subscribe

Get Fit

Watch this video to jumpstart your exercise program.
Details
Much below average risk means you don’t have many risk factors. But it’s just an estimate, and it doesn’t mean you’ll never get osteoporosis or break a bone because of the disease. If you have any concerns, talk to a doctor.

Watch Your Risk Drop
You have 1 thing 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 calcium supplement or eat dairy foods every day or nearly every day. Aim for 1200mg of calcium a day. [Tips]

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

- You take a vitamin D or multivitamin supplement. [More]
- You eat green leafy vegetables on most days. [More]
- You don’t smoke cigarettes. [More]
- You’re at a healthy weight. [More]
- You drink only moderately, if at all. [More]
- You are physically active for at least 30 minutes a day. [More]
Different values, levels of precision

**Calculator 1**
- 55 years old
- white
- no sisters, daughters, mother with breast cancer
- no breast biopsies
- began menstrual cycles at 13
- first child at age 23

- 10-year risk: **2.1%**

**Calculator 2**
- 55 years old
- white
- maternal aunt with breast cancer

- 10-year risk: **5.05399%**

Calc 1: [http://www.halls.md/breast/risk.htm](http://www.halls.md/breast/risk.htm); Calc 2: [http://www.estronaut.com/a/breastInteractive2.htm](http://www.estronaut.com/a/breastInteractive2.htm)
Background: Health Risk

- Mixed results on whether ranges (5-13%) or point estimates (9%) more credible (Han et al. 2009, 2010)
- Nothing specifically on decimal places
Background: Other Contexts

- House bids closer to list price when price is more precise (Janiszewski & Uy, 2008)
- People prefer specifications given with more granularity (Zhang & Schwarz, 2011)
- Prices: Digits after decimal may be truncated (Schindler & Kirby, 1997; Stiving, 2000; Sonnemans, 2006)
Objective

- Isolate effects of precision (number of decimal places) in communicating health risk
  - Believability
  - Risk magnitude
  - Recall
Methods

- Mock risk calculator
- Online survey (N = 3422)
  - Demographically diverse
  - Approximately representative of the US adult population on age, gender, and race
Kidney Cancer: Your Lifetime Risk

Do you have high blood pressure? (choose one)
- Yes
- No
- I don’t know

Do you smoke tobacco? (choose one)
- I smoke 20 or more cigarettes (or equivalent) per day
- I smoke less than 20 cigarettes (or equivalent) per day
- I smoke socially, but not regularly
- I used to smoke, and I quit 10 or more years ago
- I used to smoke, and I quit less than 10 years ago
- I have never smoked

How often do you drink alcohol? (choose one)
- 3 or more times per week
- 1-2 times a week
- Occasionally (less than once a week)
- Never

1 2 3 4 Next

DISCLAIMER: This is not medical advice. If you have medical concerns or questions, please talk to your doctor.
## Assigned “result”

<table>
<thead>
<tr>
<th>“result”</th>
<th>0 decimals</th>
<th>1 decimal</th>
<th>2 decimals</th>
<th>3 decimals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>2%</td>
<td>1.9%</td>
<td>1.87%</td>
<td>1.867%</td>
</tr>
<tr>
<td>Group 2</td>
<td>2%</td>
<td>2.1%</td>
<td>2.13%</td>
<td>2.133%</td>
</tr>
</tbody>
</table>
“In your opinion, how **believable** is this number?”
(1 = not at all, 6 = extremely)

* integers most believable ($F_{3,3384} = 2.94, P = .03$)
* high believability = 5 or 6 on scale
  - with decimal places, 7-10% fewer people found the estimate highly believable ($\chi^2_3 = 17.8, P < .001$)
Results: Risk magnitude

- “How large or small does this risk feel to you?” (slider, left “extremely small”, right “extremely large”)
  - integers felt smallest ($F_{3,3384} = 4.70, P = .003$)
Results: Recall

- Even generously approximate recall (+/- 50%) drops off with use of decimal places

<table>
<thead>
<tr>
<th>Decimal places</th>
<th>OR Approximate Recall</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1 (reference)</td>
</tr>
<tr>
<td>1</td>
<td>0.65 (95% CI 0.49, 0.86)</td>
</tr>
<tr>
<td>2</td>
<td>0.70 (95% CI 0.53, 0.94)</td>
</tr>
<tr>
<td>3</td>
<td>0.61 (95% CI 0.45, 0.81)</td>
</tr>
</tbody>
</table>
Conclusions

- Integers likely preferable for expressing risk estimates when possible.
  - More believable
  - Better recall

- Decimals may be appropriate in some cases.
  - When needed to show differences
  - When believability and recall not important
Acknowledgments

- Funding: NIH R01 CA087595 (PI: Ubel)
- Photos from flickr.com licensed under Creative Commons courtesy of users:
  - Horia Varlan (chemistry lab equipment)
  - Mark Sardella (ivy-covered building)
DECISION MAKING

How to help people evaluate tradeoffs?
Background: Humans ≠ Rational

- People frequently make judgments and decisions that run counter to assumptions of rationality
- Affected by (a few examples among many):
  - Heuristics and biases
  - Framing effects
  - Preferences
  - How many options
  - + many other issues (anchoring, representativeness, affect, heuristics as weakness vs. strengths)
Background: Availability heuristic

- If it comes to mind more easily, it’s more likely
  - Tversky & Kahneman (1973): Lists of male and female famous people

- Can happen when something has happened
  - to you/someone you know
  - recently

- E.g., Simulated rupture of asymptomatic abdominal aortic aneurysms: surgeons more likely to operate earlier (contrary to guidelines) (Dale et al., 2006)

- E.g., Recent adverse events: midwives more likely to refer to consultant OB (Styles et al., 2011)
Background: Framing

- Gain vs. loss frame
  - Gain: 98% chance therapy will be successful
  - Loss: 2% chance patient will die

- Absolute vs. relative frame
  - Absolute: Risk factor increases risk of problem from 1 in 1000 to 3 in 1000
  - Relative: Risk factor triples risk
Background: Framing

- E.g., New drug has survival benefit but also more side effects. Is the new drug better? (Perneger & Agoritsas, 2011)

<table>
<thead>
<tr>
<th>New drug is “clearly better”</th>
<th>Physicians (n=1431)</th>
<th>Patients (n=1121)</th>
</tr>
</thead>
<tbody>
<tr>
<td>New drug: 96% survive vs. Old drug: 94% survive</td>
<td>8%</td>
<td>15%</td>
</tr>
<tr>
<td>New drug: 4% die vs. Old drug: 6% die</td>
<td>27%</td>
<td>21%</td>
</tr>
<tr>
<td>New drug reduces mortality by a third</td>
<td>67%</td>
<td>48%</td>
</tr>
</tbody>
</table>

- Showing mortality curves only (vs. survival and mortality curves, or only survival) leads to less accurate knowledge and lower likelihood of choosing treatment (Armstrong et al., 2002)
Background: Preferences

- E.g., Fixed budget: Which screening test for colon cancer?
  - Test 1: Less expensive, less effective screening test, can screen everyone, 1000 lives saved
  - Test 2: More expensive, more effective screening test, can screen half of population, 1100 lives saved

- 56% of general population, 53% of medical ethicists and 41% of medical decision making experts preferred Test 1 (less effective test, fewer lives saved) (Ubel et al., 2001)
Background: Number of Options

- E.g., “The Jam Study” (Iyengar & Lepper, 2000)
- E.g., library or author (21% library) vs. library or author or movie (40% library) (Shafir 1993)
Background: Number of Options

- Medical and health policy applications (Redelmeier & Shafir, 1995)
  - Family physicians: prescribe ibuprofen for osteoarthritis in addition to referral to orthopedic consult (47% prescribe) vs. prescribe ibuprofen or piroxicam in addition to referral (28% prescribe)
  - Neurologists and neurosurgeons: choose between two different patients for surgery, patients A and B (38% choose patient A) vs. two similar and one different patients, patients A, B1, and B2 (58% choose patient A)
  - Provincial legislators: whether or not to recommend closing an underperforming hospital (26% chose to defer decision) vs. one of two underperforming hospitals (64% chose to defer decision)
WHEN PEOPLE SAY THEY PREFER ONE THING, BUT THEN CHOOSE ANOTHER
Investigators

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Andrea Fuhrer-Forbis, MA (1)
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Kiss

$50

?
% favouring money

Rottenstreich & Hsee, Psychological Science, 2001
1% chance of a kiss

1% chance of $50

?
% favouring money

Rottenstreich & Hsee, Psychological Science, 2001
WHAT DOES THIS MEAN FOR HEALTH DECISIONS?
**SURGERY 1**

- 80 people out of 100 are cured (80%)
- 20 people die (20%)

**SURGERY 2**

- 80 people out of 100 are cured (80%)
- 16 people die (16%)
- 4 people are cured but have a colostomy (4%)
Methods

- Online survey, n=1656
- Ages 30-70 (mean 50, SD 11)
- 51% women
- 14% Hispanic, 15% African American, 4% Asian American
- 46% college degree (72% some college)
- Between subjects, randomized to one of two questions
death

colostomy

?
4% chance of death

4% chance of colostomy

?
Most recent data: % favouring colostomy

$\chi^2 = 250, P < .001$
(n = 3859)
% favouring (surgery with) colostomy

\[ \chi^2 (2) = 10.3, \ P = .006 \]  
(n = 2604)

- Preference
- Choice
Implications re: stated preferences

- 100% vs. 100% ≠ 4% vs. 4%
Implications re: decision analysis
WHERE TO?
Further research

- Ways to debias (or deal with) effect
  - Effect itself
  - Impact of effect on choices
- What this might mean for
  - Preference elicitation methods
  - Values exploration and clarification
  - Risk communication
Conclusions

- Unexpectedly different patterns of response in discrete choice task at different (equal) probabilities.
- This difference may explain some of preference reversal.
- Stated preferences = nonlinear f (probability)
  - f may be different for different health states
Acknowledgments

- Funding: US NIH R01 CA087595
- Modeling discussions: Mike Paulden, William Witteman at THETA
DEVELOPING AND EVALUATING DYNAMIC AND INTERACTIVE INTERFACES FOR VALUES CLARIFICATION

grant obtained during postdoc from Foundation for Informed Medical Decision Making
Investigators

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Background: Values Clarification

- Values clarification noted as important part of informed decision making (Elwyn et al., 2006)
- Very little evidence about how to facilitate the process
  - Enormous variety of techniques and approaches
  - Minimal evaluation
  - Design questions:
    - Is an iterative process more useful?
    - What happens when people are shown how values relate to options?
Part 1: User-centered design process

- UCD core technique in Human Factors
  - Observation >> Direct questioning
  - Iterative process
  - Start with low-fidelity prototypes (e.g., paper) and gradually refine
Part 1: User-centered design process

- Context: breast/prostate cancer treatment
- 7 rounds of UCD with 2-4 people per round
  - Complex topic
  - Indications that it would be preferable to integrate VCE with information acquisition
- Technique: sliders
Depends on Your Choice

This page lists things that are different for the different options. This means your experience of each of these could be different, depending on which prostate cancer option you choose. Click each gray box to read about that issue.

**Right away**
- How much surgery is needed?
- Time for treatment and recovery
- Fighting the cancer

**First 3 months after**
- Side effects (leaking urine, frequent or painful peeing, problems having erections, diarrhea) in the first 3 months after treatment
- Contact with pregnant women and children

**Rest of my life**
- Leaking urine
- Frequent or painful peeing
- Problems having erections
- Diarrhea, pain, and bleeding from rectum

**What happens over time**
- Time for follow-up doctor visits
- What if it doesn't work or the cancer gets worse? Are there backup options?
- Do side effects increase or stay the same
How much surgery is needed?

Depending on which treatment you choose, you will have more or less surgery. Different treatments have different levels of surgery required. Some do not have surgery at all.

<table>
<thead>
<tr>
<th>Watchful Waiting (Active Surveillance)</th>
<th>Surgery</th>
<th>External &quot;beam&quot; Radiation</th>
<th>Internal &quot;seed&quot; Radiation</th>
</tr>
</thead>
<tbody>
<tr>
<td>No surgery.</td>
<td>Major surgery. This has small but serious risks.</td>
<td>No surgery.</td>
<td>Minor surgery. This is less serious than major surgery but still carries risks.</td>
</tr>
<tr>
<td>No surgery.</td>
<td>- You will need to be admitted to hospital for one or more days. - Overnight stay in hospital may be necessary. - Recovery usually takes a while.</td>
<td>No surgery.</td>
<td>- You will need to go to the hospital for outpatient surgery. - Won't need to stay overnight. - Recovery usually takes a little while (but less time than for major surgery.)</td>
</tr>
</tbody>
</table>

I want as little surgery as possible
Survival

No matter which treatment you choose, you are very likely to survive prostate cancer. In the United States, about 2-4 men out of 100 will die from prostate cancer within 5 years of their diagnosis, no matter which treatment they choose. This means that 96-98 men out of 100 will survive at least 5 years, and usually much longer. Most men with prostate cancer will live long lives, and will eventually die from something else. You can use the slider below to mark how important survival is to you, but it will not change which option fits best with your preferences.

I want to survive
# Summary Table

<table>
<thead>
<tr>
<th>not at all important</th>
<th>extremely important</th>
<th>Watchful Waiting (Active Surveillance)</th>
<th>Surgery</th>
<th>External &quot;beam&quot; Radiation</th>
<th>Internal &quot;seed&quot; Radiation</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don't want to have problems having erections for the rest of my life</td>
<td></td>
<td>0 in 100</td>
<td>60 in 100</td>
<td>45 in 100</td>
<td>45 in 100</td>
</tr>
<tr>
<td>I don't want frequent or painful peeing for the rest of my life</td>
<td></td>
<td>0 in 100</td>
<td>15 in 100 (for the rest of their lives)</td>
<td>8 in 100 (for a couple of years)</td>
<td>15 in 100 (for a couple of years)</td>
</tr>
<tr>
<td>I don't want to leak urine for the rest of my life</td>
<td></td>
<td>0 in 100</td>
<td>9 in 100</td>
<td>0 in 100</td>
<td>3 in 100</td>
</tr>
<tr>
<td>I want to fight the cancer</td>
<td></td>
<td>Doesn't fight</td>
<td>Cuts cancer out</td>
<td>Kills cancer</td>
<td>Kills cancer</td>
</tr>
<tr>
<td>I don't want diarrhea for the rest of my life</td>
<td></td>
<td>0 in 100</td>
<td>0 in 100</td>
<td>8 in 100</td>
<td>8 in 100</td>
</tr>
<tr>
<td>I want as little surgery as possible</td>
<td></td>
<td>None</td>
<td>Major</td>
<td>None</td>
<td>Minor</td>
</tr>
</tbody>
</table>
Part 2: Evaluation

- Online
  - Which summary page is most useful?
  - Does scaffolding help?
Destination Photos

<table>
<thead>
<tr>
<th>New Zealand Adventure</th>
<th>Maldives Beach Vacation</th>
<th>Culture and History in Turkey</th>
<th>Going Local in British Columbia</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1" alt="New Zealand Adventure" /></td>
<td><img src="image2" alt="Maldives Beach Vacation" /></td>
<td><img src="image3" alt="Culture and History in Turkey" /></td>
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<td><img src="image7" alt="Culture and History in Turkey" /></td>
<td><img src="image8" alt="Going Local in British Columbia" /></td>
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<tr>
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<td><img src="image10" alt="Maldives Beach Vacation" /></td>
<td><img src="image11" alt="Culture and History in Turkey" /></td>
<td><img src="image12" alt="Going Local in British Columbia" /></td>
</tr>
<tr>
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<td><img src="image14" alt="Maldives Beach Vacation" /></td>
<td><img src="image15" alt="Culture and History in Turkey" /></td>
<td><img src="image16" alt="Going Local in British Columbia" /></td>
</tr>
<tr>
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<td><img src="image18" alt="Maldives Beach Vacation" /></td>
<td><img src="image19" alt="Culture and History in Turkey" /></td>
<td><img src="image20" alt="Going Local in British Columbia" /></td>
</tr>
<tr>
<td><img src="image21" alt="New Zealand Adventure" /></td>
<td><img src="image22" alt="Maldives Beach Vacation" /></td>
<td><img src="image23" alt="Culture and History in Turkey" /></td>
<td><img src="image24" alt="Going Local in British Columbia" /></td>
</tr>
<tr>
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<td><img src="image26" alt="Maldives Beach Vacation" /></td>
<td><img src="image27" alt="Culture and History in Turkey" /></td>
<td><img src="image28" alt="Going Local in British Columbia" /></td>
</tr>
<tr>
<td><img src="image29" alt="New Zealand Adventure" /></td>
<td><img src="image30" alt="Maldives Beach Vacation" /></td>
<td><img src="image31" alt="Culture and History in Turkey" /></td>
<td><img src="image32" alt="Going Local in British Columbia" /></td>
</tr>
<tr>
<td><img src="image33" alt="New Zealand Adventure" /></td>
<td><img src="image34" alt="Maldives Beach Vacation" /></td>
<td><img src="image35" alt="Culture and History in Turkey" /></td>
<td><img src="image36" alt="Going Local in British Columbia" /></td>
</tr>
</tbody>
</table>

---

**Vacation**  |  **My Options**  |  **Photos**  |  **Impact on My Life**  |  **Important to me**
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction</strong></td>
<td><strong>Photos</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
 Depends on Your Choice

This page lists things that are different for the different options. This means your experience of each of these could be different, depending on which vacation option you choose. Click each gray box to read about that issue.
Part 3: Evaluation

- Lab:
  - Role of emotion on interaction
    - Eye-tracking
    - Heart rate variability
    - Galvanic skin response
In the meantime ...

- Online factorial experiment
- Impact of:
  - Making tradeoffs explicit
  - Showing implications of preferences
Context, Procedure

- Hypothetical decision between 2 surgeries for colon cancer
- First assess preference
- Then explain scenario

Summary Table

<table>
<thead>
<tr>
<th>Surgery 1</th>
<th>Surgery 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>80 out of 100 patients cured with no complications</td>
<td>80 out of 100 patients cured with no complications</td>
</tr>
<tr>
<td>20 out of 100 patients die within 2 years</td>
<td>16 out of 100 patients die within 2 years</td>
</tr>
<tr>
<td></td>
<td>4 out of 100 patients cured, but have a colostomy</td>
</tr>
</tbody>
</table>
What is important to you

Before you make a choice between the two surgeries, please take a moment to consider what is important to you. Play with the sliders below while you consider your feelings. Remember that there are no wrong answers. Please stay on this page for at least 20 seconds.

what matters to me for this decision

- avoiding a colostomy
- avoiding death

If you have any questions, comments, or concerns, please contact us here.
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Outcome

- Which surgery?
  - Is choice concordant with stated preference?
Results

![Bar chart showing % discordant for different conditions: control, no tradeoffs, no implications, implications only, tradeoffs only, tradeoffs and implications. The control condition has the highest % discordant, followed by no tradeoffs, no implications, then implications only, tradeoffs only, and tradeoffs and implications, which have the lowest.]
Conclusions

- Values clarification = the fundamental process of decision making
- Awareness of tradeoffs essential for almost all decisions at almost all levels
- No best practices for how to help people do this
- Web and mobile technology are creating opportunities for more interactive interfaces
- Lots of design and evaluation work to do
WORK IN PROGRESS
Missing slides

- 6 slides of work in progress removed
Social media & risk

HEALTH

Doctor’s discredited vaccine-autism link leaves a legacy of preventable death and disease

ANDRÉ PICARD  |  Columnist profile  |  E-mail
PUBLIC HEALTH REPORTER— From Thursday's Globe and Mail
Published Wednesday, Jan. 12, 2011 7:30PM EST
Last updated Thursday, Jan. 13, 2011 9:04AM EST

295 comments

The sordid details of the elaborate fraud perpetuated by Dr. Andrew Wakefield continue to emerge and astound. And the impact of the purported link between the measles-mumps-rubella (MMR) vaccine and bowel disease and autism continues to be seen daily in a resurgence of eradicated childhood diseases across the Western world and, close to home, emergency rooms overflowing with flu sufferers.
SOCIAL MEDIA & CHOICE OF BIRTH PLACE AND ATTENDANT(S)

Grant obtained during graduate school
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Jacqueline Bender, PhD (1)
Erica Sutton, MA (1)
Michelle Janutka, RM (1)
Laura O’Grady, PhD (1)
Carolynn Prior, RM (3)
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Nadine Wathen, PhD (5)

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(2) University of Waterloo, Waterloo, ON
(3) Sages Femmes Rouge Valley Midwives, Scarborough, ON
(4) McMaster University, Hamilton, ON
(5) University of Western Ontario, London, ON
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- Human Factors, Mechanical and Industrial Engineering, U of T
- English, University of Waterloo
- Centre for Global eHealth Innovation, Toronto
- Public Health Sciences, U of T
- Joint Centre for Bioethics, U of T
- Ontario Institute for Studies in Education, U of T
- Midwifery Care North Don River Valley, Toronto
- Health Policy, Management and Evaluation, U of T
- Sages Femmes Rouge Valley Midwives, Scarborough
- Clinical Epidemiology and Biostatistics, and Obstetrics and Gynecology, McMaster University
- Information and Media Studies, University of Western Ontario
Perceived Influence of Social Media

"Has participating in any of the above online communities influenced your opinions about birth choices in any way?"

\( \chi^2(5) = 53.31, \quad p < .001 \)
First birth, planning home birth with midwife: “Statistically speaking it is far safer to birth at home than in a hospital or birth centre as less intervention occurs.”
Planning hospital birth with midwife: “It's important to mitigate the risks involved. I know problems can arise at the last minute and I like the safety of birthing at the hospital, just in case.”
birth in hospital

extremely risky

More medically-oriented

Less medically oriented

extremely safe

OB hosp  FP hosp  MW hosp  MW bc  MW home  UC home
birth in hospital

extremely risky

perceived risk

neutral

perceived safety

extremely safe

OB hosp  |  FP hosp  |  MW hosp  |  MW bc  |  MW home  |  UC home
birth in hospital

extremely risky

Green = chose this or something associated with this

Pink = did not choose this

extremely safe

OB hosp  FP hosp  MW hosp  MW bc  MW home  UC home
homebirth with midwife

extremely risky

extremely safe

<table>
<thead>
<tr>
<th>Location</th>
<th>Safety Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>OB hosp</td>
<td>Extremely risky</td>
</tr>
<tr>
<td>FP hosp</td>
<td>Extremely risky</td>
</tr>
<tr>
<td>MW hosp</td>
<td>Safe</td>
</tr>
<tr>
<td>MW bc</td>
<td>Safe</td>
</tr>
<tr>
<td>MW home</td>
<td>Safe</td>
</tr>
<tr>
<td>UC home</td>
<td>Safe</td>
</tr>
</tbody>
</table>
unassisted birth

extremely risky

extremely safe

- OB hosp
- FP hosp
- MW hosp
- MW bc
- MW home
- UC home
cesarean

- Extremely risky:
  - OB hosp
  - FP hosp
  - MW hosp
  - MW bc
  - MW home
  - UC home

- Extremely safe:
  - OB hosp
  - FP hosp
  - MW hosp
  - MW bc
  - MW home
  - UC home
epidural

extremely risky

extremely safe

OB hosp  FP hosp  MW hosp  MW bc  MW home  UC home
Conclusions

- Concepts of risk and safety can vary dramatically
- Women who make less medically-oriented choices feel more influenced by social media
Health Informatics and Decision Support for Human Users

- Can help mitigate cognitive and affective biases through thoughtful design
- Place user needs, strengths and limitations at centre of design process
- Human users exist at all levels
Acknowledgments: Funding

HEALTH CARE, TECHNOLOGY, AND PLACE

A strategic research and training initiative based at the University of Toronto.

R01 CA087595

NATIONAL INSTITUTES OF HEALTH

FOUNDATION FOR INFORMED MEDICAL DECISION MAKING

CIHR IRSC
THANK YOU

hollywit@umich.edu
Acknowledgments: Image Credits

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  - D’Arcy Norman
  - Kelly Sue
  - Tama Leaver
EXTRA SLIDES

If needed
Interdisciplinary fellowship

- “... produce humanistically-informed scientists and scientifically-informed humanists.”

HEALTH CARE, TECHNOLOGY, AND PLACE
A strategic research and training initiative based at the University of Toronto.
Like re: risk calculator sites

- “Good nomograms”
- “Informative on risks and outcomes”
- “Interesting to see some numbers”
Concerns re: risk calculator sites

- “Not sure I trust the calculations behind this.”
- “It is dangerous to allow the general patient public to ‘calculate’ their survival chances on the basis of a few test results. The tools pays no attention to other aspects, like life style, diet, attitude, and could do more harm than good.”
- “Statistics form the foundation of all nomograms, and may not apply to individuals.”
Planning UBAC (unassisted VBAC):

“My midwife is out of town and there are no other providers willing to attend me. I would not feel comfortable in the hospital considering my VBAC status and previous hospital experience. I would love to birth at a birth center, but in my state this is outside the scope of practice for birth center midwives. The one hospital that has a birth center and would accept my VBAC status does not accept my insurance.”
Planning repeat cesarean with OB:

“My OB says there is a small chance that a VBAC could end with uterine rupture and that this would/could cause serious neurological problems for my child, even death. I do not feel the need to experience a VBAC and possibly put our child in harm’s way.”
Nonlinear risk in diabetes
SAME
For every 100 people who have either Surgery 1 or Surgery 2, this shows how many people have the same results.

- 80 are cured (80%)
- 16 die (16%)

DIFFERENT
For every 100 people who have either Surgery 1 or Surgery 2, this shows how many people have different results.

- 4 more people die (4%)

Select: I would choose Surgery 1

- 4 people are cured, but must have a colostomy (4%)

Select: I would choose Surgery 2
# Interdisciplinary fellowship

<table>
<thead>
<tr>
<th></th>
<th>Multi-disciplinary</th>
<th>Inter-disciplinary</th>
<th>Trans-disciplinary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keyword</td>
<td>Additive</td>
<td>Interactive</td>
<td>Holistic</td>
</tr>
<tr>
<td>Equation</td>
<td>$2 + 2 = 4$</td>
<td>$2 + 2 = 5$</td>
<td>$2 + 2 = yellow$</td>
</tr>
<tr>
<td>Food metaphor</td>
<td>Salad</td>
<td>Melting pot</td>
<td>Cake</td>
</tr>
</tbody>
</table>

Choi & Pak, 2006
### Estimate your risk of breast cancer by answering these questions.

1. **How many of your sisters, daughters or mother had breast cancer?**  
   - None

2. **How many benign breast biopsies have you had?**  
   - None

3. **At what age did your menstrual cycles begin?**  
   - 12–13 yrs

4. **At what age did you give birth to your first child?**  
   - 20–24 yrs

5. **What is your age?**  
   - 55 years

6. **My Race is:**  
   - White (Caucasian)

---

<table>
<thead>
<tr>
<th>Time Frame</th>
<th>Estimated Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>within 5 years</td>
<td>1.1%</td>
</tr>
<tr>
<td>within 10 years</td>
<td>2.1%</td>
</tr>
<tr>
<td>within 20 years</td>
<td>4.2%</td>
</tr>
<tr>
<td>within 30 years</td>
<td>6.3%</td>
</tr>
</tbody>
</table>

*Your chance of being diagnosed with breast cancer is estimated to be: **7.3%** within lifetime (to age 90). Your true risk could be somewhere within a range around these estimates.*

---

*Risk increases with number of first degree relatives affected.*

*Benign* means no cancer. Have you ever had a biopsy result showing "atypical hyperplasia"?  
- Not applicable or unknown

*Risk increases with earlier menarche.*

Risk increases with older age at first term live birth. (But if you have first degree relatives with carcinoma of the breast, then risk goes down. *It's a weird statistical thing*).

*Risk increases with age. Age is the biggest risk factor. In other words, all women have some risk. Hence the need to promote awareness and take steps for prevention. 76% of women who develop breast cancer had no other risk factors.*

*White women in North America have slightly higher risk than Black, Hispanic or Asian women, and considerably higher risk than women who have recently emigrated from Asia.*
Please Enter your Age: 55

Please select your Race

- White Female ✓
- Black Female □
- Other □

Who else in your Family has Breast Cancer?

Please select that which applies to you:

- Mother □
- Sister □
- Two or more sisters OR mother and sister □
- Maternal grandmother or Aunt ✓
- Paternal grandmother or aunt □
- Two or more grandmothers or aunt □

This is your percentage risk for breast cancer in the next 30 years:

+10yrs 5.0539% (percent)
+20yrs 10% (percent)
+30yrs 13% (percent)
PROSTATE CANCER WEBSITES: ONE SIZE DOES NOT FIT ALL
Background

- Prostate cancer = uncertainty
  - screening, treatment, coping with symptoms, recurrence
- Information needs:
  - vary significantly between people
Methods: Study 1

- User needs assessment
  - We don’t need another website
Central aim

- personal attributes
- website attributes
- relevance, usefulness
Personal attributes

- Clinical
  - E.g., diagnosed with prostate cancer or not, time since diagnosis, treatment(s) received, aggressiveness of cancer

- Socio-demographic, structural
  - E.g., age, race, geography (incl. health care system, urban/rural), education

- Cognitive
  - E.g., health literacy, numeracy, eHealth literacy

- Psychosocial
  - E.g., health locus of control, personality, trust in physician
Website attributes (Study 2)

Literature
Focus group
Hypotheses
Automated?

89 attributes
Website attributes

- Content
  - E.g., Credibility, Risk assessment, Commercial content
- Presentation
  - E.g., Aesthetics, Design complexity
- Function
  - E.g., Loading speed, Accessibility, Interactivity, Usability
Website attributes

- Literature
- Focus group
- Hypotheses
- Automated?

89 attributes

- 40 sites
- 5 trained raters
Methods: Study 3: Online survey

- n = 65
- People seeking prostate cancer information online
  - majority (58/65) men with prostate cancer
- Survey to assess personal attributes
- Rate 20 sites randomly selected from 40
  - 1-5 stars: ‘how relevant and useful it is to you’
- 80% training set tested on 20% remaining
Results

- Algorithm with respectable predictive capabilities
- Also tested a number of specific hypotheses
Conclusions

- People seeking information can have different needs
  - Different from each other (even with same clinical situation)
  - Different from what traditional sources provide
- Discernable patterns about how a given person will judge a given website
  - Potential for recommender systems
6 main options

- **OB hosp** = hospital birth with OB
- **FP hosp** = hospital birth with family physician
- **MW hosp** = hospital birth with midwife
- **MW bc** = birth centre with midwife
- **MW home** = home birth with midwife
- **UC home** = home birth unassisted
Methods

- Detailed analysis of 60 threads in 4 communities
- Survey of community members (n = 744)
  - Currently pregnant
  - <12 months postpartum
- Purposeful subsampling for
  - Geographic diversity
  - Diversity in choices
Some results

- How concepts of risk and safety are constructed
- A sampler ...