

# Visualizing uncertainty in health care: present needs and future directions

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## Objectives

- Identify key uncertainties in health care that need to be communicated to patients
- Describe recent efforts to develop novel representations for visualizing uncertainty in clinical risk prediction
- Outline potential directions for future uncertainty visualization efforts in health care

# Communicating uncertainty to patients: a growing need

- Growth of evidence-based medicine (EBM)
  - “The conscientious, explicit, and judicious use of current best evidence in making decisions *about individual patients.*”
- Increasing visibility of medical controversies
- Rise of shared decision making (SDM) movement
  - Ethical justification: respect for patient autonomy
  - Idea that patients need to understand uncertainty to make well-informed decisions
- Growing need communicate uncertainty not only to physicians but to **patients**:  
what do they need to know?

# Uncertainty

Main Entry: un·cer·tain·ty

Pronunciation: \-tən-tē\

Function: *noun*

Date: 14th century

1 : the **quality** or state of being **uncertain** : **doubt**

2 : something that is **uncertain**

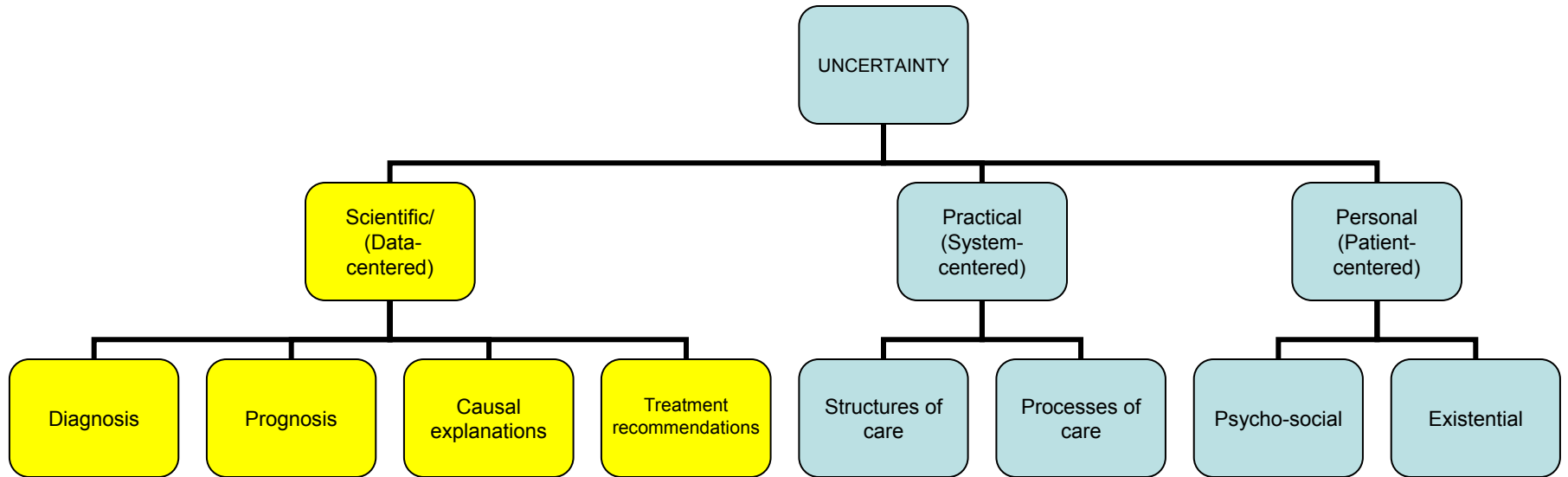
synonyms **uncertainty**, **doubt**, **dubiety**, **skepticism**, **suspicion**, **mistrust** mean lack of sureness about someone or something. **uncertainty** may range from a falling short of certainty to an almost complete lack of conviction or knowledge especially about an outcome or result <assumed the role of manager without hesitation or *uncertainty*>. **doubt** suggests both uncertainty and inability to make a decision <plagued by *doubts* as to what to do>. **dubiety** stresses a wavering between conclusions <felt some *dubiety* about its practicality>. **skepticism** implies unwillingness to believe without conclusive evidence <an economic forecast greeted with *skepticism*>. **suspicion** stresses lack of faith in the truth, reality, fairness, or reliability of something or someone <regarded the stranger with *suspicion*>. **mistrust** implies a genuine doubt based upon suspicion <had a great *mistrust* of doctors>.

- *A metacognition*: the conscious awareness of ignorance...
- **Multiple varieties in health care**

## Uncertainty in health care: **domains**

- Prevention and early detection
  - Disease risk estimates
  - Risks and benefits of preventive interventions
  - Performance characteristics of screening tests
- Diagnosis
  - Interpretation of symptoms
  - Performance characteristics of screening tests
- Treatment
  - Risks and benefits of therapeutic, palliative interventions
  - Prognostic estimates

# Uncertainty in health care: **issues**



## DISEASE-CENTERED

## PATIENT-CENTERED

Malignant vs. benign

Life expectancy,  
response to treatment

Cancer risk factors,  
carcinogenic events

Efficacy and safety of  
cancer treatment

Identity, competence  
of health care provider

Required actions for  
accessing health care

Effects of treatment on  
personal relationships

Effects of illness on  
sense of meaning in life

## Examples of specific uncertainty issues: cancer treatment

Han PKJ, Klein WMP, Arora NK. Varieties of uncertainty in health care: a conceptual taxonomy. *Med Decis Making*. 2011; Jan 18. [Epub ahead of print]

## Uncertainty in health care: **sources**

- Probability: indeterminacy of future outcomes, 1<sup>st</sup> order, “aleatory”
- Ambiguity: indeterminacy of knowledge, 2<sup>nd</sup> order, “epistemic” uncertainty
- Complexity: incomprehensibility of information

Han PKJ, Klein WMP, Arora NK. Varieties of uncertainty in health care: a conceptual taxonomy. *Med Decis Making*. 2011; Jan 18. [Epub ahead of print]

# Probability

- Formal language of uncertainty
- Expression of indeterminacy/randomness
- Alternative interpretations
  - Objective (frequentist) interpretation
  - Subjective (Bayesian) interpretation



# Ambiguity

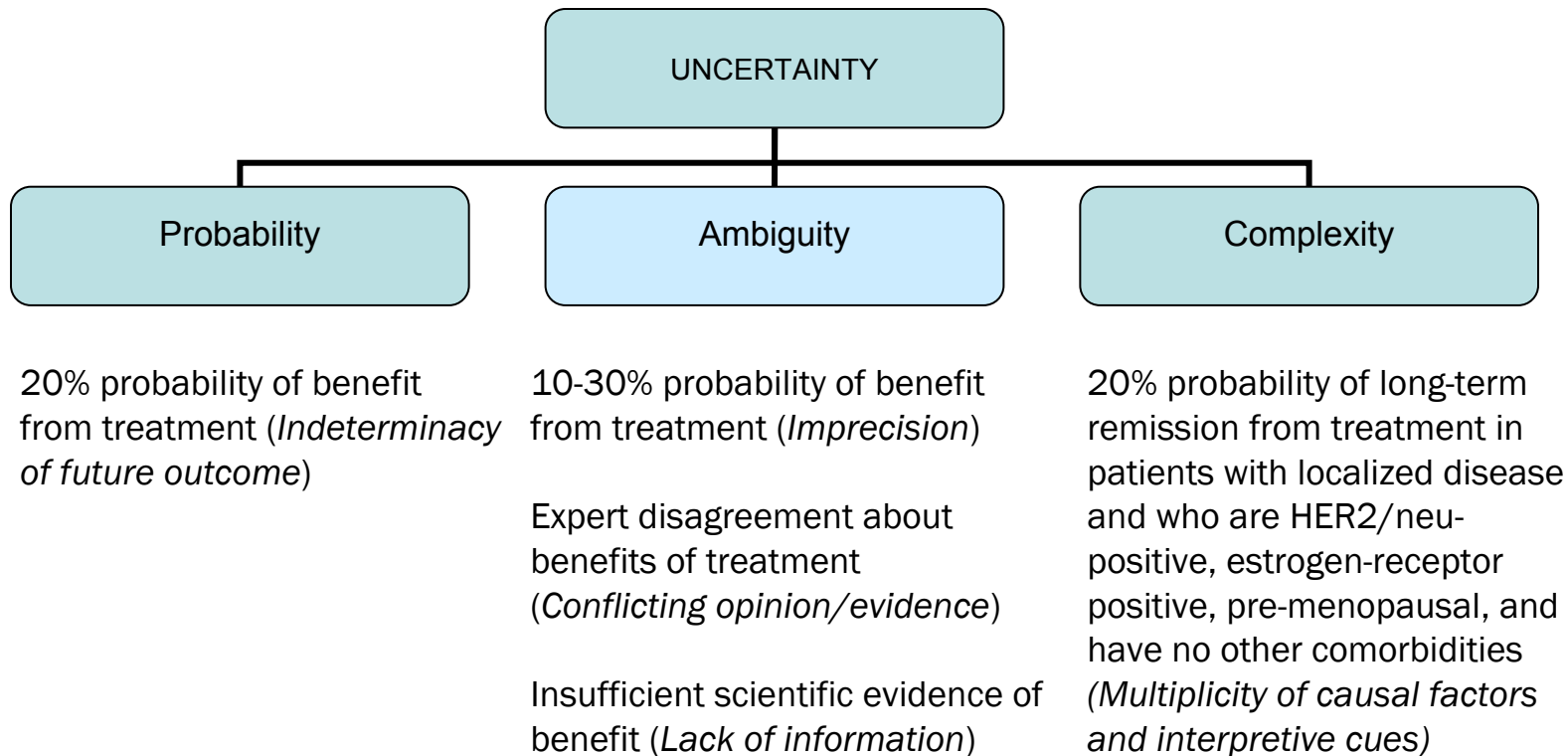
- Decision theory construct (Ellsberg\*)
- A specific type of uncertainty: “second order” vs. “1<sup>st</sup> order risk”, “epistemic” vs. “aleatory”
- Lack of “reliability, credibility, adequacy”
  - Incomplete / missing information
    - *Amount or quality of available evidence*
  - Questionable precision or accuracy
    - *Wide confidence intervals*
  - Questionable reliability
    - *Inconsistent findings, reproducibility*
    - *Conflicting expert opinion*

\*Ellsberg D. (1961) Risk, ambiguity and the Savage axioms. *Quart J Econ*, 75

# Complexity

- Features of information that make it difficult to understand
- Conditional probabilities, multiple risk factors, attributes, outcomes

# Sources of uncertainty in health care



Examples and representations of different sources of uncertainty pertaining to breast cancer treatment outcomes

# Challenges in communicating uncertainty **to patients**

- Topic-related
  - Multiplicity of sources, issues
  - Conceptual complexity
- User-related
- Innumeracy
- Cultural barriers
- Individual preferences, tolerance of uncertainty
- Potential adverse effects: “ambiguity aversion”
- Method-related
- Optimal representational methods unknown
- Unclear outcomes: acceptability, understanding, adverse effects (?)

# Can communicating uncertainty be bad?

- “Ambiguity aversion”: propensity to choose against ambiguous options, outcome probabilities being otherwise equal
- Underlying cognitive process: pessimistic bias in the interpretation of ambiguous risk information
- Psychological consequences:
  - Heightened perceptions of risk
  - Diminished expectations of benefit
  - Indecision / inaction
- Greater complexity, potential for confusion

\*Ellsberg, D. (1961) Risk, ambiguity and the Savage axioms. *Quart J Econ*, 75

## Uncertainty visualization for patients: present needs

- Need for effective representational methods
  - Promote understanding
  - Minimize potential adverse effects
- Promising work on visual approaches
  - Can aid comprehension particularly in low numerate individuals
- Initial work, more research needed

## Clinical prediction models (CPMs)

- Statistical models to predict future health outcomes
  - “...provide the evidence-based input for shared decision making, by providing estimates of *the individual probabilities* of risks and benefits...combine a number of characteristics (e.g., related to the patient, the disease, or treatment) to predict a diagnostic or therapeutic outcome.”
- “Individualized” risk estimates used increasingly for clinical decision making
- Numerous uncertainties in risk estimates, but not often communicated to patients

Steyerberg E. *Clinical Prediction Models: a Practical Approach to Development, Validation, and Updating*. New York: Springer; 2010.

# Uncertainty in CPMs: multiple varieties, levels

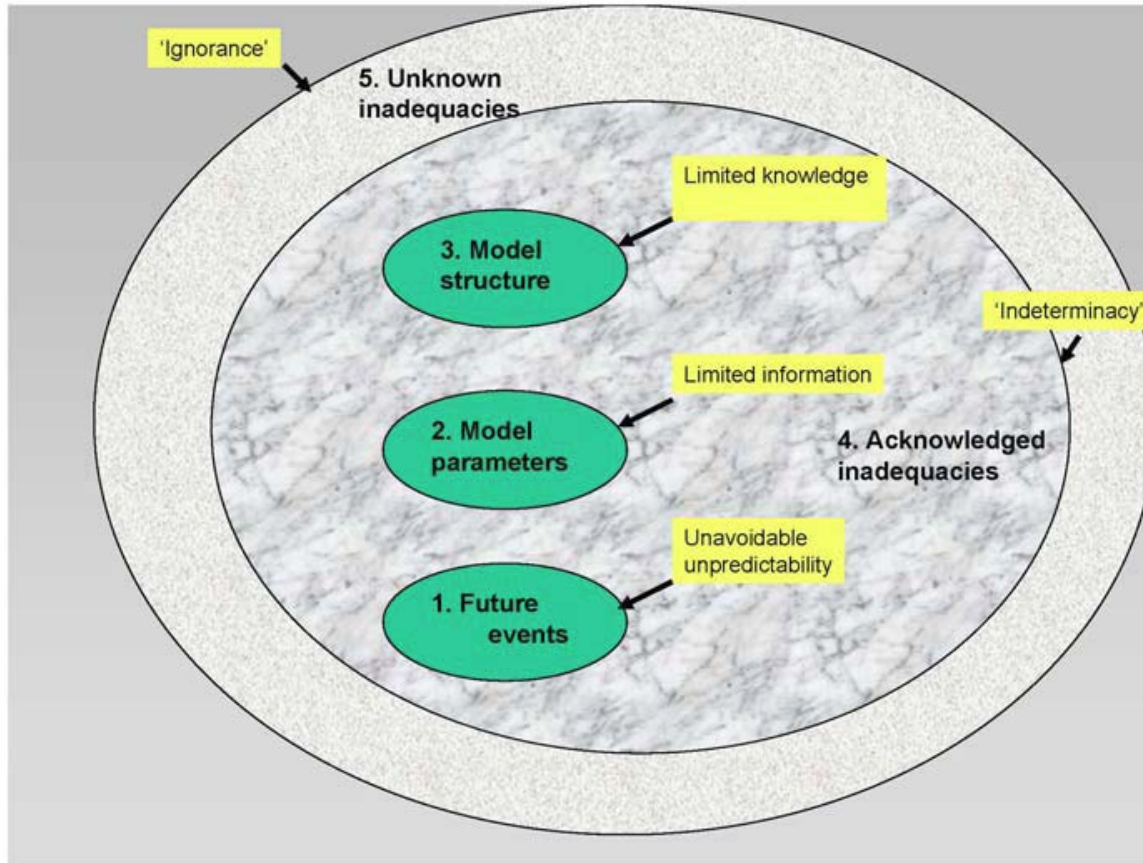


Figure 1: Five levels of uncertainty. While the first three form a natural hierarchy, Levels 4 and 5 apply to the entire modelling process and may exist even if there is little uncertainty expressed within the modelling framework.



# Visualizing uncertainty in risk estimates: past efforts

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my results:

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Heart disease  
Osteoporosis  
Stroke

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Risk  
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How to...  
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Community Action

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**Cancer—Colon cancer**

**Results: Colon cancer**  
Compared to a typical man your age, your risk is **much above average**

**Screening Tip**  
You may need to get screening tests earlier and more often than most people. Talk to your doctor. [More >>](#)

Much above average risk doesn't mean you'll definitely get 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.

**Your risk is much above average**

**Watch Your Risk Drop**  
You have 6 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! [\[Tips\]](#)
- Increase your physical activity: work towards at least 30 minutes a day. [\[Tips\]](#)
- Get screened for colon cancer regularly. [\[Tips\]](#)
- Take a calcium supplement or eat more dairy foods regularly. [\[Tips\]](#)
- 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 don't eat more than 2 servings of red meat a week. [\[More\]](#)
- + You aren't too overweight. Still, losing some weight would be healthy. [\[More\]](#)
- + You drink less than 2 servings of alcohol a day. [\[More\]](#)

**What makes up my risk?**

The risk assessment tool uses a vertical bar chart to visualize risk levels. The y-axis is labeled 'HIGH', 'AVERAGE', and 'LOW'. The bar is divided into segments of color: red (top), orange, yellow, green, blue, and dark blue (bottom). A horizontal line indicates the 'Your Risk' level, which is above the 'AVERAGE' line. Another horizontal line indicates the 'Your Lowest Possible Risk' level, which is below the 'AVERAGE' line.

<http://www.yourdiseaserisk.wustl.edu/>

# Visualizing uncertainty in risk estimates: past efforts

## Treatment with statins to reduce the risk of heart attacks and strokes

Figure 1. Control group risk. [Next Figure >>](#)

[\(Click here to save Figure 1\)](#)



In the control group 20 people out of 100 had a heart attack, stroke or bypass surgery over 10 years, compared to 15 (95% CI 14 to 17) out of 100 for the active treatment group.

[http://www.nntonline.net/visualrx/v3/display.aspx#Figure\\_1](http://www.nntonline.net/visualrx/v3/display.aspx#Figure_1)

## Visualizing uncertainty in risk estimates: past efforts

- No attention to fundamental uncertainties
  - Aleatory (first-order): indeterminacy/randomness
  - Epistemic (second-order): ambiguity
- Mental visualization, understanding of users is assumed
- Need to better represent these uncertainties
  - Users need to understand, but do have problems
- How should effectiveness be evaluated?
  - Risk perceptions
  - Affective response
  - Decision making
  - Understanding / insight

# Visualizing uncertainty in risk estimates: new approaches

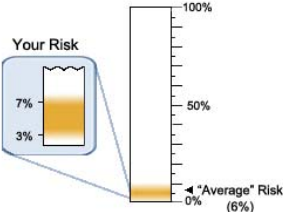
National Cancer Institute U.S. National Institutes of Health | www.cancer.gov

## Colorectal Cancer Assessment Tool [Printer friendly version](#)

Your lifetime risk is estimated to be **between 3% and 7%**.

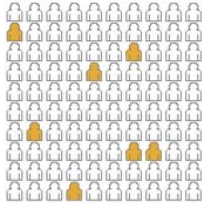
Show:

### How high is my risk?



Estimates are not exact. We can say **your** risk for developing colorectal cancer in **your lifetime** is most likely in the **range of 3%-7%**, but it could be higher or lower. The average risk for developing colorectal cancer for **all white males over the age of 55** is **6%**.

### Will I get colorectal cancer?



Though we estimate that somewhere between 3 and 7 out of every 100 people **similar to you** in the US will develop colorectal cancer in their lifetime, **we can't tell for any one person if they will develop it or not.**

\* Lorem ipsum dolor sit amet, consectetur

[NCI Home](#) | [Contact Us](#) | [Policies](#) | [Accessibility](#)

A Service of the National Cancer Institute

<http://www.cancer.gov/colorectalcancerrisk/Default.aspx>

# Communicating uncertainty in cancer risk estimates: effects

- NCI Colorectal Cancer Risk Assessment Tool (CCRAT) – Freedman et al 2008
- Effort to develop patient-centered communication tool using visual representations of uncertainty:
  - Ambiguity (imprecision): model misspecification, error
  - Randomness: indeterminacy
- Use of new visualization methods: blurring, disarraying
- Mixed-methods study examining effects of different representational formats

Han PKJ, Klein WMP, Lehman TC, Massett H, Lee SC, Freedman AN. 2009. Laypersons' responses to the communication of uncertainty regarding cancer risk estimates. *Medical Decision Making* 29(3): 391-403.

Han PKJ, Lehman TC, Massett H, Lee SC, Klein WMP, Freedman AN. 2009. Conceptual problems in laypersons' understanding of individualized cancer risk: a qualitative study. *Health Expectations* 12 (1): 4-17

Han PKJ, Klein WMP, Lehman TC, Killam B, Massett H, Freedman AN. 2010. Communication of uncertainty regarding individualized cancer risk estimates: effects and influential factors. *Medical Decision Making* 2011 Mar-Apr;31(2):354-66. Epub 2010 Jul 29.

Han PKJ, Klein WMP, Lehman TC, Killam B, Massett H, Freedman AN. 2011. Representing randomness in the communication of individualized cancer risk estimates: effects on cancer risk perceptions, worry, and subjective uncertainty about risk. *Patient Educ Counseling* 2011 Mar 3. [Epub ahead of print]

# Visual representations of uncertainty: imprecision

Textual, ambiguity absent

Your chances of developing colon cancer in your lifetime are 9%

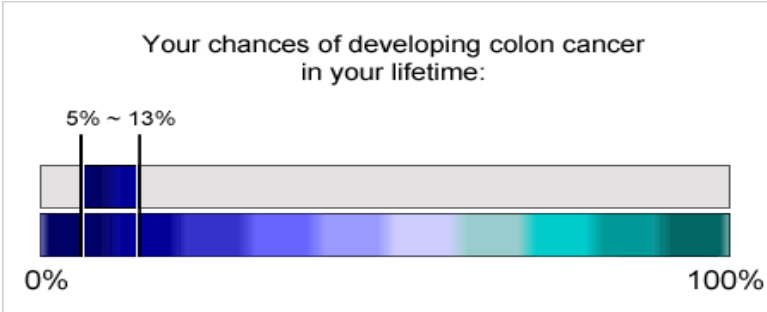
Textual, ambiguity present

Your chances of developing colon cancer in your lifetime are between 5%-13%

Visual, ambiguity absent



Visual, ambiguity present

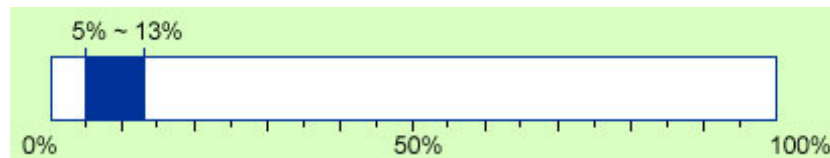


# Visual representations of uncertainty: imprecision

Textual only

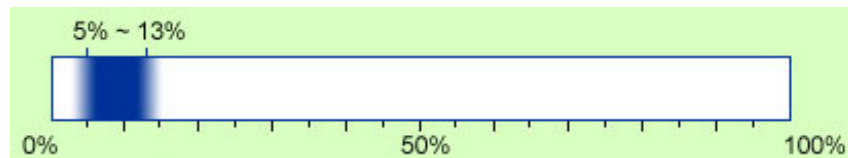
Your chances of developing colon cancer in your lifetime are most likely between 5%-13%, but they could be higher or lower.  
Risk estimates are not exact.

Integrated textual + visual:  
Solid bar



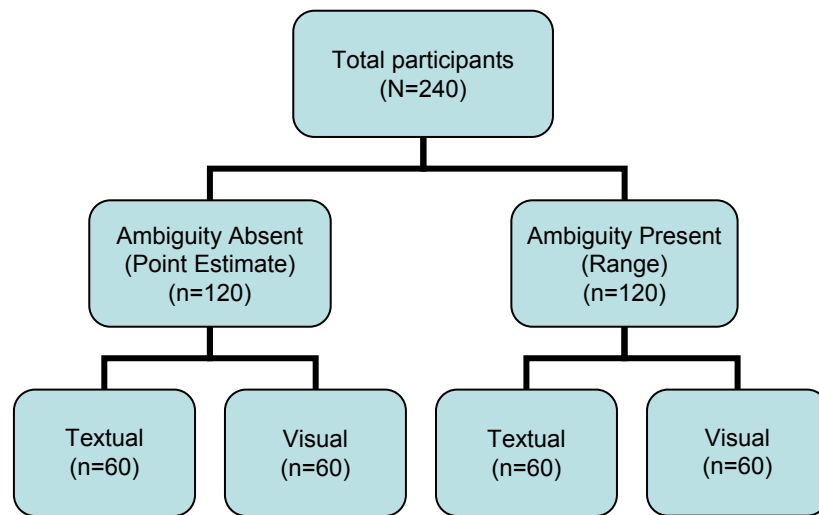
Your chances of developing colon cancer in your lifetime are most likely between 5%-13%, but they could be higher or lower.  
Risk estimates are not exact.

Integrated textual + visual:  
Blurred bar



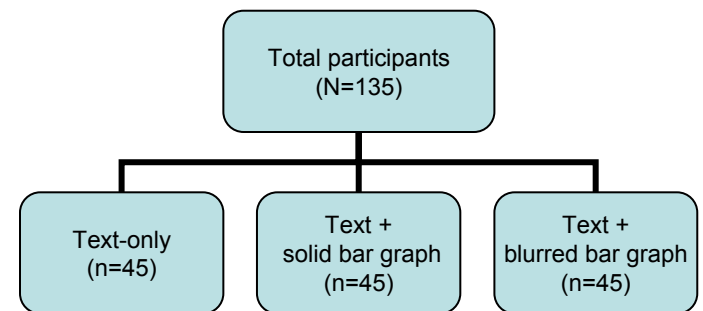
Your chances of developing colon cancer in your lifetime are most likely between 5%-13%, but they could be higher or lower.  
Risk estimates are not exact.

# Effects of visual representations of imprecision: experimental evaluation



Experiment 1: 2 x 2 x 2 design testing effects of ambiguity (absent vs. present), representational format (textual vs. visual).

Additional test of comparative risk information (pre- / post-)

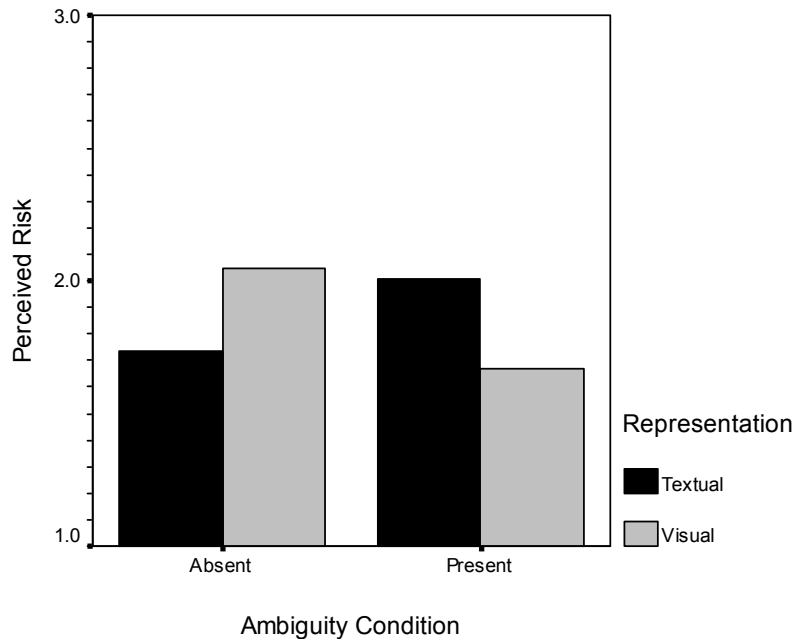


Experiment 2: 3-condition design testing effects of enhanced representations of imprecision

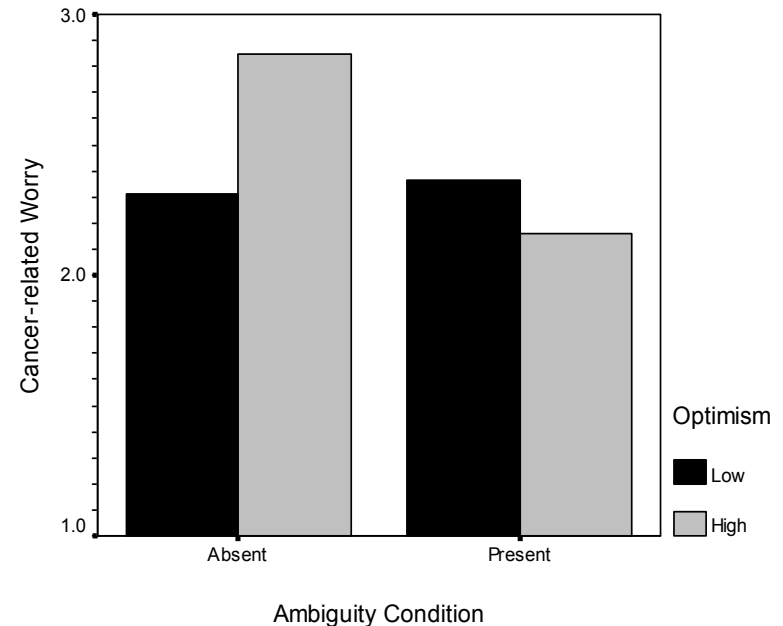


# Representing imprecision: effects on perceived risk, worry

- **Main effect of ambiguity** (Wilks'  $\lambda = .97$ ,  $F(3, 230)=3.54$ ,  $p=.03$ )
  - Primary effect: increased cancer-related worry ( $F(1, 231)=5.19$ ,  $p=.02$ )
- **Interactions:**
  - Ambiguity x Representational format (visual format  $\rightarrow$  ambiguity tolerance)
  - Ambiguity x Dispositional optimism (high optimism  $\rightarrow$  ambiguity tolerance)
- **No difference between enhanced text+visual representations**



Interaction of ambiguity and representational format on level of perceived risk



Interaction of ambiguity and dispositional optimism on cancer-related worry

# Visual representations of uncertainty: randomness

Text-only, non-random

Your chances of developing colon cancer in your lifetime are 9%

Text-only, random

Lifetime Risk: 9.0%

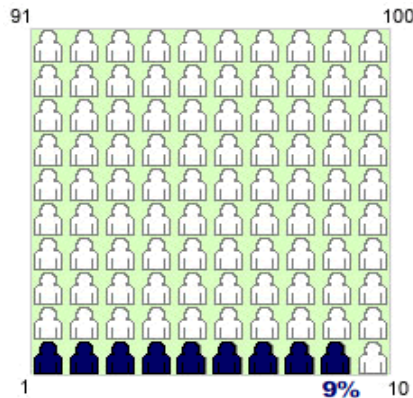
Explanation: Based on the information provided, the estimated chance for developing colorectal cancer over the lifetime is 9%.

We can't predict the future of any one person. Risk estimates only tell us **how many** people in a population are likely to get colon cancer; they can't tell us **who** will get the disease or not.

Visual non-random

Lifetime Risk: 9.0%

Explanation: Based on the information provided, the estimated chance for developing colorectal cancer over the lifetime is 9%.



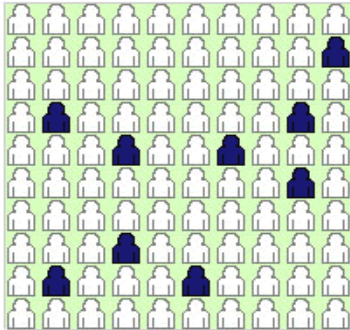
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# Visual representations of uncertainty: randomness

## Visual random static

Lifetime Risk: 9.0%

Explanation: Based on the information provided, the estimated chance for developing colorectal cancer over the lifetime is 9%.



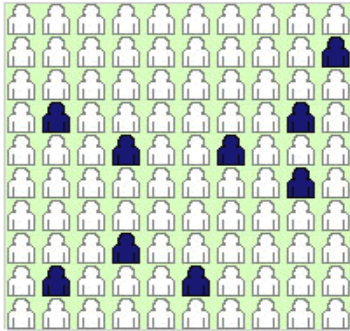
We can't predict the future of any one person. Risk estimates only tell us **how many** people in a population are likely to get colon cancer; they can't tell us **who** will get the disease or not.

# Visual representations of uncertainty: randomness

## Visual random static

Lifetime Risk: 9.0%

Explanation: Based on the information provided, the estimated chance for developing colorectal cancer over the lifetime is 9%.

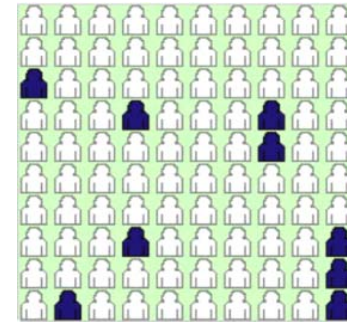


q 2 sec

## Visual random dynamic

Lifetime Risk: 9.0%

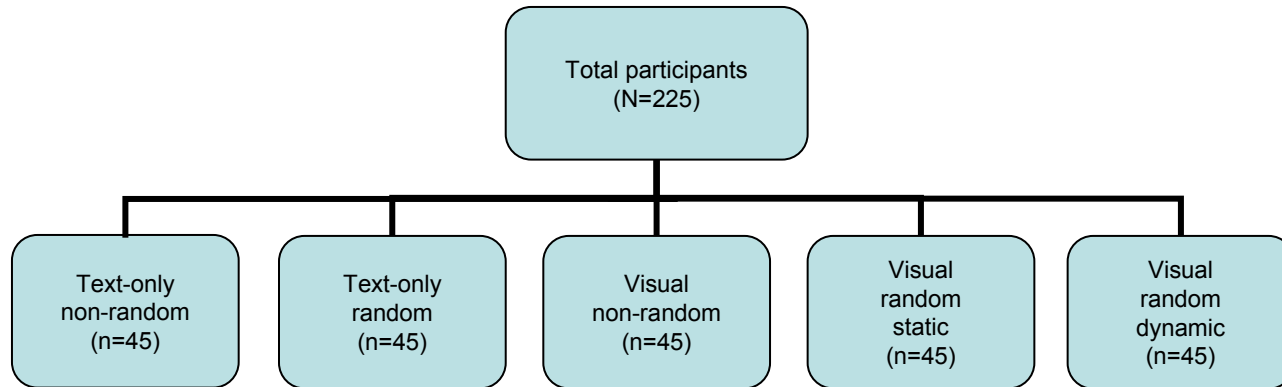
Explanation: Based on the information provided, the estimated chance for developing colorectal cancer over the lifetime is 9%.



We can't predict the future of any one person. Risk estimates only tell us **how many** people in a population are likely to get colon cancer; they can't tell us **who** will get the disease or not.

We can't predict the future of any one person. Risk estimates only tell us **how many** people in a population are likely to get colon cancer; they can't tell us **who** will get the disease or not.

# Effects of visual representations of randomness: experimental evaluation

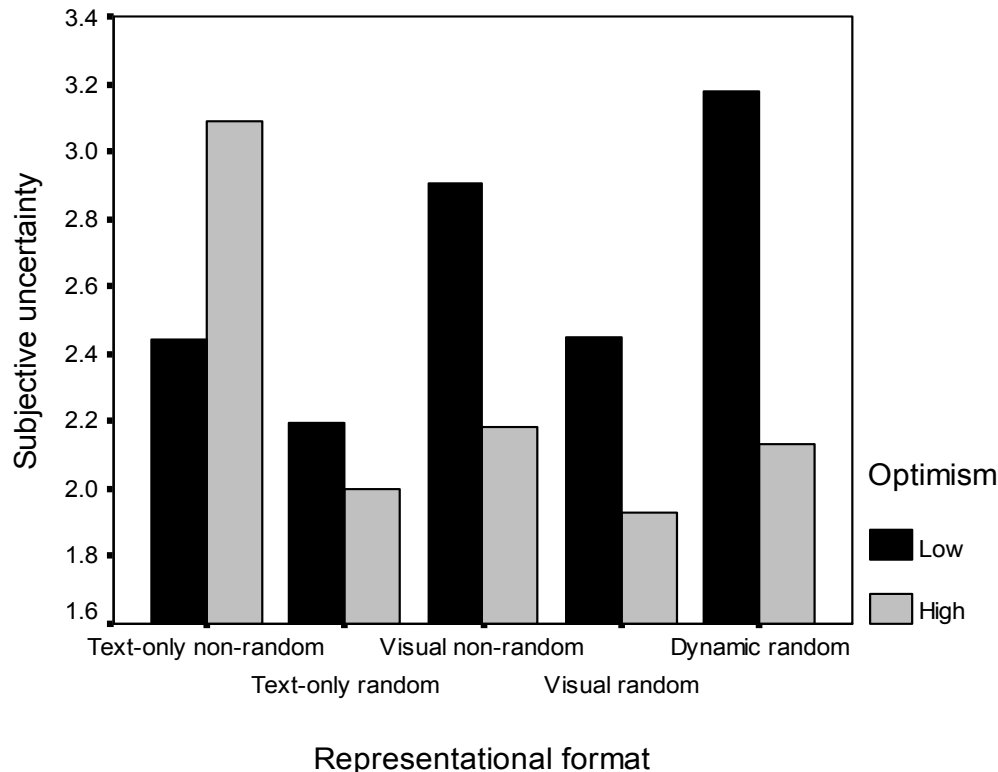


5-condition design testing effects of alternative representations of randomness

Han PKJ, Klein WMP, Lehman TC, Killam B, Massett H, Freedman AN. 2011. Representing randomness in the communication of individualized cancer risk estimates: effects on cancer risk perceptions, worry, and subjective uncertainty about risk. *Patient Educ Counseling* 2011 Mar 3. [Epub ahead of print]

# Representing randomness: effects on subjective uncertainty

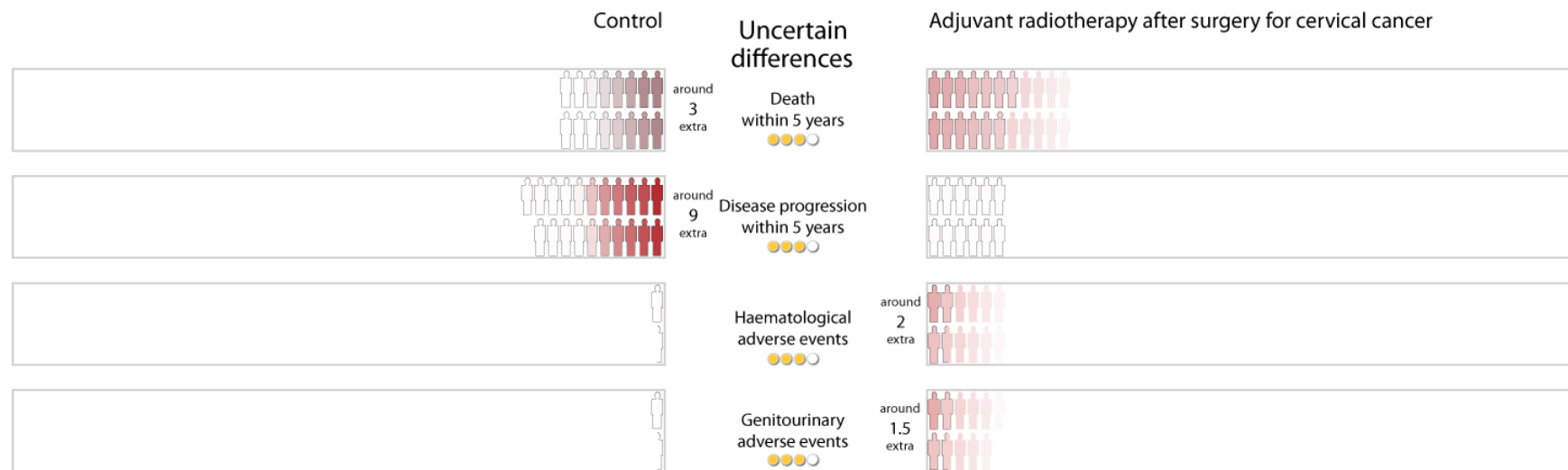
- **Main effect of representational format** ( $F(4, 210)=2.98, p=.02$ )
  - Subjective Uncertainty greatest for Dynamic Random vs. Text-only Random
  - No effects on perceived risk, worry (no “ambiguity aversion” with randomness)
- **Format x Optimism interaction:** ( $F(4, 210)=3.51, p=.01$ )
  - Low optimism → greater sensitivity to format effect , in expected direction



# Visualizing uncertainty in cancer risk estimates: initial lessons

- Communicating imprecision leads to effects consistent with “ambiguity aversion”
  - Heightened worry
  - Heightened perceptions of risk, but moderated by individual optimism
- Visual representations appear to reduce ambiguity aversion
  - Enhanced textual representations may also be effective
- Communicating randomness increases subjective uncertainty about risk
  - A desired effect, although problematic
  - No effect on risk perceptions (akin to ambiguity aversion)
- Unanswered questions
  - Effects on understanding
  - Mechanisms
  - Right amount of information, for different users

# Visualizing uncertainty in risk estimates: new approaches



<http://understandinguncertainty.org/files/animations/CochraneAnimation/CochraneSlides.html>



# Visualizing uncertainty in risk estimates: new approaches


The screenshot shows the homepage of the 'Understanding Uncertainty' website. The header features the 'UU' logo and a navigation menu with links to Home, Blog, Articles, Videos, Animations, Guest Articles, Links, and About Us. The main content area is titled 'Spinning the Risk' and includes a search bar, a featured content dropdown, and a user login section. The article text explains that the animation is designed to alert users to misleading ways risks can be presented. A preview of the animation is shown, titled 'Harms of eating bacon', with options to customize the risk presentation (Absolute, Relative, No. Needed to Treat) and a 'Personalise' button.

UU Understanding Uncertainty

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Home » Content

## Spinning the Risk

 This animation is designed to alert you to the huge number of sometimes misleading ways that the same risks can be presented - relative or absolute, positive or negative framing, percentage chance or natural frequency, both graphically and in text.

See [2845 ways to spin the risk.](#)

Some help on how to customise this animation appears below the animation itself.

UU Spinning the Risk About Embed Print Full Sc


What's the Risk? Personalise

Back Next

Absolute  
 Relative  
 No. Needed to Treat

### Harms of eating bacon

Your chance of experiencing bow  
Bacon sandwiches is 1 in 10, whi  
in 10 with Bacon sand

 experience anyway

User login

Username \*

Password \*

[Create new account](#)  
[Request new password](#)

Log in

<http://understandinguncertainty.org/spinning>

# Visualizing uncertainty in health care: future directions

- Novel representational methods
  - Aleatory uncertainty: dynamic representations, risk over time
  - Epistemic uncertainty: beyond fuzziness
- Novel functionality: interactivity, tailorability
- Evaluation of outcomes
  - Usability
  - Understanding
  - Psychological, behavioral outcomes; clinical care settings
- Other uncertainty issues, domains, users

Thank you!

Questions, ideas:

[hanp@mmc.org](mailto:hanp@mmc.org)