I Know My Number, But What Does It Mean?

Barriers to Patient Use of Health Data

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A Story

Total Bilirubin: 1.4 mg/dL
A Story

“Don’t worry!”

“I’ll tell you when to worry”
Numeracy

- The ability to *understand*, *transform*, and *derive meaning from* quantitative (health) information
Numeracy Measures

Which of the following numbers represents the biggest risk of getting a disease?
- 1 in 100, 1 in 1000, or 1 in 10?
### Age: a major factor

A woman’s chance of getting breast cancer increases with age. Your chance by your current age is:

<table>
<thead>
<tr>
<th>Age</th>
<th>Chance</th>
</tr>
</thead>
<tbody>
<tr>
<td>age 20</td>
<td>1 in 1,681</td>
</tr>
<tr>
<td>age 30</td>
<td>1 in 232</td>
</tr>
<tr>
<td>age 40</td>
<td>1 in 69</td>
</tr>
<tr>
<td>age 50</td>
<td>1 in 42</td>
</tr>
<tr>
<td>age 60</td>
<td>1 in 29</td>
</tr>
<tr>
<td>age 70</td>
<td>1 in 27</td>
</tr>
<tr>
<td>Lifetime</td>
<td>1 in 8</td>
</tr>
</tbody>
</table>
Avoid ‘1 in X’ Formats

- Very bad for communicating changes in risk or comparisons between risks
  - Cuite, Weinstein, et al., 2008, Medical Decision Making

“The traditional use of proportions [e.g., 1 in 384 vs. 1 in 112], to express risk in genetic counseling lacks scientific basis.”
  - Grimes & Snively, 1999, Obstetrics and Gynecology
"We need to move the conversation about 1-in-X formats past mere documentation of problems and address the significant need to change clinical practice. . . . any continued use of 1-in-X formats to communicate medical risk is . . . intolerable" (p.704)
Subjective Numeracy

- How good are you at working with fractions?
- How good are you at figuring out how much a shirt will cost if it is 25% off?
- How often do you find numerical information to be useful?

Numeracy Is Related To...

- Understanding the uncertainty, yet predictability, of health
  - What is a risk factor?
  - Population rates vs. individual propensity
  - Clinical trials

Numeracy Is Related To...

- Understanding the uncertainty, yet predictability, of health
- Using data
  - Translating between formats
  - Interpreting visuals and finding relevant data
  - Adjusting decisions based on data

Numeracy Is Related To...

- Understanding the uncertainty, yet predictability, of health
- Using data
- Completing tasks requiring number skills:
  - Medication dose calculation
  - Self-monitoring

Numeracy, Not Literacy, Relates To Anticoagulation Control

Numeracy as *Deriving Meaning*
Imagine Robert

Your 10-year risk of cardiovascular disease is: 11.22%
Robert’s Tale

“Am I at high risk, or not?”
Problems

- Excess precision
  - Do we really think we know Robert’s risk to a hundredth of a percent?
  - Integers are more believable and easier to recall than decimals
Problems

- Excess precision
- Number-only formats
Visual Displays
Robert’s Risk

Your 10-Year Risk of Cardiovascular Disease

- 11 out of 100 people like you will develop cardiovascular disease
- 89 out of 100 people like you will NOT develop cardiovascular disease

Created at iconarray.com
Welcome to Clinician.IconArray.com

1 Risk/Benefit
Use one risk/benefit to show the effect one treatment option.
Get Started >>

2 Risks/Benefits
Use two risks/benefits to compare 2 treatment options side-by-side.
Get Started >>

3 Risks/Benefits
Use three risks/benefits to compare multiple treatment options.
Get Started >>
Problems

- Excess precision
- Number-only formats
- Unmet information needs
Needs

- What Robert wanted:
  - "I am a person who has a high risk"

- What Robert got:
  - "My risk is this"

Zikmund-Fisher BJ. The right tool is what they need, not what we have: A taxonomy of appropriate precision in patient risk communication. Medical Care Research & Review, 2013
# A Taxonomy of Risk Concepts

<table>
<thead>
<tr>
<th>Risk Concept</th>
<th>Illustrative Risk Messages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Possibility</td>
<td>“It could happen to me.”</td>
</tr>
</tbody>
</table>
| Relative / Comparative Possibility | “It is more likely to happen to me.”  
|                             | “I am more likely to have this happen to me than to have that happen to me.”                                                                               |
| Categorical Possibility    | “I am a person who has a high chance of this happening.”                                                                                                |
| Relative Probability       | “I have a risk that is higher to this degree.”                                                                                                         |
| Absolute Probability       | “My risk is this.”                                                                                                                                       |
| Comparative Probability    | “My (group’s) risk is this, which is higher than another’s (group’s) risk.”  
|                             | “My risk is this if I do X, which is higher than my risk if I do Y which is that.”                                                                       |
| Incremental Probability    | “My risk will change that much if I do this.”                                                                                                          |

Zikmund-Fisher BJ. The right tool is what they need, not what we have: A taxonomy of appropriate precision in patient risk communication. *Medical Care Research & Review*, 2013
## Need-Congruent Types of Risk Knowledge

<table>
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<tr>
<th>Need</th>
<th>What Patients Care About</th>
<th>Congruent Types of Risk Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid Surprise and Regret</td>
<td>Care that this could happen</td>
<td>Possibility</td>
</tr>
<tr>
<td>Recognize Dominant Options</td>
<td>Care that this is most / least</td>
<td>Relative / Comparative Possibility</td>
</tr>
<tr>
<td>Motivate to Act or Not Act</td>
<td>Care that this is good / bad</td>
<td>Categorical Possibility</td>
</tr>
<tr>
<td>Make Multi-Attribute Tradeoff Decisions</td>
<td>Care about this more than that</td>
<td>Comparative Possibility and/or Comparative Probability</td>
</tr>
<tr>
<td>Make Magnitude-Dependent Decisions</td>
<td>Care that this is X% not Y%</td>
<td>Precise Comparative or Incremental Probabilities</td>
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Zikmund-Fisher BJ. The right tool is what they need, not what we have: A taxonomy of appropriate precision in patient risk communication. *Medical Care Research & Review*, 2013
Does Robert need a *number*?
Non-Numerical Risk Displays

Historic Return
- Above
- High
Historic Risk
- Low
- High

www.schwab.com

Consumer Reports
Labels?

- E.g., “above average,” “high levels,” “above threshold”

- BUT: When statistics and evaluative labels are presented together, the label, NOT the number, dictates what people do.

What & Why
Data can help people make better decisions about their health. But it's not always clear what sort of presentation will make the most sense to the most people. ... READ MORE

How
Visualizing Health contains graphic displays of health information that we've validated through research among the general public. ... READ MORE

Who
Visualizing Health was developed by the University of Michigan, with funding from the Robert Wood Johnson Foundation. ... READ MORE
The Wizard

In order to help guide you to images that would best meet your communications needs, we'd like to ask you two questions about your primary goals. You may find these difficult to answer, as often we have multiple goals when communicating risk. But, if you can be clear about what matters most to you, we can help guide you to visual displays that are likely to better fit your needs.

What is your primary goal for communicating this specific piece of risk information?

- To make people feel more or less concerned about a risk.
- To increase or decrease awareness of a risk but NOT necessarily change people’s concern.
- To help people classify a risk (as “borderline high,” “below average,” or “excellent”).
- To help people identify how much risk can change because of actions they take or because of a risk factor.
- To show differences in risk between groups.
- To help people compare options that differ in their degree of risk.
- To help people recognize a risk tradeoff (situations where one option has more of one risk and less of another than another option).

Do people need to know or remember exact risk numbers or is it enough for them to get the basic idea (the gist) about the risk?

- The basic idea
- Exact risk numbers
Visual Displays That Aid Categorization

http://www.vizhealth.org/using/calculator/
Information

Evaluability

Good or Bad?

Good or Bad?

Radon: 6 pCi/L
Good or Bad?

Radon Action Level: 4 pCi/L

Radon: 3.6 pCi/L
Good or Bad?

5-year Breast Cancer Risk: 2.6%
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)

Reminder: 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%
Good or Bad?

Dioxin Blood Concentration:

33 parts per trillion TEQ
“The Curse of Knowledge”

“Once we know something, we find it hard to imagine what it was like to not know it.”

Decision Making

- Hard-to-evaluate data require reference standards to be meaningful
  - Such data are generally ignored unless comparative data are provided

Information Evaluability

Functional Numeracy
Can Patients *Use* This?

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Patient Portals

- Increasing direct access to test results

- But, the value of data is in its meaning
  - Recognizing out-of-range values is the first, essential step to meaningful use
### What Is Out of Range?

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Scenario

- Type 2 diabetes scenario
  - Hemoglobin A1c 3 months ago = 6.8%
  - Explicit goal of A1c<7%
  - Being tested in-between appointments
Test Results

- Participants received tables of:
  - CBC counts
  - CBC differential %’s
  - Hemoglobin A1c
  - Renal panel

- Tables included standard range but did not include high/low flags
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<td>fl</td>
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</tbody>
</table>

**Auto Diff**

<table>
<thead>
<tr>
<th>Component</th>
<th>Your Value</th>
<th>Standard Range</th>
<th>Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neutrophil % (Sysmex)</td>
<td>54.7</td>
<td>36.0-71.0</td>
<td>%</td>
</tr>
<tr>
<td>Lymphocyte % (Sysmex)</td>
<td>34.0</td>
<td>20.0-50.0</td>
<td>%</td>
</tr>
<tr>
<td>Monocyte % (Sysmex)</td>
<td>9.3</td>
<td>6.0-13.0</td>
<td>%</td>
</tr>
<tr>
<td>Eosinophil % (Sysmex)</td>
<td>1.4</td>
<td>0.0-5.0</td>
<td>%</td>
</tr>
<tr>
<td>Basophil % (Sysmex)</td>
<td>0.4</td>
<td>0.0-1.0</td>
<td>%</td>
</tr>
<tr>
<td>Immature Granulocyte % (Sysmex)</td>
<td>0.2</td>
<td>0.0-1.0</td>
<td>%</td>
</tr>
</tbody>
</table>

**Absolute Counts**

<table>
<thead>
<tr>
<th>Component</th>
<th>Your Value</th>
<th>Standard Range</th>
<th>Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Absolute Neutrophil Count</td>
<td>2.8</td>
<td>1.5-7.2</td>
<td>K/MM3</td>
</tr>
<tr>
<td>Absolute Lymphocyte Count</td>
<td>1.8</td>
<td>1.2-4.0</td>
<td>K/MM3</td>
</tr>
<tr>
<td>Absolute Monocyte Count</td>
<td>0.5</td>
<td>0.1-1.1</td>
<td>K/MM3</td>
</tr>
<tr>
<td>Absolute Eosinophil Count</td>
<td>0.1</td>
<td>0.0-0.5</td>
<td>K/MM3</td>
</tr>
<tr>
<td>Absolute Basophil Count</td>
<td>0.0</td>
<td>0.0-0.2</td>
<td>K/MM3</td>
</tr>
<tr>
<td>Absolute Early Gran Count</td>
<td>0.0</td>
<td>0.0-0.1</td>
<td>K/MM3</td>
</tr>
</tbody>
</table>

**Hemoglobin A1c**

<table>
<thead>
<tr>
<th>Component</th>
<th>Your Value</th>
<th>Standard Range</th>
<th>Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hemoglobin A1c</td>
<td>8.4</td>
<td>3.8-6.4</td>
<td>%</td>
</tr>
</tbody>
</table>

**Basic Metablic Panel**

<table>
<thead>
<tr>
<th>Component</th>
<th>Your Value</th>
<th>Standard Range</th>
<th>Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glucose</td>
<td>125</td>
<td>70-140</td>
<td>mg/dL</td>
</tr>
<tr>
<td>Urea Nitrogen</td>
<td>10</td>
<td>8.0-20.0</td>
<td>mg/dL</td>
</tr>
<tr>
<td>Creatinine</td>
<td>1.0</td>
<td>0.7-1.3</td>
<td>mg/dL</td>
</tr>
<tr>
<td>Calcium</td>
<td>8.7</td>
<td>8.6-10.3</td>
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</tr>
<tr>
<td>Sodium</td>
<td>143</td>
<td>136-146</td>
<td>mmol/L</td>
</tr>
<tr>
<td>Potassium</td>
<td>4.9</td>
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</tr>
<tr>
<td>Chloride</td>
<td>100</td>
<td>88-108</td>
<td>mmol/L</td>
</tr>
<tr>
<td>CO2</td>
<td>24</td>
<td>22-34</td>
<td>mmol/L</td>
</tr>
</tbody>
</table>
Experimental Design

- **A1c level**
  - 7.1%
  - 8.4%

- **Number of out-of-range values**
  - A1c only
  - A1c + viral infection
    - WBC, platelet, MCH, MCHC, neutrophil %, lymphocyte %, monocyte %, ANC, and serum glucose
Participants

- 1817 adults age 40-70
  - Recruited from a demographically diverse Internet panel
  - Measured both health literacy and numeracy
Effects of Numeracy and Literacy

Estimated Likelihood of Calling a Doctor

<table>
<thead>
<tr>
<th>Test</th>
<th>Your Result</th>
<th>Standard Range</th>
<th>Units</th>
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<tbody>
<tr>
<td>Hemoglobin A1c</td>
<td>8.6</td>
<td>H</td>
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</table>
Ongoing Design Research
Ongoing Design Research

Hemoglobin A1c Test Result

Your Result
6.2%

4.0 4.5 5.7 6.0 7.0 8.0 9.0

STANDARD RANGE

DRAFT Concept Images
AHRQ R01 HS021681
(B.J. Zikmund-Fisher, PI)
Ongoing Design Research

Hemoglobin A1c Test Result

Your Result
6.2%

Goal Range for People with Type 2 Diabetes

Standard Range

4.0 4.5 5.7 6.0 7.0 8.0 9.0
Ongoing Design Research

Hemoglobin A1c Test Result

Your Result

6.2%

GOAL RANGE FOR PEOPLE WITH TYPE 2 DIABETES

4.0 4.5 5.7 6.5 8.0 9.0

Low Borderline Standard Borderline High High Very High Low Range
Ongoing Design Research

Hemoglobin A1c Test Result

Your Result

6.2%

GOAL RANGE FOR PEOPLE WITH TYPE 2 DIABETES
Ongoing Design Research

Hemoglobin A1c Test Result

Your Result

6.2%

4.0  5.0  6.0  6.5  7.5  8.0  9.0

Very Low  Low  Borderline Low  GOAL RANGE FOR PEOPLE WITH TYPE 2 DIABETES  High  Very High
Good or Bad?

Platelets: 135 x 10⁹/L

(Standard range: 150-400)
What is normal?

Vs.

What is dangerous?
Ongoing Design Research

Platelet Count (Plt) Test Result

Your Result

135 x 10^9/L

0 150 400 500

Get blood transfusion right away

Many doctors are not concerned until here

STANDARD RANGE

DRAFT Concept Images AHRQ R01 HS021681 (B.J. Zikmund-Fisher, PI)
## What Is Dangerous?

### Component Results

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Patient Needs

- ALWAYS consider the congruence of data type, format, and especially context with patients' immediate and specific needs

"The Right Tool at the Right Time"
“...neutral way of presenting the data?”
Does Not Exist
Take Away Messages

- We must recognize *why* we are providing data *before* we provide numbers

- *Context* to create evaluability
Providing the *right number* does NOT guarantee *the right message*.