# Tools and Processes to Support Decisions and Enhance Risk Communication

Mary C. Politi, Ph.D.

Department of Surgery
Division of Public Health Sciences

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  - Bill & Melinda Gates Foundation
  - Centers for Disease Control and Prevention
  - Department of Defense

## Communicating Risk is Evidence-Based Medicine

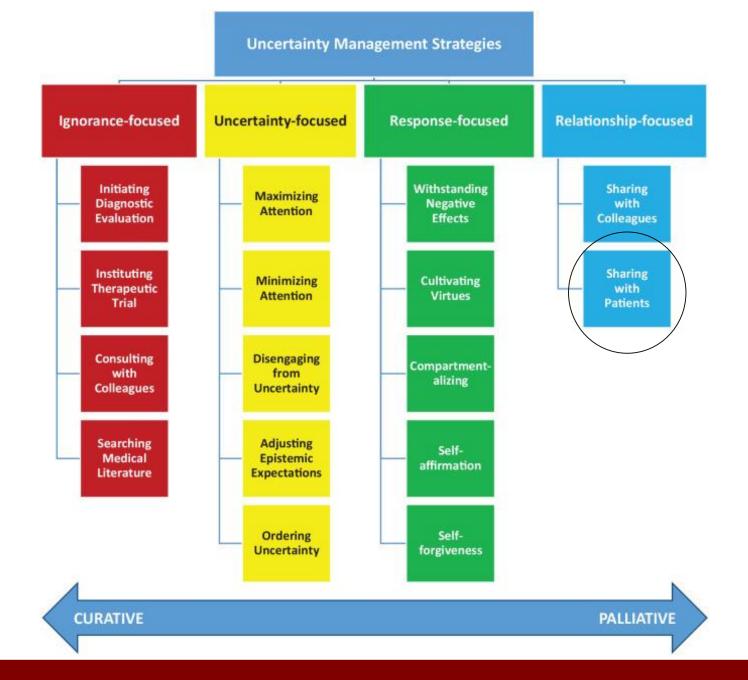
"The use of mathematical estimates of the risk of benefit and harm, derived from high-quality research on <u>population samples</u>, to inform clinical decision-making...of individual patients." (Greenhalgh, 2006; 2009)

- Key steps:
  - Translate uncertainty to an answerable question
  - Systematically retrieve best evidence available
  - Critically appraise evidence
  - Apply results in practice [to individuals]

## What does risk mean to (some) patients?



https://www.stmweather.com/blog/meteorology-101/what-does-50-chance-of-rain-really-mean



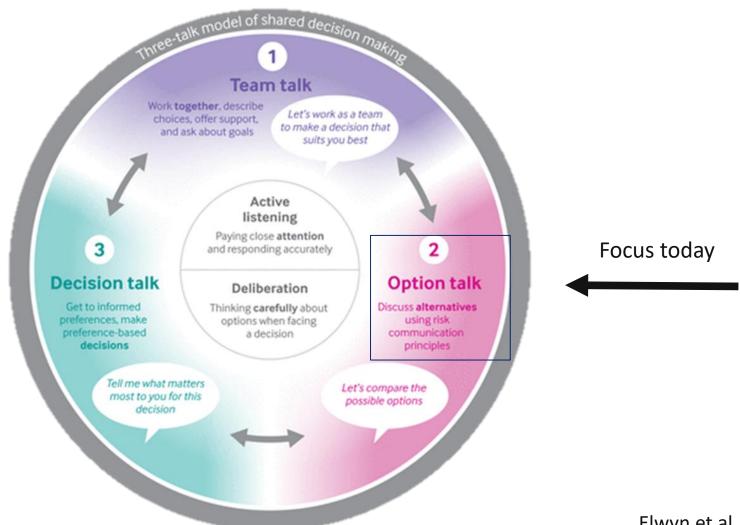
Han et al., 2021, Med Decis Making; 41(3): 275–291.

## What does risk mean to (some) clinicians?

"...I underestimated, was maybe a bit naïve in thinking that clinical practice would have these relevant definitive arenas of black and white and very statistically quantitative processes...the more I got into it, the more I realized there's more gray, and that even when we try to quantify things...they're not always as certain as we would think....it's helped me shift more from the science to the art...where we aren't certain, we give the patient information, help them make their choice, and make it more of a personalized element....part of you wants to get rid of uncertainty. Like, Well let's get a better equation. But then...another part of me says...you kind of have to embrace it." (IM-A-9)

Han et al., 2021, Med Decis Making; 41(3): 275–291.

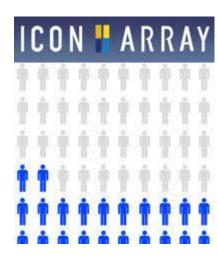
## SDM: Team Talk, Option Talk, Decision Talk



Elwyn et al. (2017), BMJ

## Option talk: Risks, benefits, uncertainty

- Use numbers. Otherwise, people underestimate risk, overestimate benefit.
- Use frequencies, e.g. X out of 100
- Use visuals: most say "icon arrays"
- Keep denominator consistent for comparisons.
- Provide a reference group, time period, and use absolute (vs. relative) risk.



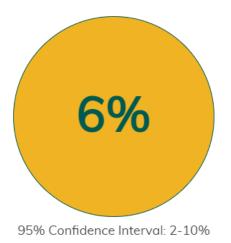
New drug reduced cancer incidence by 50% ABSOLUTE RISK

New drug reduced cancer incidence from 2 per 1000 to 1 per 1000

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

## Clinician decision support For use with patients during visits

#### **Sentinel Node Metastasis Risk**

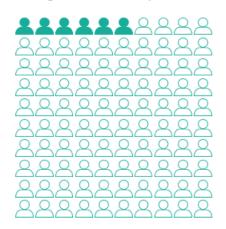


#### These results are based on:

Age 66
Thickness 1.1mm
Subtype Nodular
Mitoses 2/mm²
Ulceration Unknown
LV Invasion Unknown

### **Results Interpretation**

The following information may be useful for clinicians when discussing with patients



The probability of having spread of melanoma to the lymph nodes is 6%. In other words, 6 out of 100 people with melanoma and the same risk factors as your patient will have spread of the melanoma to the lymph nodes.

Typically a sentinel node biopsy is recommended for patients with a risk greater than 10% and may be considered for those with a risk between 5% and 10%.

Where indicated, sentinel node biopsy should be done at the same time as wide local excision of the primary melanoma is undertaken.

https://www.melanomarisk.org .au/SNLForm

### Patient Decision Aid (part) + Clinician Summary, For use pre- or post-visit, reviewed during visit

### Your Risk from Having Breast Reconstruction Surgery

Breast reconstruction can help some women feel better about their body after their breast is removed. It can also increase the chance of having a major wound infection, wound opening, or tissue damage. This chance is higher if women start the process at the time their breast is removed for cancer, compared to delaying reconstruction.

With no

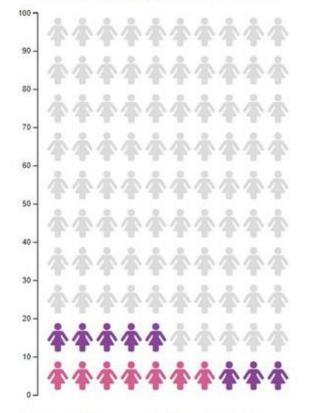
risk factors, 7 out of 100 women have a major wound infection, wound opening, or tissue damage after a mastectomy plus immediate breast reconstruction.

To help you understand your own risks from breast reconstruction done at the time your breast is removed, we reviewed your current health. With the same risk factors you have, **15** out of 100 women have a major wound infection, wound opening, or tissue damage. Your risk is higher because you have a number of conditions that have been related to complications and delayed wound healing. Click here to learn more about those conditions. Talk to your doctor about how this might affect your choice.

### What does my risk mean?

Your risk shows the chance of having a major wound opening, wound infection or tissue damage compared to a person who has no risk factors. The risk estimate comes from looking at thousands of women and their outcomes from breast reconstruction. It's just an estimate. No one knows who will or will not have one of these outcomes. Talk to your doctor or nurse if you want to learn ways to lower your risk.

Your Chance of Wound Infection, Wound Opening, or Tissue Damage after Breast Reconstruction

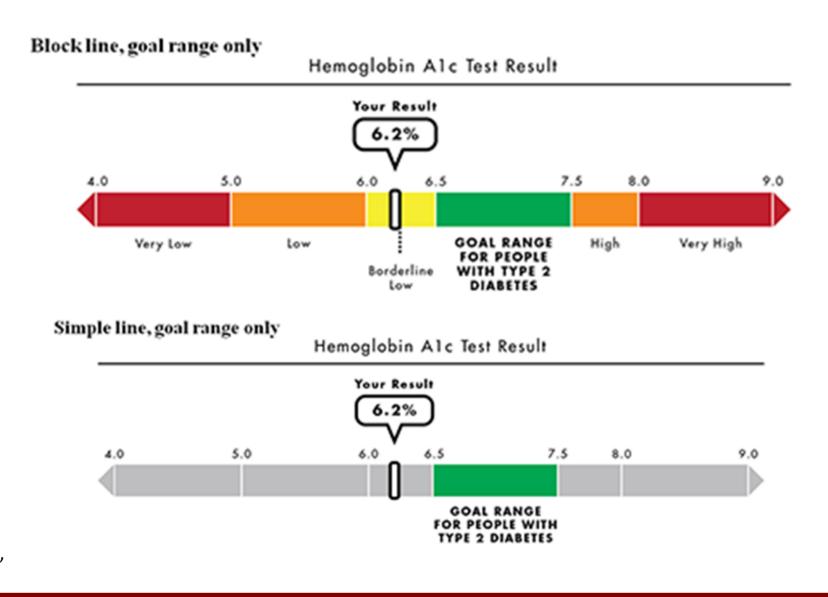


7 out of 100 women have these outcomes after breast reconstruction, even with no risk factors.

15 out of 100 women with the same risk factors as you have these outcomes after breast reconstruction.

Politi, Lee, Philpott-Streiff, Foraker, Olsen, Merrill, Tao & Myckatyn., 2020, Annals of Surgery

### Out-of-range lab results For display in patient portal



Scherer, Witteman, Solomon, Exe, Fagerlin & Zikmund-Fisher, 2018, JMIR

# Conversation Aid vs. Digital Tool Pre- or Post-Visit: Context Matters

"The fact that this [conversation aid] is like all in one page...it is just really easy for the patient to read and it's easy to go through quickly...while you are in the office."

OBGYN, 3-5 years in practice, preferred conversation aid

Politi, Adsul, Kuzemchak, Zeuner, Frosch (2014)

# Conversation Aid vs. Digital Tool Pre- or Post-Visit: Context Matters

"We do have computers in the clinic rooms, but it takes so long for them to load anything...I have to log in, then it freezes, then I have to un freeze it and then have to get to the website...pulling out a pencil and paper thing would be so much more accessible"

— Medical Oncology, 3-5 years in practice, preferred paper

Politi, Adsul, Kuzemchak, Zeuner, Frosch (2014)

# Conversation Aid vs. Digital Tool Pre- or Post-Visit: Context Matters

"...When someone hears they have cancer, it takes a couple visits to let that sink in before even talking about treatment options, so having this [digital DA] at home [to let] that sink in would help"

— Internal Medicine, 3-5 years in practice, preferred digital tool

Politi, Adsul, Kuzemchak, Zeuner, Frosch (2014)

# Conversation Aid vs. Digital Tool Pre- or Post-Visit: Level-Setting

"Pain, complications...I don't really tell them about that."

Surgeon 10, about minimizing risks about breast reconstruction

Hasak, Myckatyn...Politi, 2017. Plastic and Reconstructive Surgery Global Open.

## Precision Communication/SDM in 1892: Not New Ideas, but Implementation Lags Behind!

"It is much more important to know what sort of a patient has a disease, than what sort of disease a patient has."

William Osler, The Principles and Practice of Medicine, 1892

## Questions/Follow-Up

Mary C. Politi, PhD

mpoliti@wustl.edu
http://publichealthsciences.wustl.edu/Faculty/PolitiMary
www.collaborativecare.wustl.edu

