Human-Centered Quantitative Communication for Clinicians and Patients

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Why does communicating statistical information feel so hard?

Because it’s a really,
really hard thing to do.
Harder than science communication.

Science vs Stats

Empirical things <—> Abstract numbers

Tasty cake <—> New baking pans

Gas pedal <—> Brake

People's lives <—> The world's information

Truth <—> Uncertainty

"This beautiful, approachable book not only teaches you how to cook, but captures how it should *feel* to cook: full of exploration, spontaneity and joy. Samin is one of the great teachers I know." —Alice Waters

SALT FAT ACID HEAT

MASTERING THE ELEMENTS of GOOD COOKING

by SAMIN NOSRAT

and ART by WENDY MacNAUGHTON

with A FOREWORD by MICHAEL POLLAN

We need
Human-Centered Quantitative Communication

- Magnitudes
- Relationships
- Data Summaries

- Unknowns in knowledge
- Unknowns in future
- Confidence
- Possibilities

NUMBERS CERTAINTY ABSTRACTIONS CONTEXT

- “Drawn away” from concrete world
- Data collection
- Algorithms
- Methodology
- Models

- “Weave together”
- Updating knowledge
- Predictions
- Decisions

- Magnitudes
- Relationships
- Data Summaries

- Unknowns in knowledge
- Unknowns in future
- Confidence
- Possibilities

NUMBERS CERTAINTY

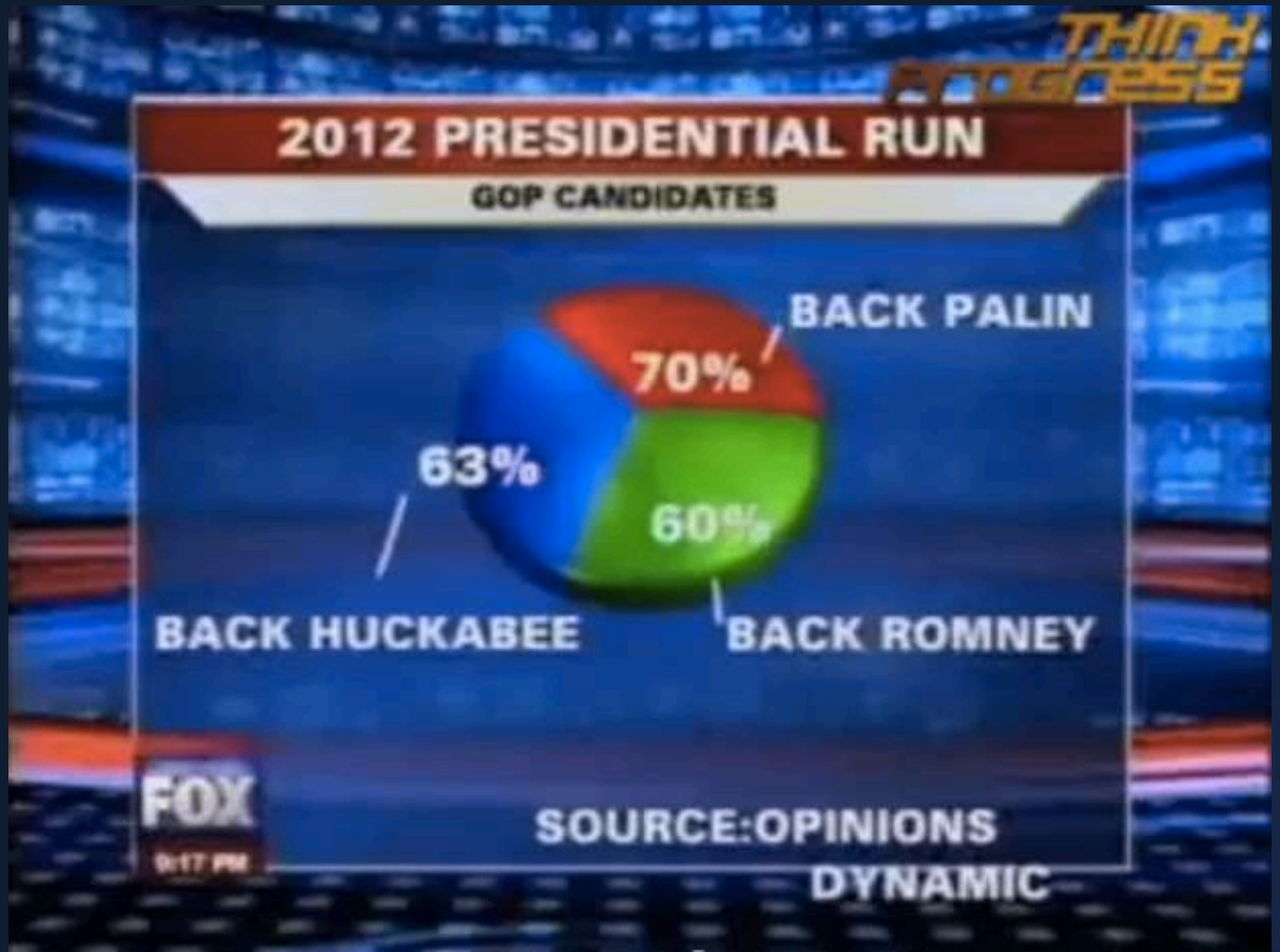
Numbers

"No one ever made a decision because of a number. They need a story."

-- Daniel Kahneman

Anecdotes → Data → Stories?

Numbers??


THINK PROGRESS
2012 PRESIDENTIAL RUN
GOP CANDIDATES
BACK PALIN
70%
63%
60%
BACK HUCKABEE
BACK ROMNEY
FOX
SOURCE:OPINIONS DYNAMIC

Numbers: Mammograms

Most people see things like this:

Important things to know about mammograms

- **They can save your life.** Finding breast cancer early reduces your risk of dying from the disease by 25-30% or more. Women should begin having mammograms yearly at age 40, or earlier if they're at high risk.

http://stopcancerfund.org/p-breast-cancer/women-undergo-mammograms-yes/

Long-term effects of mammography screening: updated overview of the Swedish randomised trials

THE LANCET • Vol 359 • March 16, 2002 •

Lennarth Nyström, Ingvar Andersson, Nils Bjurstam, Jan Frisell, Bo Nordenskjöld, Lars Erik Rutqvist

Findings The median trial time—the time from randomisation until the first round was completed for the control group or if the control group was not invited, until end of follow-up—was 6·5 years (range 3·0–18·1). The median follow-up time, the time from randomisation, to the end of follow-up, was 15·8 years (5·8–20·2). There were 511 breast cancer deaths in 1 864 770 women-years in the invited groups and 584 breast cancer deaths in 1 688 440 women-years in the control groups, a significant 21% reduction in breast cancer mortality (RR=0·79, 95% CI 0·70–0·89). The reduction was

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IN SCREENING GROUP:

$$\frac{511 \text{ DEATHS}}{1{,}864{,}770 \text{ WOMEN·YEARS}} = \frac{0.000274 \text{ deaths}}{1 \text{ woman-year}} \cdot \frac{15.8 \text{ years}}{\text{study}} = \frac{0.0043 \text{ deaths}}{1 \text{ woman·study}} \cdot 1000 \text{ women}$$

$$= \frac{4.3 \text{ deaths}}{1000 \text{ women}}$$

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NON-SCREENED:

$$\frac{584 \text{ DEATHS}}{1{,}688{,}440 \text{ WOMEN} \cdot \text{YEARS}} \cdot \frac{15.8 \text{ YEARS}}{\text{STUDY}} \cdot \frac{1000 \text{ WOMEN}}{1}$$

$$= \frac{5.5 \text{ deaths}}{1000 \text{ women}}$$

1000 WOMEN SCREENED → ~4.3 DEATHS

1000 WOMEN NOT SCREENED → ~5.5 DEATHS

Absolute numbers vs Relative numbers?

Researchers estimate that over a 15-year period, the chances of a woman dying of breast cancer if she's not screened are 0.52%. That number will drop to 0.41% with regular screening.

Researchers estimate women who are regularly screened are 21% less likely to die of breast cancer.

Gigerenzer, Gerd, et al. "Helping doctors and patients make sense of health statistics." Psychological science in the public interest 8.2 (2007): 53-96.

Natural Frequencies vs Percentages?

. . . for every 1,000 women who are not screened, about 5 will die of breast cancer over 15 years, but this number will drop to only about 4 deaths for women who are screened.

. . . over a 15-year period, the chances of a woman dying of breast cancer if she's not screened are 0.52%. That number will drop to 0.41% with regular screening.

Varying Denominator vs Varying Numerator?

. . . without regular screening, about one in every 192 women will die of breast cancer over a 15-year period, compared to one in about 244 who do get screening.

. . . for every 1,000 women who are not screened, about 5 will die of breast cancer over 15 years, but this number will drop to only about 4 deaths for women who are screened.

Large Denominator vs Tribe-Sized Denominator?

… for every 10,000 women who are not screened, about 52 will die of breast cancer, compared to about 41 who will die even if they are screened.

... for every 1,000 women who are not screened, about 5 will die of breast cancer, but this number will drop to only about 4 deaths for women who are screened.

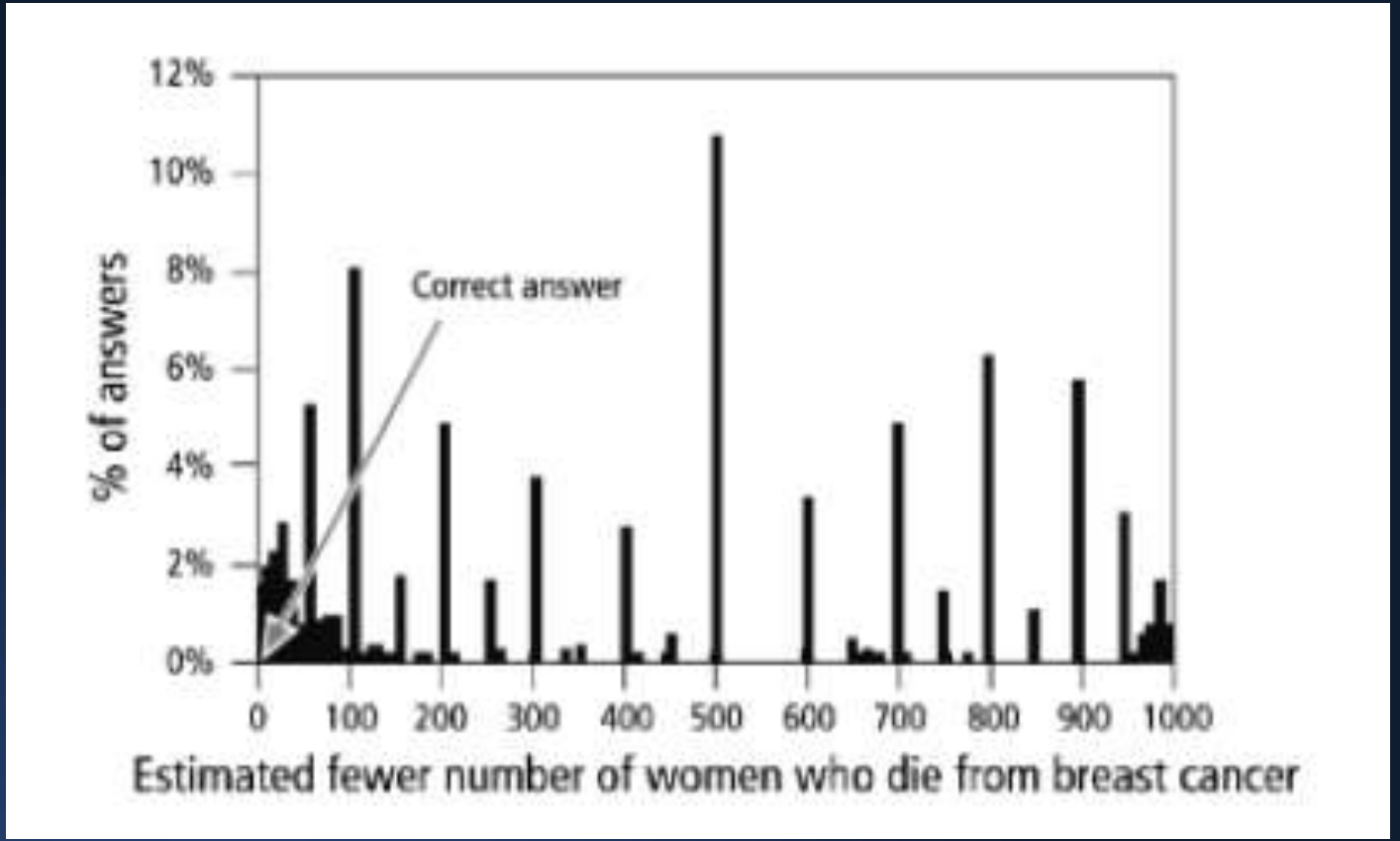
… for every 10,000 women who are not screened, about 52 will die of breast cancer, compared to about 41 who will die even if they are screened.

… for every 1,000 women who are not screened, about 5 will die of breast cancer, but this number will drop to only about 4 deaths for women who are screened.

… for every 100 women who are not screened, about 0.5 will die of breast cancer, but this number will drop to only about 0.4 deaths for women who are screened.

IN THE REAL WORLD:

"Early detection with mammography reduces the risk of dying from breast cancer by 25%. Assume that 1,000 women aged 40 and older participate regularly in screening. How many fewer would die of breast cancer?"



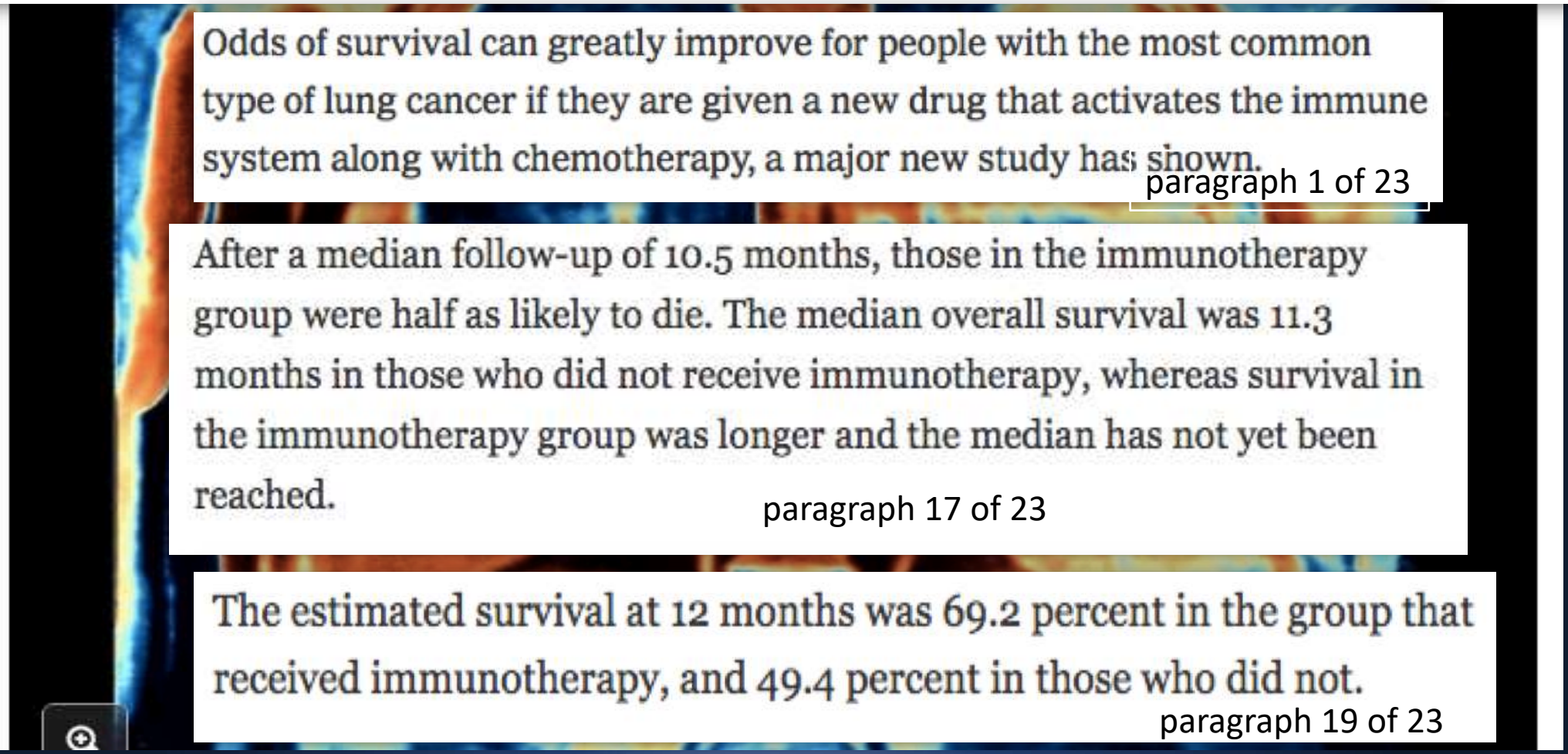
Gigerenzer, Gerd, et al. "Helping doctors and patients make sense of health statistics." *Psychological science in the public interest* 8.2 (2007): 53-96.

The New York Times

NUMBERS: Lung Cancer

Lung Cancer Patients Live Longer With Immune Therapy

By DENISE GRADY APRIL 16, 2018



Odds of survival can greatly improve for people with the most common type of lung cancer if they are given a new drug that activates the immune system along with chemotherapy, a major new study has shown.

paragraph 1 of 23

After a median follow-up of 10.5 months, those in the immunotherapy group were half as likely to die. The median overall survival was 11.3 months in those who did not receive immunotherapy, whereas survival in the immunotherapy group was longer and the median has not yet been reached.

paragraph 17 of 23

The estimated survival at 12 months was 69.2 percent in the group that received immunotherapy, and 49.4 percent in those who did not.

paragraph 19 of 23

Link to article

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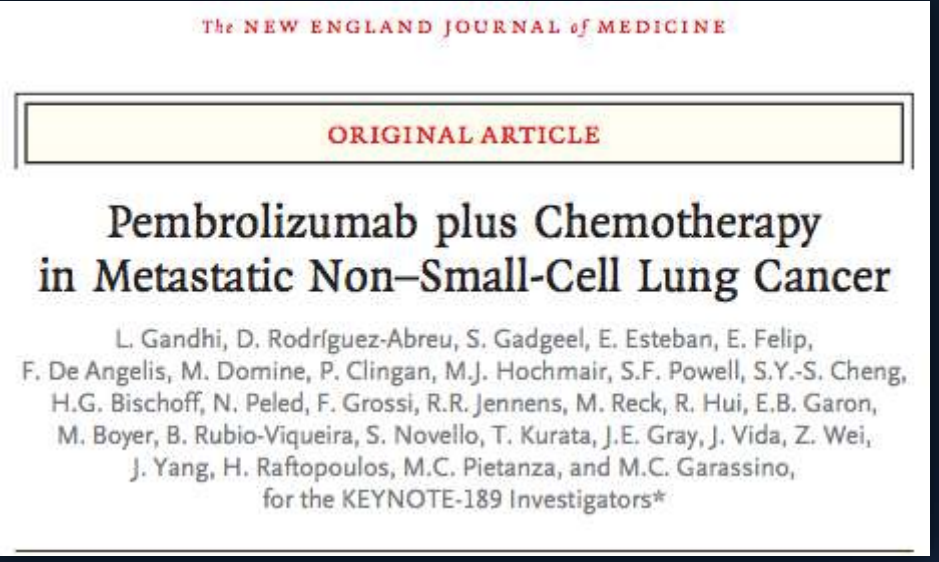


The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Pembrolizumab plus Chemotherapy in Metastatic Non–Small-Cell Lung Cancer

L. Gandhi, D. Rodríguez-Abreu, S. Gadgeel, E. Esteban, E. Felip, F. De Angelis, M. Domine, P. Clingan, M.J. Hochmair, S.F. Powell, S.Y.-S. Cheng, H.G. Bischoff, N. Peled, F. Grossi, R.R. Jennens, M. Reck, R. Hui, E.B. Garon, M. Boyer, B. Rubio-Viqueira, S. Novello, T. Kurata, J.E. Gray, J. Vida, Z. Wei, J. Yang, H. Raftopoulos, M.C. Pietanza, and M.C. Garassino, for the KEYNOTE-189 Investigators*

OVERALL SURVIVAL: With 235 deaths in the intention-to-treat population, the estimated proportion of patients who were alive at 12 months was 69.2% (95% confidence interval [CI], 64.1 to 73.8) in the pembrolizumab-combination group and 49.4% (95% CI, 42.1 to 56.2) in the placebo-combination group.

?

The estimated survival at 12 months was 69.2 percent in the group that received immunotherapy, and 49.4 percent in those who did not.

For every 100 patients on the regular treatment, about 49 were still alive after one year. That number rose to about 69 for those who had the immunotherapy.

G… cell lung cancer." *New England Journal of Medicine* (2018).

Living or dying?

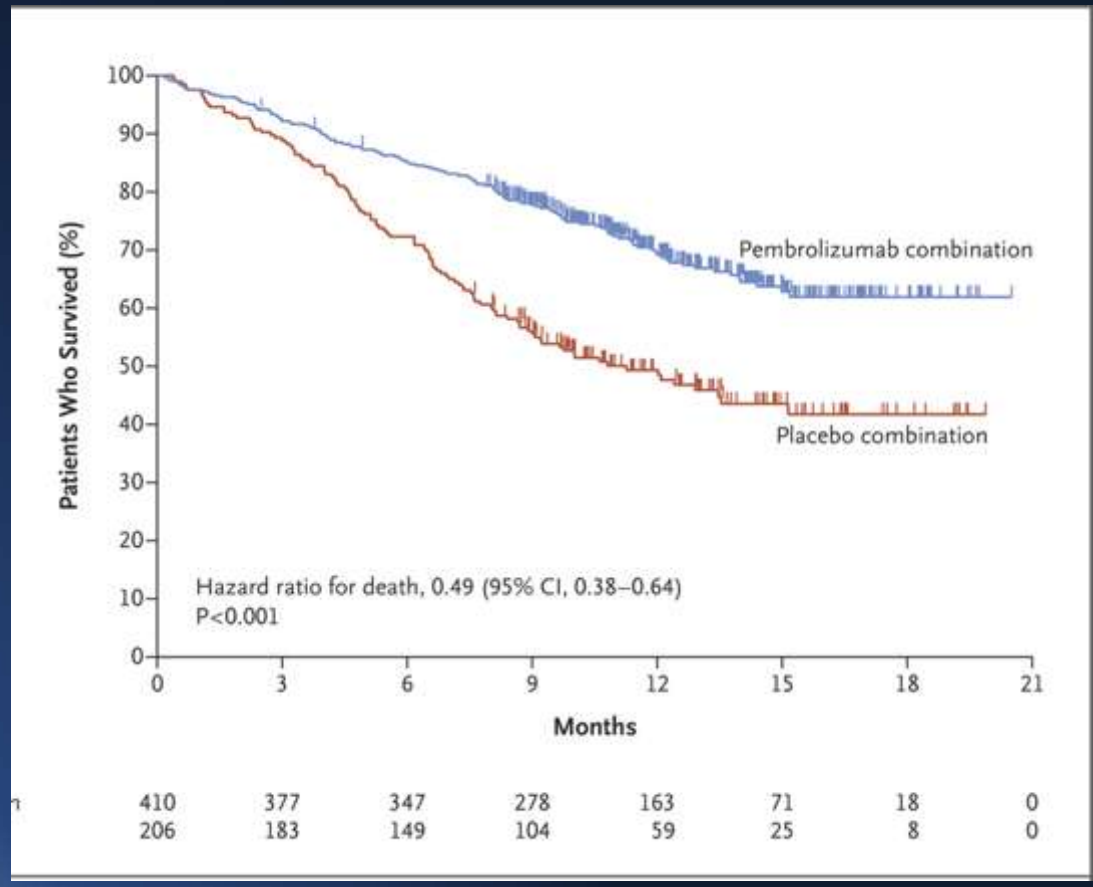
For every 100 patients on the regular treatment, about 51 died within a year. For those who had the immunotherapy, that number dropped to about 31.

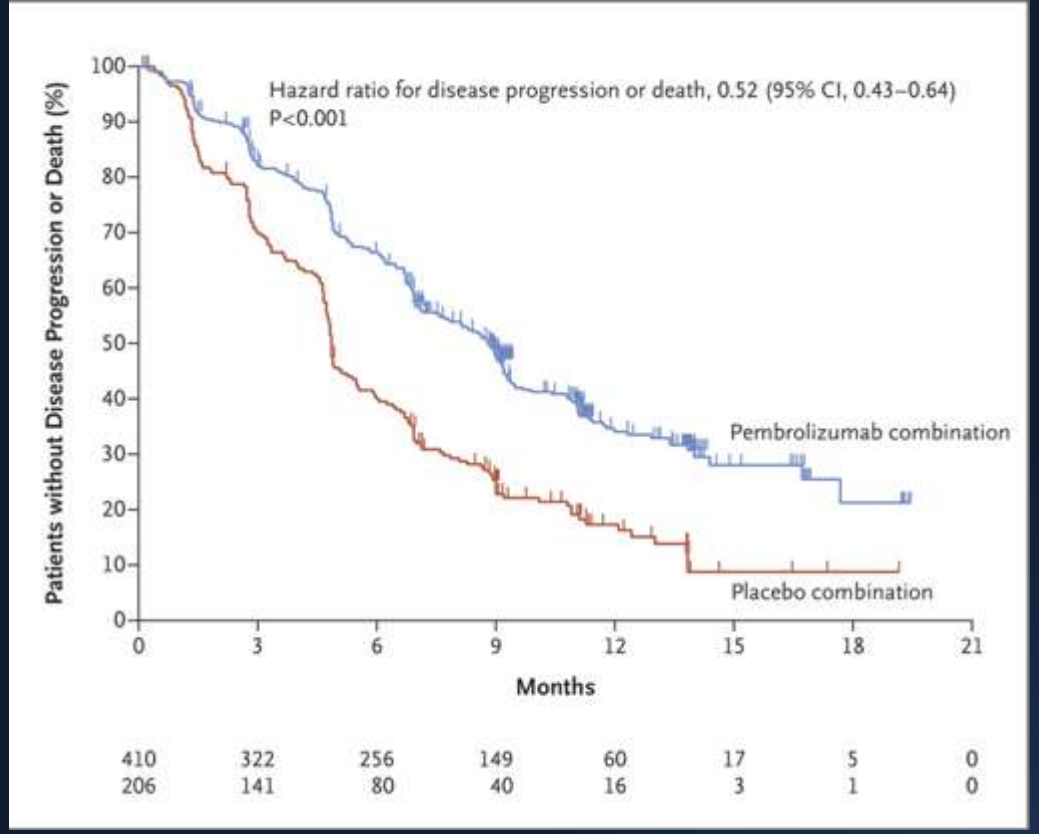
For every 100 patients on the regular treatment, about 49 were still alive after one year. For those who had the immunotherapy, that number rose to about 69.

NYT Used Overall Survival

The median overall survival was not reached in the pembrolizumab-combination group and was 11.3 months (95% CI, 8.7 to 15.1) in the placebo-combination group (hazard ratio for death, 0.49; 95% CI, 0.38 to 0.64; P<0.001)

After a median follow-up of 10.5 months, those in the immunotherapy group were half as likely to die. The median overall survival was 11.3 months in those who did not receive immunotherapy, whereas survival in the immunotherapy group was longer and the median has not yet been reached.





Use Progression-Free Survival Instead?

With 410 events of progression or death, the median progression-free survival was 8.8 months (95% CI, 7.6 to 9.2) in the pembrolizumab-combination group and 4.9 months (95% CI, 4.7 to 5.5) in the placebo-combination group (hazard ratio for progression or death, 0.52; 95% CI, 0.43 to 0.64; P<0.001)

After a median follow-up of 10.5 months, those in the immunotherapy group were half as likely to die. The median overall survival was 11.3 months in those who did not receive immunotherapy, whereas survival in the immunotherapy group was longer and the median has not yet been reached.

The researchers also looked at how much the cancers in each group progressed. For every 100 patients on the regular treatment, about 50 lived at least five months progression-free; for those on immunotherapy, that number rose to almost nine months.

Personal or Group orientation?

With the regular treatment, patients could expect to live an average of almost five months progression-free; for those who had the immunotherapy, that number rose to almost nine months.

For every 100 patients on the regular treatment, about 50 lived at least 5 months progression-free; for those on immunotherapy, that number rose to almost nine months.

Gandhi, Leena, et al. "Pembrolizumab plus chemotherapy in metastatic non–small-cell lung cancer." *New England Journal of Medicine* (2018).

NUMBERS: Rain

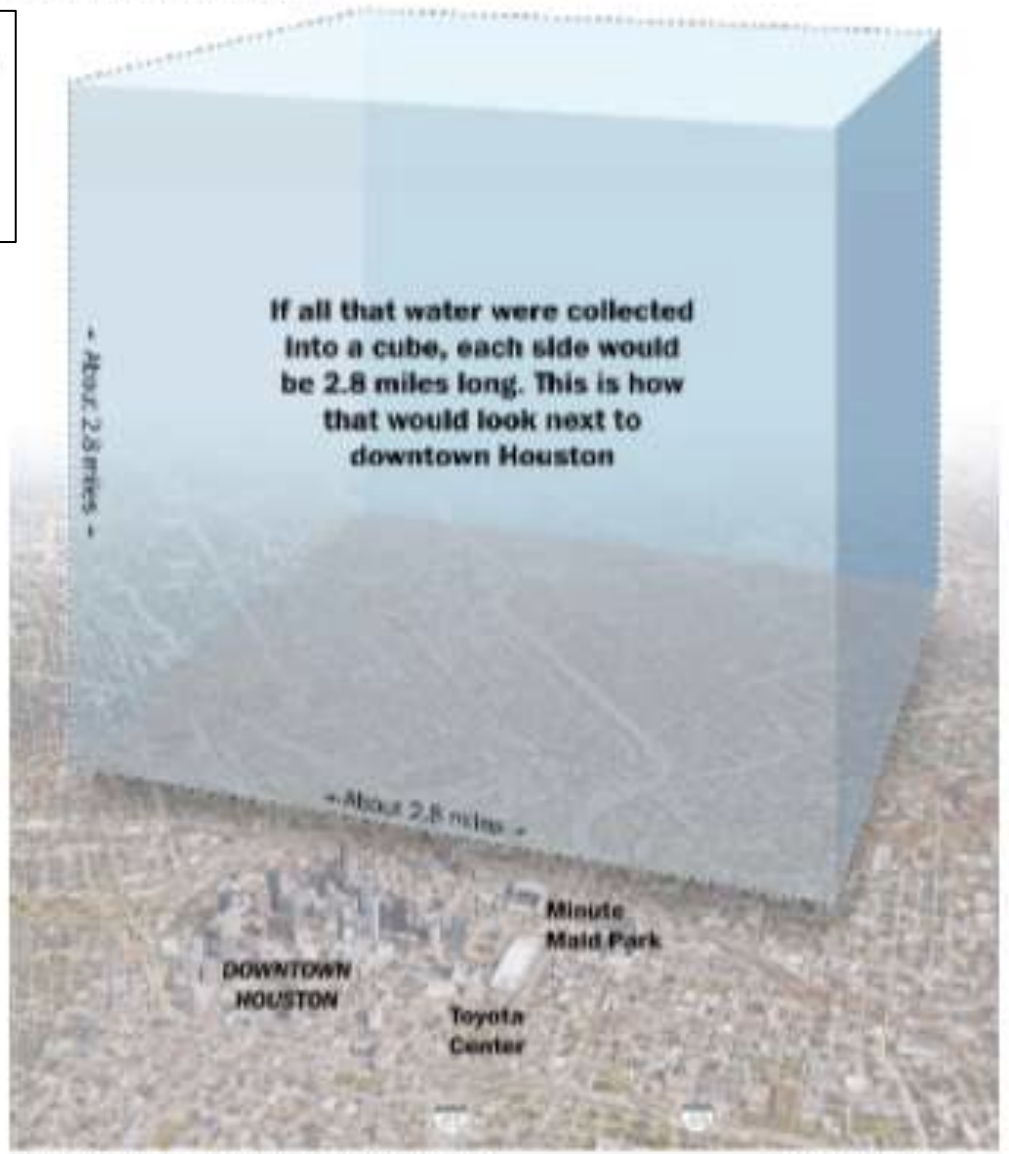
Capital Weather Gang

Harvey unloaded 33 trillion gallons of water in the U.S.

By Angela Fritz and Jason Samenow September 2, 2017 Email the author

What would 24.5 trillion gallons of water look like?

As of Wednesday morning, about 24.5 trillion gallons of rain have fallen along the Gulf of Mexico. About 19 trillion gallons across the greater Houston area and Southeast Texas, as well as an additional 5.5 trillion in Louisiana.



Harvey data: Capital Weather Gang, Google Earth

THE WASHINGTON POST

https://www.washingtonpost.com/news/capital-weather-gang/wp/2017/08/24-5-trillion-gallons-of-water-on-texas-and-louisiana/

If you piled up 20 trillion gallons of water over the District of Columbia (approximately 68 square miles), the height of the water would be 1,410 feet — or almost the height of the Empire State Building. (Ryan Maue)

The amount of rain that fell in Texas and Louisiana would have ended the historic California drought, twice over. (Paul Deanno)

It's enough to cover the entire state of Arizona in more than a foot of water.

Over Harris County alone — which is home to Houston — 1 trillion gallons of water fell in the four days from Saturday through Tuesday. That's as much water as flows over Niagara Falls in 15 days. (Jeff Lindner)

https://www.washingtonpost.com/news/capital-weather-gang/wp/2017/08/30/harvey-has-unloaded-24-5-trillion-gallons-of-water-on-texas-and-louisiana/

Near Mont Belvieu, Tex., 51.88 inches of rain fell. That's the highest rainfall total in any storm in the history of the United States.

- It's approximately how much rain falls in Houston in an entire (average) year.

- It has taken Death Valley 23 years to accumulate that much rain. (Ian Livingston)

- It would take Los Angeles four years to hit 52 inches. (New York Times)

- In the arid climate of Southern California, it would take more than a decade for 52 inches of rain to accumulate

CERTAINTY: Ebola Vaccine

HEALTH

The New York Times

New Ebola Vaccine Gives 100 Percent Protection

By DONALD G. McNEIL Jr. DEC. 22, 2016

In a scientific triumph that will change the way the world fights a terrifying killer, an experimental Ebola vaccine tested on humans in the waning days of the West African epidemic has been shown to provide 100 percent protection against the lethal disease.

THE LANCET

Efficacy and effectiveness of an rVSV-vectored vaccine in preventing Ebola virus disease: final results from the Guinea ring vaccination, open-label, cluster-randomised trial (Ebola Ça Suffit!)

www.thelancet.com Vol 389 February 4, 2017

No cases of Ebola virus disease occurred 10 days or more after randomisation among randomly assigned contact
and contacts of contacts vaccinated in immediate clusters versus 16 cases (7 clusters affected) among all eligibl
individuals in delayed clusters. Vaccine efficacy was 100% (95% CI 68·9–100·0, p=0·0045), and the calculate
intraclass correlation coefficient was 0·035. Additionally, we defined 19 non-randomised clusters in which w
enumerated 2745 contacts and contacts of contacts, 2006 of whom were eligible and 1677 were immediatel

A Taxonomy of Uncertainty

1st Order: Aleatory

- "Risk"
- What is random?
- What is unknowable to us humans?

2nd Order: Epistemic

- "Confidence intervals"
- How uncertain are we about the parameters (or summaries or results)?
- What knowledge do we humans lack?

3rd Order: Ontological

- "Ignorance"
- What are the unknown unknowns?
- What do we need humility around?

Spiegelhalter, David. "Risk and Uncertainty Communication." Annual Review of Statistics and Its Application 4 (2017): 31-60.

New Ebola Vaccine Gives 100 Percent Protection in Trial

Epistemic:
It's not guaranteed that the vaccine will be 100 percent effective in the real world. Right now, researchers' best guess is that it will be at least 69 percent effective.

Aleatory:
That means that for every 100 people who get the vaccine, at least 69 of them will be fully protected against the virus. (It doesn't mean that each person will be 69% protected.)

Ontological:
Researchers will have a better estimate of the true efficacy after more studies. It seems certain, however, that . . .

There are other important questions around the vaccine. For example . . .

HEALTH

First Ebola Vaccine Likely To Stop The Next Outbreak

December 22, 2016 · 6:31 PM ET
Heard on Morning Edition

MICHAELEEN DOUCLEFF

When Ebola struck West Africa a few years ago, the world was defenseless. There was no cure. No vaccine. And the result was catastrophic: More than 11,000 people died. Nearly 30,000 were infected.

Now it looks like such a large outbreak is unlikely to ever happen again. Ever.

The world now has a potent weapon against Ebola: a vaccine that brings outbreaks to a screeching halt, scientists report Thursday in *The Lancet*.

"We were able to estimate the efficacy of the vaccine as being 100 percent in a trial," says Ira Longini, a biostatistician at the University of Florida, who helped test the vaccine. "It's very unusual to have a vaccine that protects people perfectly."

Now, no vaccine — or drug for that matter — is *perfect*. The efficacy of the vaccine is clearly high but not "100 percent." That value reflects the fact that they just haven't tested the vaccine on enough people yet. So it is likely to decrease as the vaccine is used over time. In the end, the efficacy is likely to sit somewhere between about 70 percent and 100 percent, Longini says.

By comparison, the flu vaccine last year was about 50 percent effective.

And there are still a few open questions about the vaccine, says Dr. Anthony Fauci, at the National Institutes of Health.

"For example, we don't know how durable the vaccine is," he says. "If you give health care workers the vaccine, for example, how long would they be protected? That's very important to learn."

What is clear is that the vaccine offers short-term protection during outbreaks. And that's exactly what's needed to stop the virus from spreading and to keep small outbreaks from getting out of control.

Strategies for numbers:

- Absolute risk reductions vs relative risk reductions
- Frequencies vs percentages
- “Tribe-sized” reference population
- Keep denominators constant
- Human-centered analogies for large numbers
- The more physical and concrete, the better

Strategies for uncertainty:

- Don’t avoid it
- Acknowledge any uncertainty about the future, especially at the individual level (aleatory)
- Gently include uncertainty about numbers, explain why, say how it will be resolved (epistemic)
- Mention open questions and unknown unknowns, with specificity (ontological)

The Big Picture

About 4.6 billion years ago the earth was formed.

About 541 million years ago, the Cambrian Period began.

About 252 million years ago the Permian Extinction occurred.

The Cenozoic began about 66 million years ago and extends into the present.

All recorded history lies within the Holocene, which began 11,700 years ago.

If you were to lift your arms and spread them wide and hold them straight out to either side and think of the distance from fingertips to fingertips as representing the earth's entire history, then you would have all the principal events in that hillside in the middle of the palm of one hand . . . Look at one hand with its line of life. The Cambrian begins in the wrist, and the Permian Extinction is at the outer end of the palm. All of the Cenozoic is in a fingerprint, and in a single stroke with a medium-grained nail file you could eradicate human history.

-- John McPhee
Annals of the Former World

Thank You!

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