VIEWPOINT

Culturally Competent Science

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Although social norms have eliminated many forms of overt discrimination, more subtle forms of bias persist. Unfortunately, the scientific community, and particularly those of us in the health sciences, may be unintentionally contributing to many of these biases. The study of population differences is important for the understanding of health outcomes. However, studies of population differences can be, and have been, negatively influenced by subjective value judgments. This has historically taken the form of the majority population being ascribed as having "normal" traits and being used to set norms for disease definitions and treatment standards. We hypothesize that this subtle "majority is normal" bias has resulted from a lack of broad-based participation in the scientific process. Although there have been great efforts to promote culturally competent care, less has been done to encourage culturally competent science. The former focuses on practicing physicians delivering

donor race negatively affects patient survival among white patients when kidneys from black donors are transplanted to white recipients; however, outcome differences by donor ethnicity did not exist when organs from black or white donors were transplanted to patients from other racial groups, suggesting that the original findings may be limited to the pairing of black donors and white recipients. This finding should raise the question of whether the negative association with survival is attributable to issues related to black organ donors, or to the immunotolerance of white recipients.[5] In the revised US Preventive Services Task Force breast cancer screening guidelines, the screening age was raised to 50 years to reflect the finding that the majority of women in the United States who develop breast cancer receive a diagnosis in their 60s. However, it was recently noted that this incidence pattern is only applicable to white women; among nonwhite women,

Disclosure

- None

Agenda

- How Gilligan Island could teach us about disparity research
- See the problem (of normality bias)
- Be the solution

Gilligan's Island:
A tale of a fateful trip

Gilligan’s Island story

- A group of strangers gathered for a boat tour
- Originally a 3-hour ocean tour
- Caught in a freak storm, almost sank, got lost
- Landed on an isolated island

The “Gilligan Islanders”

- Gilligan - A crewman of the S. S. Minnow; well-meaning but bumbling, always seems to inadvertently mess up the castaways' escape
- The Skipper - Captain of the S. S. Minnow
- Thurston Howell III - A millionaire used to luxurious living and never does any work on the island
- Mrs. Howell - Thurston's wife; can be more spoiled than Mr. Howell at times, but is always the first to want to try something new
- The Professor - Has numerous scientific degrees and uses his knowledge to build many things on the island out of available materials; he is the most well-educated of the group and always has a logical answer to everything (although not always correct)
- Ginger Grant - A movie star from Hollywood
- Mary Ann Summers - A farm girl from Winfield, Kansas; not much is known about her before she gets to the island; she is portrayed as a typical "girl next door" and does most of the laundry and cooking

Observations from Gilligan's Island

- People on Gilligan's Island will be different from the rest of the world from Day 1
  - Differences in social determinants
    - Different food
    - Different housing
  - Differences in biology
    - Different gender composition (57% male)
    - Different average age
- Artificially created groups will always be different

Lessons from Gilligan's Island

1. Race is a social construct
   - Even though biological differences exist
   - Because biological (and social) differences always exist between any random grouping of people

Imagine an allergic plant on Gilligan Island…

- If the plant was ubiquitous throughout the world, then treatment would be readily known, and it should not matter
- But if the plant was exotic, then treatment would likely be unknown, and it could degrade the health of Gilligan Islanders relative to the rest of the world

Lessons from Gilligan's Island

- Differences in characteristics should not automatically lead to different health outcomes
  - Risk factors could lead to BAD outcomes; but they should not lead to WORSE outcomes

differences in traits ≠ differences in health outcomes

Lessons from Gilligan's Island

1. Race is a social construct
   - Even though biological differences exist
   - Because biological (and social) differences always exist between any random grouping of people
2. **Racial differences should not lead to different health outcomes**
   - **Our ignorance of social/biological factors unique to an artificially / socially constructed group is what contribute to their WORSE outcomes**
   - **The social/biological factors, by themselves, do not contribute to WORSE outcomes, even if they lead to BAD outcomes**

If we want to improve the health of Gilligan Islanders

- Studying biological traits unique to the Gilligan Islanders could help them (e.g., allergy to exotic plants on that island)
- … but probably not as helpful as studying social determinants (e.g., their isolation from the rest of the world)

- Think: modifiability

Lessons from Gilligan's Island

1. Race is a social construct
   - Even though biological differences exist
   - Because biological (and social) differences always exist between any random grouping of people
2. Racial differences should not lead to different health outcomes
   - Our ignorance of social/biological factors unique to an artificially / socially constructed group is what contribute to their WORSE outcomes
   - The social/biological factors, by themselves, do not contribute to WORSE outcomes, even if they lead to BAD outcomes
3. **Studying social determinants are more helpful than studying biological determinants in healthcare disparity**

See the problem

Be the solution

Now imagine…

- Imagine if the Professor is the smartest person in the world, and he was financed by the rich couple who happened to be the richest couple in the world

Now imagine…

- The health status of Gilligan Islanders will improve
  - May ultimately have BETTER health outcomes than the rest of the world
- But again, their superior health outcomes are not due to any innate difference in biology, even though biological differences exist
  - Their superior health outcome is due to an artificial / social decision to invest in research only for them
  - They just got lucky

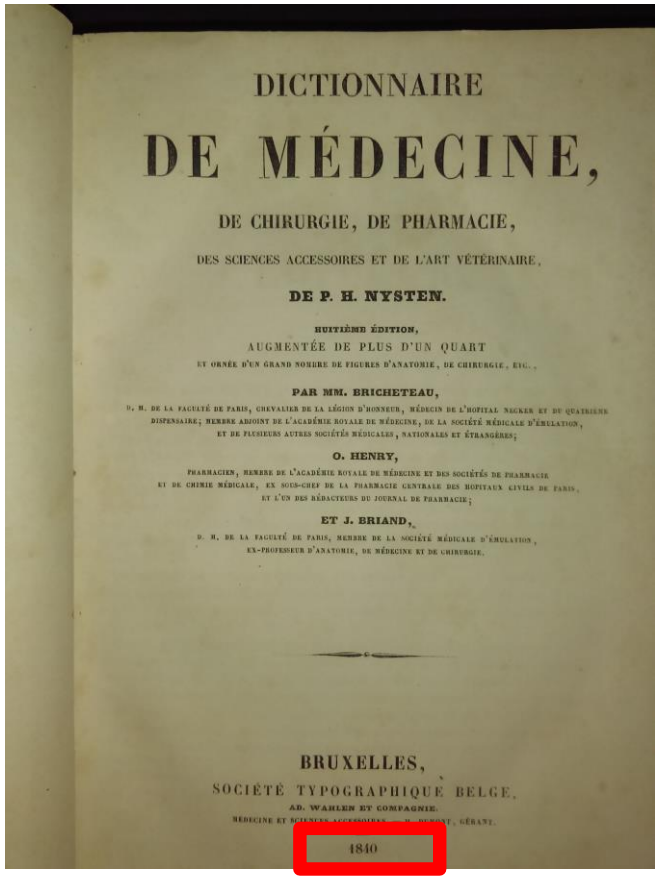
Now imagine the Gilligan Islanders got off the island

- Research done on Gilligan Islanders may or may not be exportable to the rest of the world
- Just because they have good health, doesn’t mean that “their way” is the only way to achieve good health

See the problem

Be the solution

Normality bias



DICTIONNAIRE

DE MÉDECINE,

DE CHIRURGIE, DE PHARMACIE,

DES SCIENCES ACCESSOIRES ET DE L'ART VÉTÉRINAIRE,

DE P. H. NYSTEN.

HUITIÈME ÉDITION,

AUGMENTÉE DE PLUS D'UN QUART

ET ORNÉE D'UN GRAND NOMBRE DE FIGURES D'ANATOMIE, DE CHIRURGIE, ETC.,

PAR MM. BRICHETEAU,

D. M. DE LA FACULTÉ DE PARIS, CHEVALIER DE LA LÉGION D'HONNEUR, MÉDECIN DE L'HOPITAL NECKER ET DU QUATRIÈME DISPENSAIRE; MEMBRE ADJOINT DE L'ACADÉMIE ROYALE DE MÉDECINE, DE LA SOCIÉTÉ MÉDICALE D'ÉMULATION, ET DE PLUSIEURS AUTRES SOCIÉTÉS MÉDICALES, NATIONALES ET ÉTRANGÈRES;

O. HENRY,

PHARMACIEN, MEMBRE DE L'ACADÉMIE ROYALE DE MÉDECINE ET DES SOCIÉTÉS DE PHARMACIE ET DE CHIMIE MÉDICALE, EX SOUS-CHEF DE LA PHARMACIE CENTRALE DES HOPITAUX CIVILS DE PARIS, ET L'UN DES RÉDACTEURS DU JOURNAL DE PHARMACIE;

ET J. BRIAND,

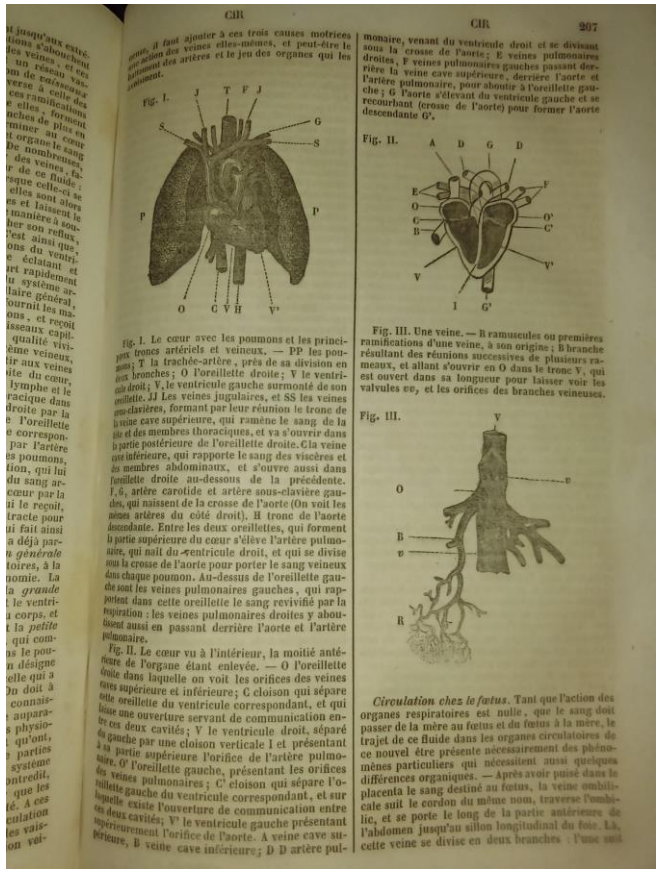
D. M. DE LA FACULTÉ DE PARIS, MEMBRE DE LA SOCIÉTÉ MÉDICALE D'ÉMULATION, EX-PROFESSEUR D'ANATOMIE, DE MÉDECINE ET DE CHIRURGIE.

BRUXELLES,

SOCIÉTÉ TYPOGRAPHIQUE BELGE.

AD. WAHLEN ET COMPAGNIE.

1840



CIR

CIR 207

Fig. I. Le cœur avec les poumons et les principaux troncs artériels et veineux. — PP les poumons; T la trachée-artère, près de sa division en deux bronches; O l'oreillette droite; V le ventricule droit; V, le ventricule gauche surmonté de son oreillette. JJ Les veines jugulaires, et SS les veines sous-clavières, formant par leur réunion le tronc de la veine cave supérieure, qui ramène le sang de la tête et des membres thoraciques, et va s'ouvrir dans la partie postérieure de l'oreillette droite. C la veine cave inférieure, qui rapporte le sang des viscères et des membres abdominaux, et s'ouvre aussi dans l'oreillette droite au-dessous de la précédente. F, G, artère carotide et artère sous-clavière gauches, qui naissent de la crosse de l'aorte (On voit les mêmes artères du côté droit). H tronc de l'aorte descendante. Entre les deux oreillettes, qui forment la partie supérieure du cœur s'élève l'artère pulmonaire, qui naît du ventricule droit, et qui se divise sous la crosse de l'aorte pour porter le sang veineux dans chaque poumon. Au-dessus de l'oreillette gauche sont les veines pulmonaires gauches, qui rapportent dans cette oreillette le sang revivifié par la respiration : les veines pulmonaires droites y aboutissent aussi en passant derrière l'aorte et l'artère pulmonaire.

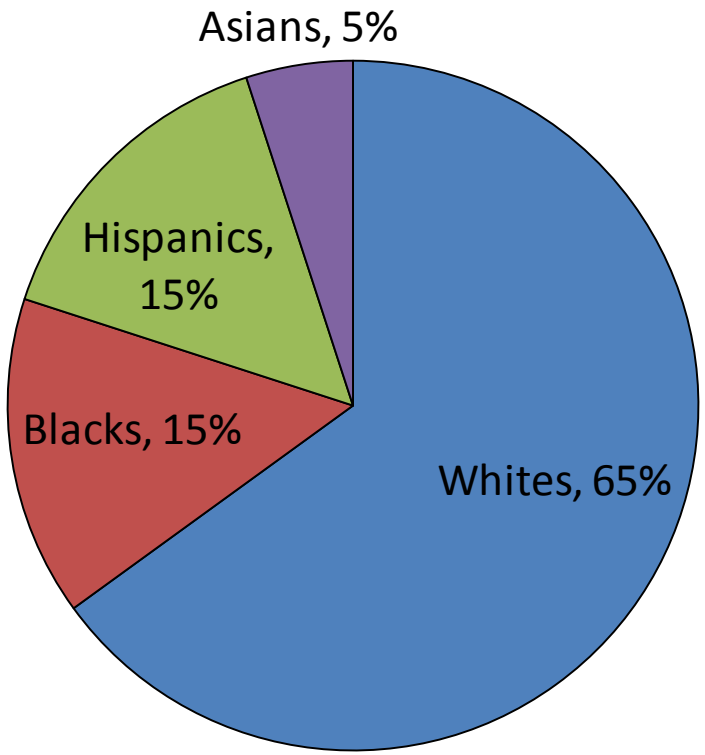
Fig. II. Le cœur vu à l'intérieur, la moitié antérieure de l'organe étant enlevée. — O l'oreillette droite dans laquelle on voit les orifices des veines cave supérieure et inférieure; C cloison qui sépare cette oreillette du ventricule correspondant, et qui laisse une ouverture servant de communication entre ces deux cavités; V le ventricule droit, séparé de gauche par une cloison verticale I et présentant à sa partie supérieure l'orifice de l'artère pulmonaire. O' l'oreillette gauche, présentant les orifices des veines pulmonaires; C' cloison qui sépare l'oreillette gauche du ventricule correspondant, et sur laquelle existe l'ouverture de communication entre ces deux cavités; V' le ventricule gauche présentant supérieurement l'orifice de l'aorte. A veine cave supérieure, B veine cave inférieure; D D artère pulmonaire, venant du ventricule droit et se divisant sous la crosse de l'aorte; E veines pulmonaires droites, F veines pulmonaires gauches passant derrière la veine cave supérieure, derrière l'aorte et l'artère pulmonaire, pour aboutir à l'oreillette gauche; G l'aorte s'élevant du ventricule gauche et se recourbant (crosse de l'aorte) pour former l'aorte descendante G'.

Fig. III. Une veine. — R ramuscules ou premières ramifications d'une veine, à son origine; B branche résultant des réunions successives de plusieurs rameaux, et allant s'ouvrir en O dans le tronc V, qui est ouvert dans sa longueur pour laisser voir les valvules ee, et les orifices des branches veineuses.

Circulation chez le fœtus. Tant que l'action des organes respiratoires est nulle, que le sang doit passer de la mère au fœtus et du fœtus à la mère, le trajet de ce fluide dans les organes circulatoires de ce nouvel être présente nécessairement des phénomènes particuliers qui nécessitent aussi quelques différences organiques. — Après avoir puisé dans le placenta le sang destiné au fœtus, la veine ombilicale suit le cordon du même nom, traverse l'ombilic, et se porte le long de la partie antérieure de l'abdomen jusqu'au sillon longitudinal du foie. Là, cette veine se divise en deux branches : l'une suit

1840 !!

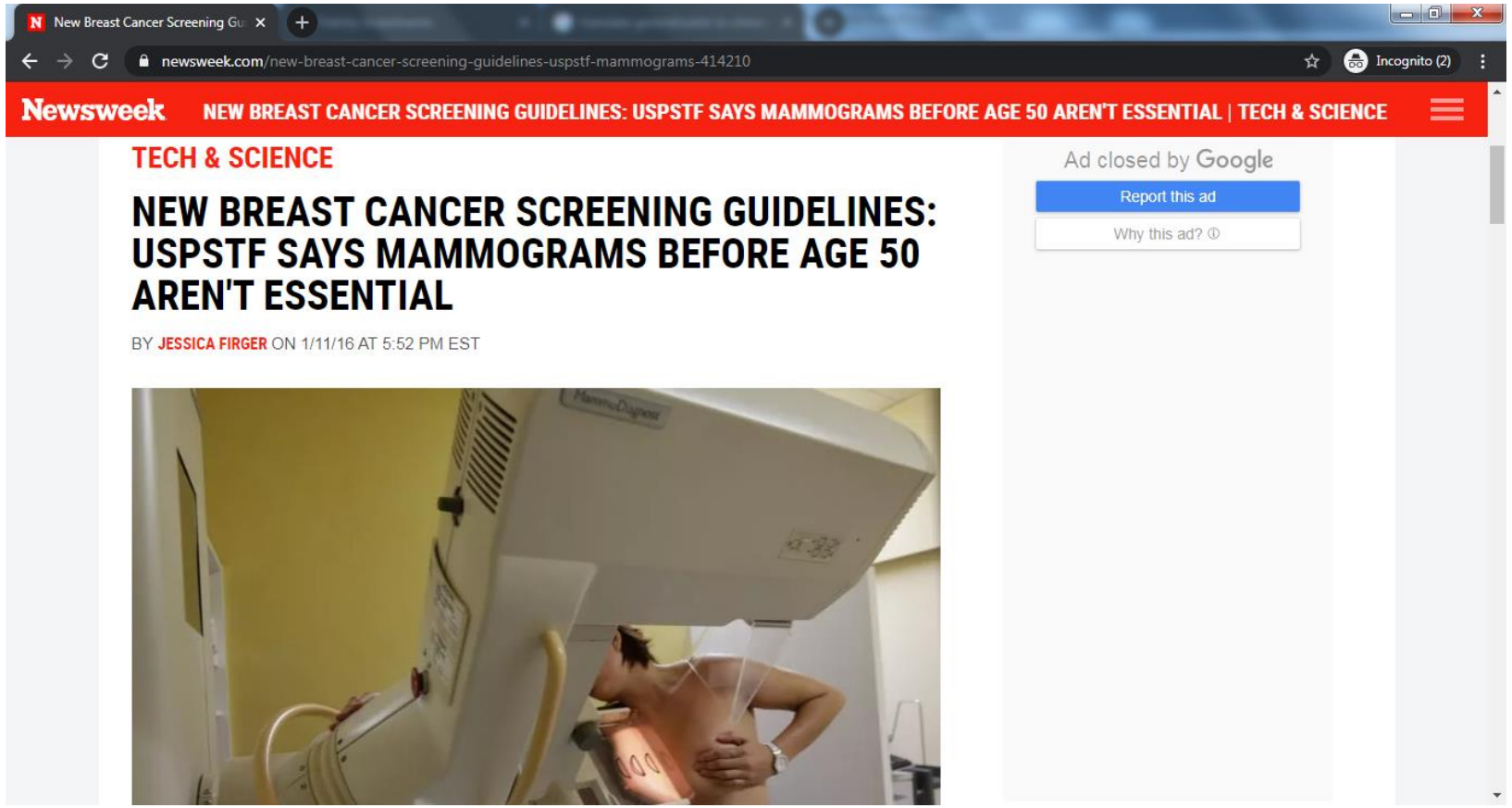
Demographic composition of US



Total 325 million

Generalizable?

US breast cancer screening guideline, 2016



JAMA Surgery, February 2018

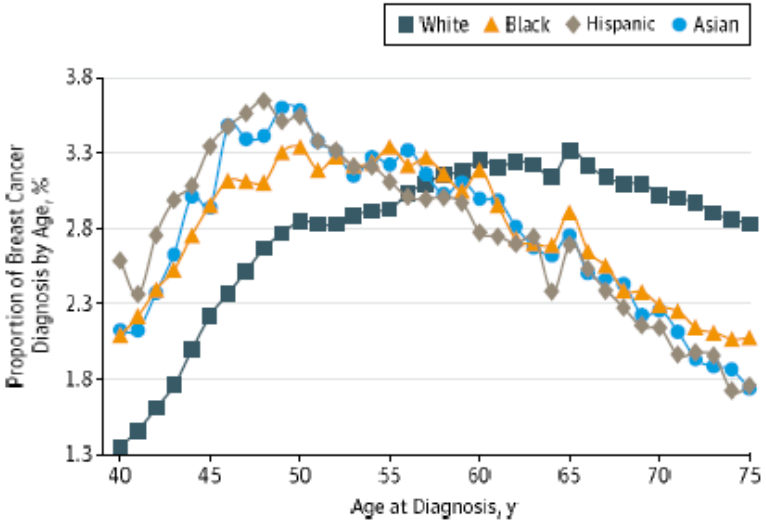
RESEARCH LETTER

Breast Cancer Screening Redefined by Taking Race Into Account

The US Preventive Services Task Force (USPSTF) currently recommends initiating breast cancer screening at 50 years of age in patients at average risk.[1] However, we hypothesize that these guidelines may not be sensitive to racial differences and may be inappropriately extrapolating data from largely white populations for use in racially diverse populations. This process could result in underscreening of nonwhite female patients. These concerns are similar to broader discussions regarding sex bias in the clinical research process, leading to recent policy changes at the National Institutes of Health and the US Food and Drug Administration.[2] The goal of this study is to assess the age distribution of breast cancer diagnosis across race/ethnicity in the United States.

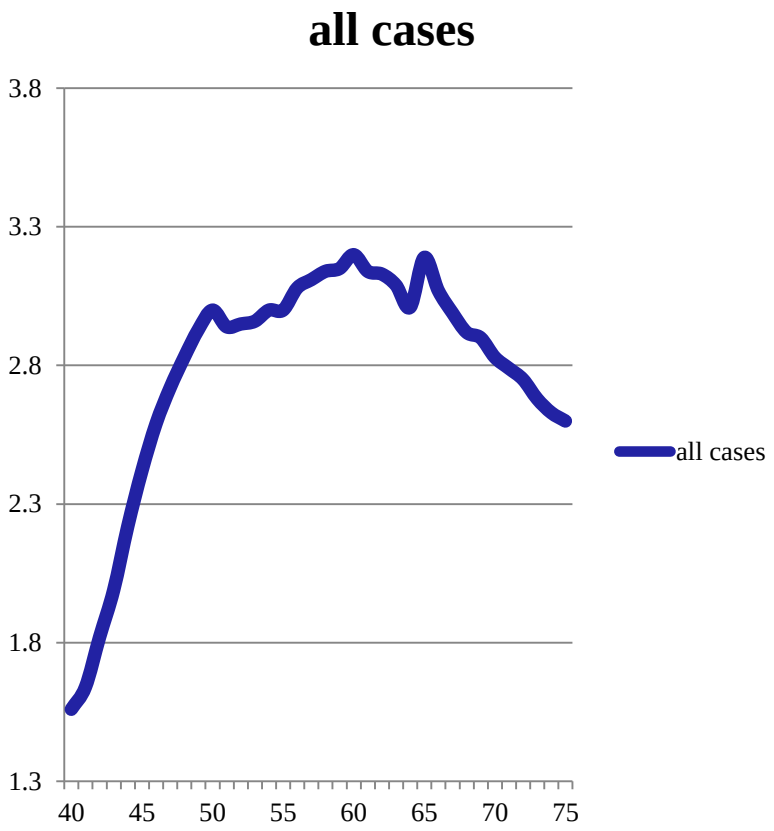
Methods | We analyzed the Surveillance, Epidemiology, and End Results Program database from January 1, 1973, through December 31, 2010. Female patients aged 40 to 75 years with ma-

Figure 1. Distribution of Age at Diagnosis for Women With Breast Cancer



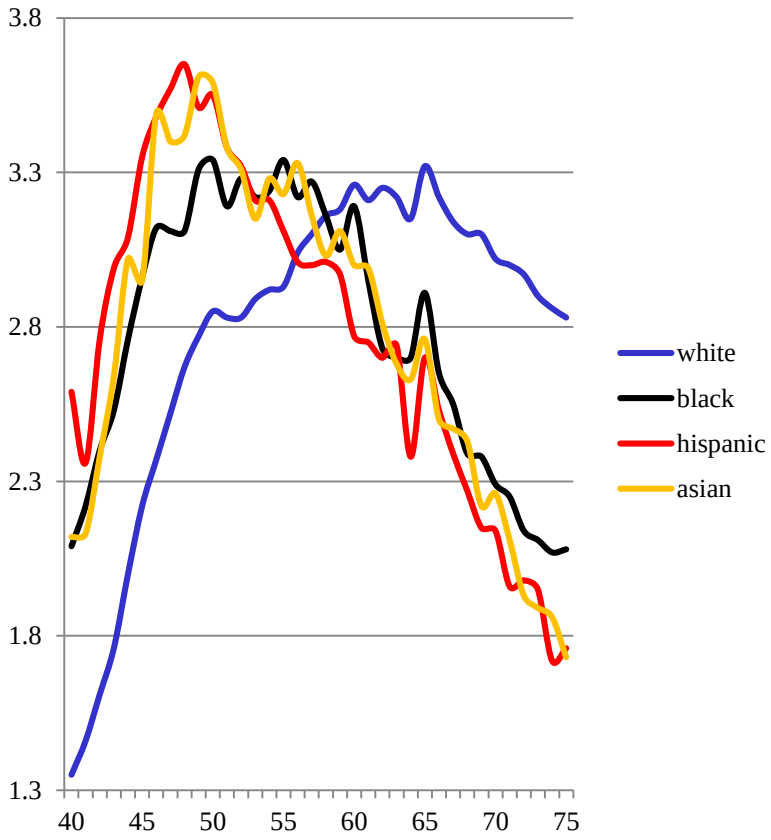
The peak age of each race represents the mode. Using peaks in white patients to set screening guidelines will disadvantage a disproportionate number of non-European patients.

Breast cancer – all US population



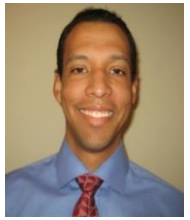
- Peaks in the 60s
- Breast cancer screening guideline was changed to start at 50

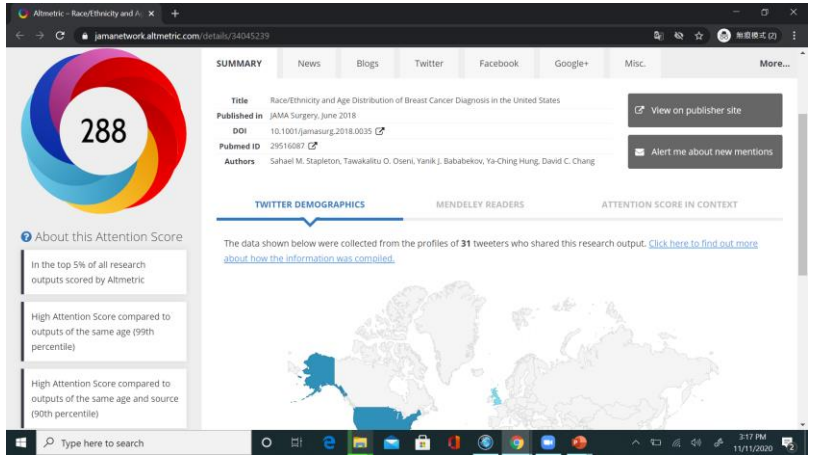
Breast cancer – US population by rac

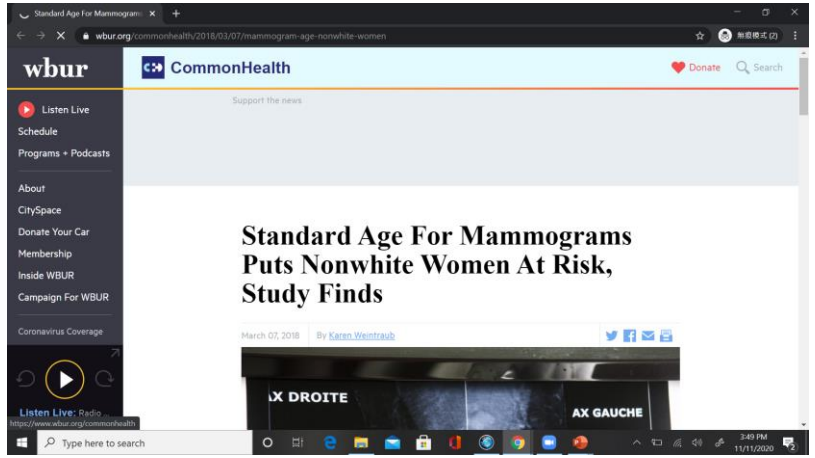


- Whites peak in the 60s
- Hispanics, blacks, Asians all peak in the 40s
- Raising screening age to 50 will negatively affect non-white women in US

“Flawed science hurts more patients than flawed care”







Post-operative DVT prophylaxis

Each Risk Factor Represents 1 Point

- ❑ Age 41-60 years
- ❑ Swollen legs (current)
- ❑ Varicose veins
- ❑ Obesity (BMI >25)
- ❑ Minor surgery planned
- ❑ Sepsis (<1 month)
- ❑ Acute myocardial infarction
- ❑ Congestive heart failure (<1 month)
- ❑ Medical patient currently at bed rest
- ❑ History of inflammatory bowel disease
- ❑ History of prior major surgery (<1 month)
- ❑ Abnormal pulmonary function (COPD)
- ❑ Serious Lung disease including pneumonia (<1 month)
- ❑ Oral contraceptives or hormone replacement therapy
- ❑ Pregnancy or postpartum (<1 month)
- ❑ History of unexplained stillborn infant, recurrent spontaneous abortion (≥ 3), premature birth with toxemia or growth-restricted infant
- ❑ Other risk factors_____

Subtotal:

Each Risk Factor Represents 5 Points

- ❑ Stroke (<1 month)
- ❑ Multiple trauma (<1 month)
- ❑ Elective major lower extremity arthroplasty
- ❑ Hip, pelvis or leg fracture (<1 month)
- ❑ Acute spinal cord injury (paralysis) (<1 month)

Subtotal:

Each Risk Factor Represents 2 Points

- ❑ Age 61-74 years
- ❑ Arthroscopic surgery
- ❑ Malignancy (present or previous)
- ❑ Laparoscopic surgery (>45 minutes)
- ❑ Patient confined to bed (>72 hours)
- ❑ Immobilizing plaster cast (<1 month)
- ❑ Central venous access
- ❑ Major surgery (>45 minutes)

Subtotal:

Each Risk Factor Represents 3 Points

- ❑ Age 75 years or older
- ❑ History of DVT/PE
- ❑ Positive Factor V Leiden
- ❑ **Family History of thrombosis***
- ❑ Positive Prothrombin 20210A
- ❑ Positive Lupus anticoagulant
- ❑ Elevated serum homocysteine
- ❑ Heparin-induced thrombocytopenia (HIT)
  (Do not use heparin or any low molecular weight heparin)
- ❑ Elevated anticardiolipin antibodies
- ❑ Other congenital or acquired thrombophilia

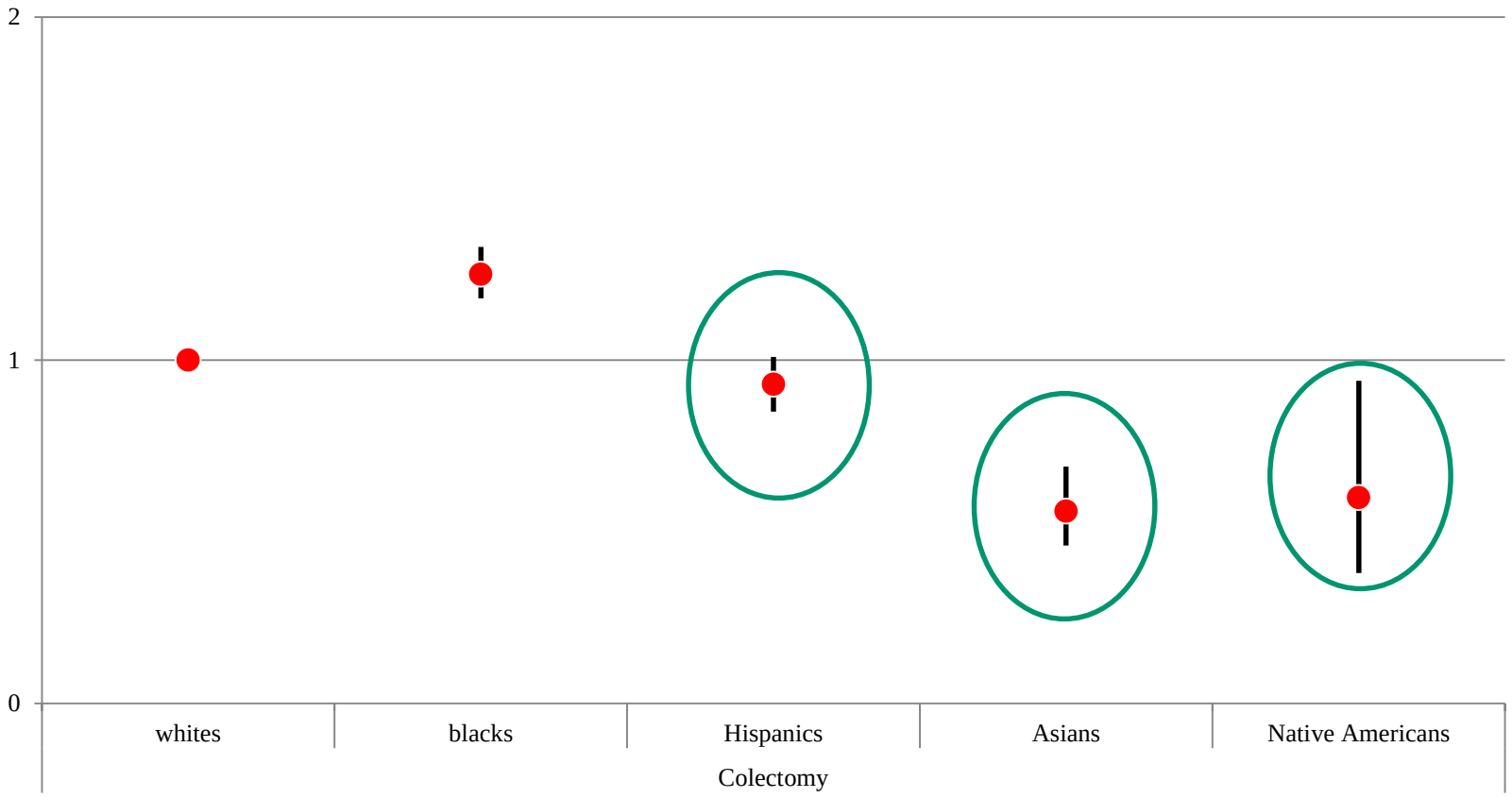
If yes: Type_____

*** most frequently missed risk factor**

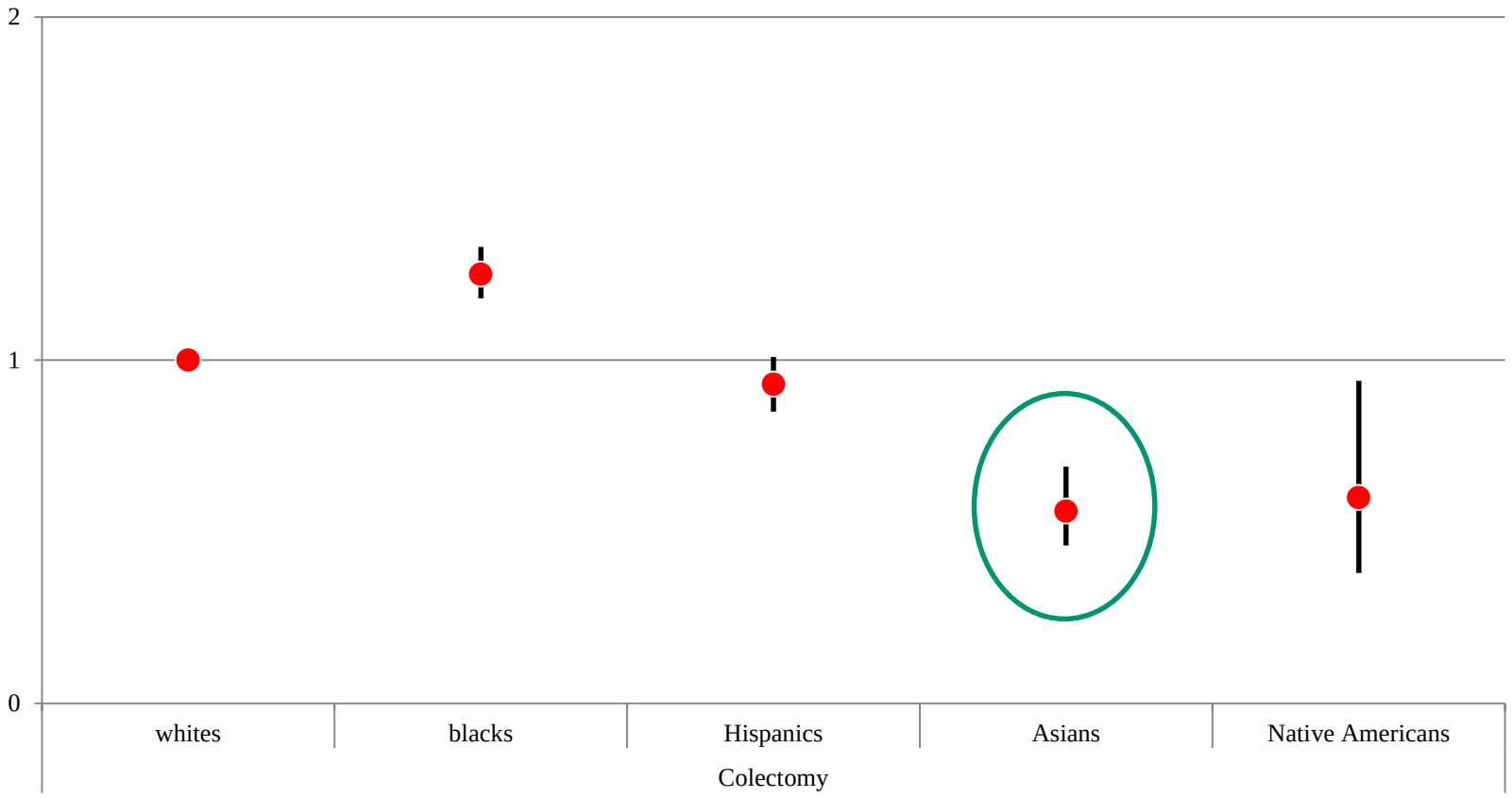
Subtotal:

TOTAL RISK FACTOR SCORE:

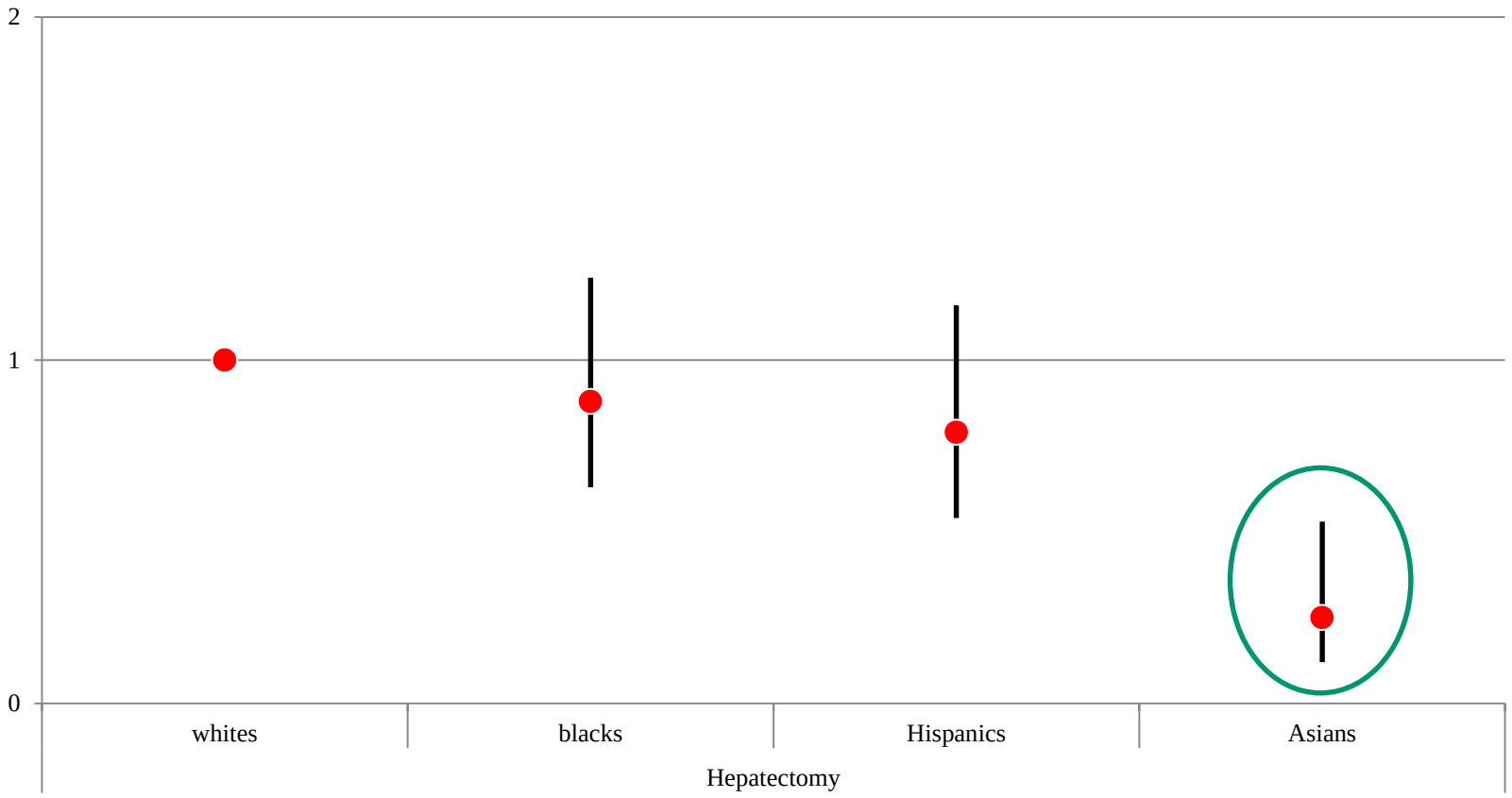
Post-operative DVT by race: Colectomy



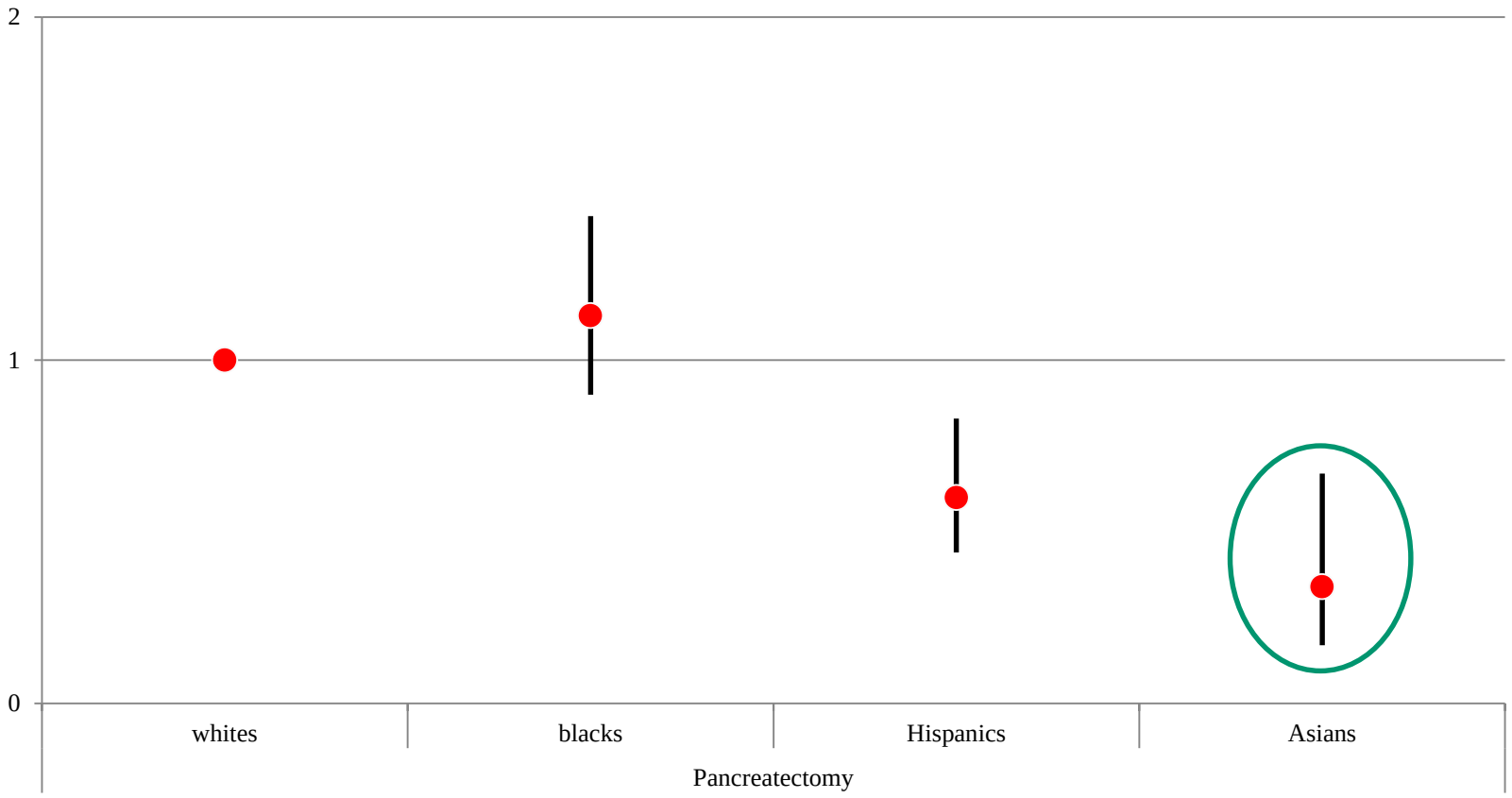
Post-operative DVT by race: Gastrectomy



Post-operative DVT by race: Hepatectomy



Post-operative DVT by race: Pancreatectomy



Mortality after ground-level falls in the elderly

TABLE 3. Multivariable Logistic Regression for Risk Factors Associated With Mortality With Head Injury at Index Fall

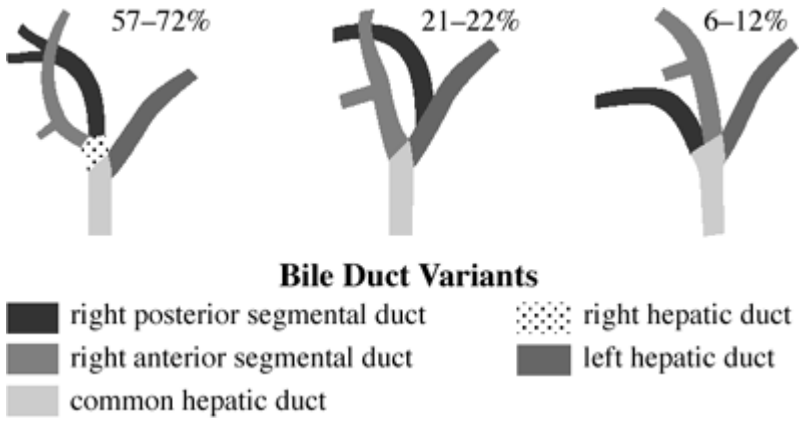
Variable	Odds Ratio	95% Confidence Interval	*p*
Age 65–74 y	Default	Default	Default
Age > 75 y	1.1	0.8 to 1.4	0.585
Any trauma center admission*	2.3	1.6 to 3.2	<0.001
White	Default	Default	Default
Black	1	0.5 to 2.2	0.922
Hispanic	1.2	0.9 to 1.7	0.221
Asian*	2.3	1.6 to 3.2	<0.001
Hawaiian/American Indian	0.9	0.4 to 1.9	0.768
Male sex*	1.9	1.6 to 2.3	<0.001
Congestive heart failure	1.1	0.9 to 1.3	0.249
Hypertension	1.1	0.9 to 1.4	0.106
Diabetes mellitus	1	0.8 to 1.3	0.774
History of vascular disease	1	0.5 to 1.7	0.949
History of stroke/TIA*	4.2	3.3 to 5.3	<0.001
ICISS*	0.0001	<0.001 to <0.001	<0.001

*$p < 0.0035$ and 95% confidence interval does not cross 1.0.

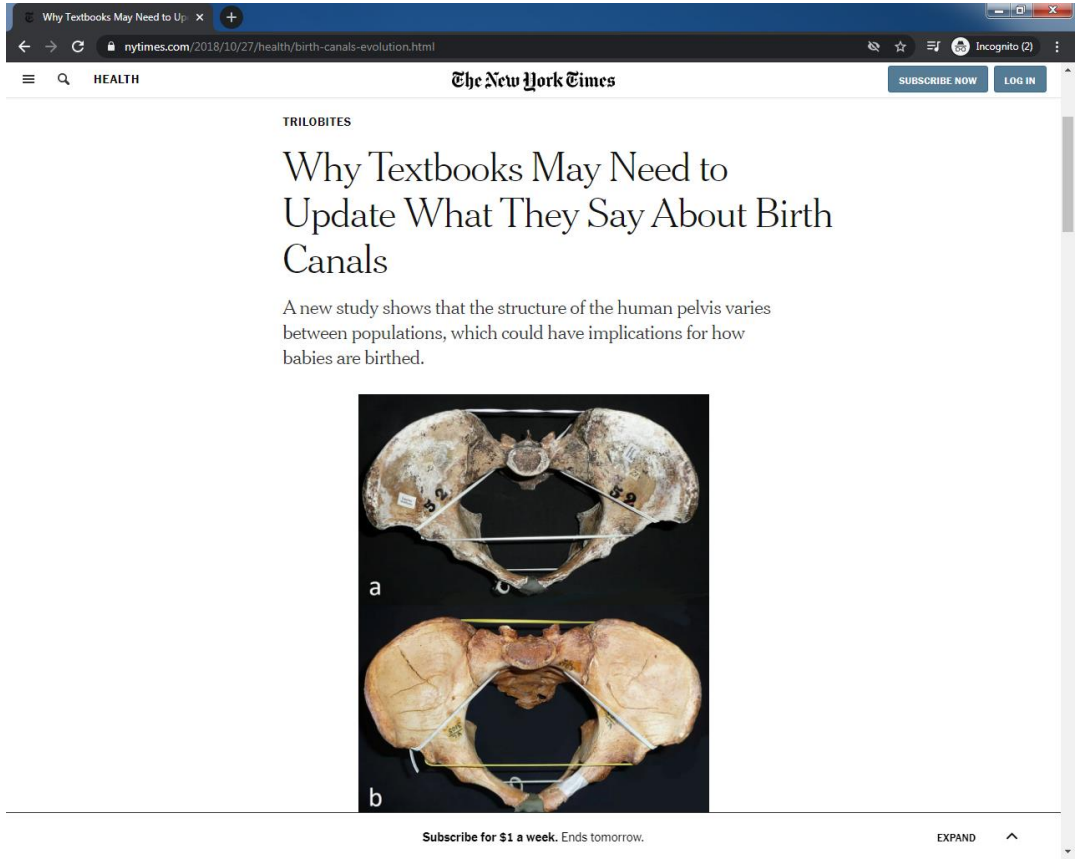
Do basic anatomy textbooks need to be revised?

Asian Race/Ethnicity as a Risk Factor for Bile Duct Injury During Cholecystectomy

Stephanie R. Downing, MD, **Ghazala Datoo, BS**, **Tolulope A. Oyetunji, MPH, MD**, **Terrence Fullum, MD**, **David C. Chang, MPH, MBA, PhD**, and **Nita Ahuja, MD**
Departments of Surgery, The Johns Hopkins University School of Medicine, Baltimore, Maryland (Drs Downing, Chang, and Ahuja and Ms Datoo); and College of Medicine, Howard University, Washington, DC (Drs Downing, Oyetunji, Fullum, and Chang)



Do basic anatomy textbooks need to be revised?



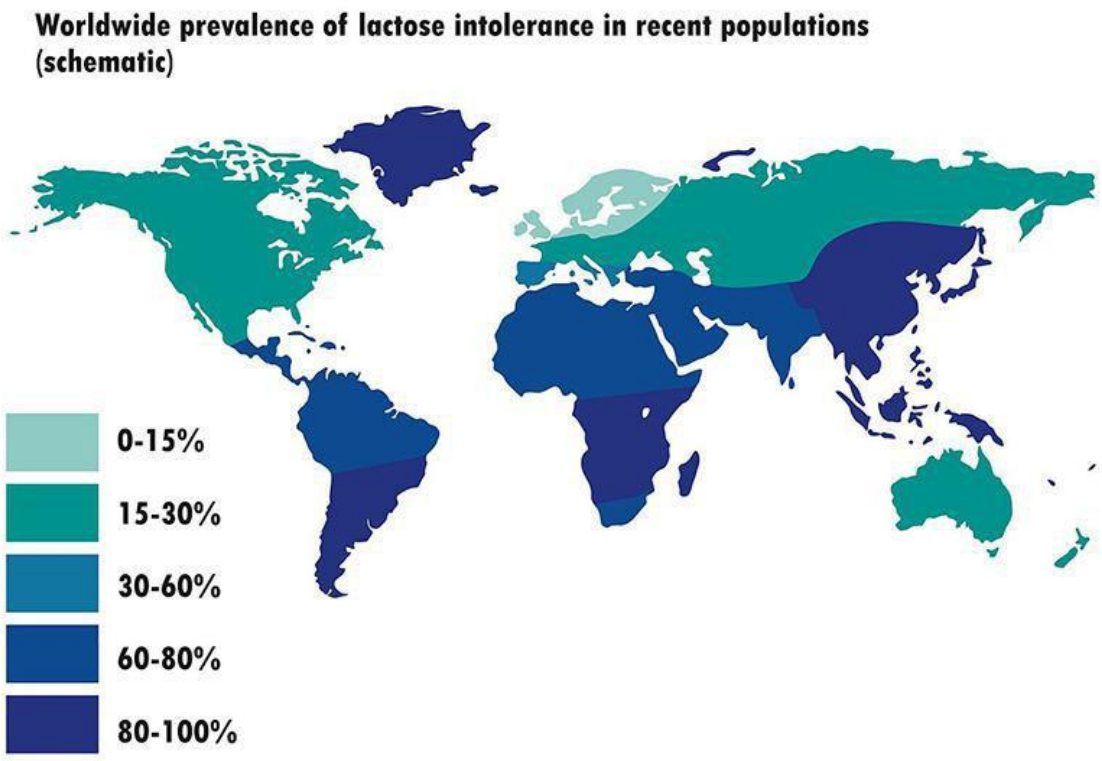
- "Well-built healthy women, who had a good diet during their childhood growth period, usually have a broad pelvis."
- Limited prescriptions of what constitutes a "normal" pelvis or birthing process might lead doctors to perform unnecessary interventions — like induced labor, cesarean sections or the use of forceps — which can further exacerbate harm
- In the early 1900s, this led to "horrific situations" in which American doctors used forceps on black mothers, trying to force babies to align with "the rotation pattern for a European classical pelvis,"

Extends beyond diseases and treatments

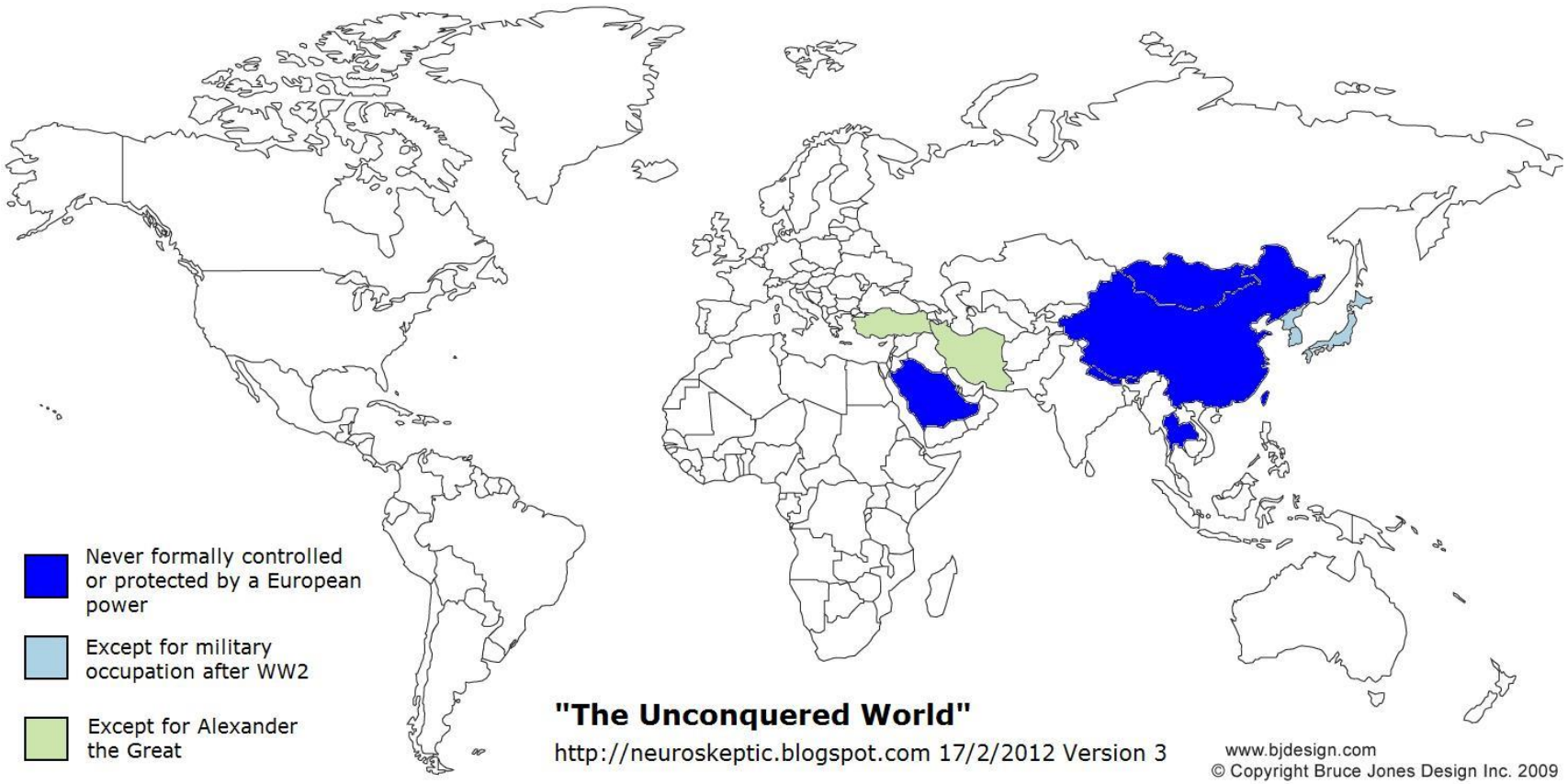
- Affects how we think about health and health norms

Milk is healthy?

Rates of lactose intolerance



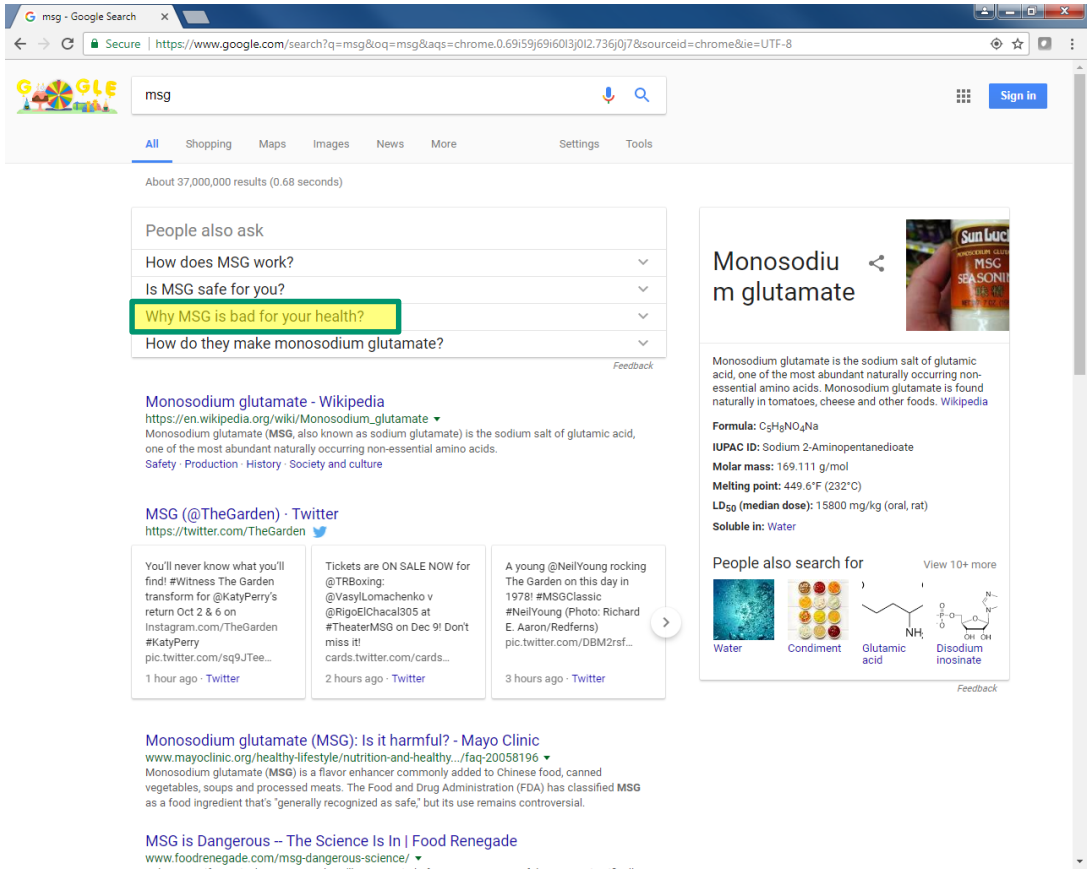
Imagine an alternate universe…



Imagine an alternate universe…

- If Asian scientists dominated biomedical research…
  - Milk would have been classified as a poison
- If African scientists dominated biomedical research…
  - Sickle cell trait would not be considered a disease
- If Latino scientists dominated biomedical research…
  - There would be no campaign to advise Latino patients to stop eating tortilla

“MSG is bad for your health”



in good health at ages considerably in excess of those at which symptoms of the disease had made their presence known in elder brothers or sisters, it is extremely unlikely that this is due to coincidence even though the numbers involved are not great enough to achieve statistical significance. To withhold treatment from anyone known to be homozygous for the gene of Wilson's disease would be neither wise nor humane, whatever statistical purpose might eventually be fulfilled by watching him acquire clinical Wilson's disease.

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Department of Investigative Medicine
University of Cambridge
Cambridge, England

1. Walshe, J. M. Physiology of copper in man and its relation to Wilson's disease. *Brain* **90**:149-176, 1967.
2. *Idem.* Some observations on natural history of Wilson's disease. In *Some Inherited Disorders of Brain and Muscle.* Edited by D. N. Raine. Edinburgh and London: Livingstone, Ltd., (in press).

To the Editor: The paper by Sternlieb and Scheinberg adds one more to a long list of unanswered questions: whether the use of penicillamine benefits or harms patients thought to be on the road to the development of clinical Wilson's disease.

The authors have taken to heart the second law ("Results can always be improved by omitting controls") and have attempted to estimate the number of clinical cases that would have occurred in the absence of the prophylactic treatment. The estimate seems to be based on observations in retrospect of a number of patients with clinical disease, applied over a brief period. There is no evidence that these developments would actually have occurred.

The authors may be right in their conclusions; if they are wrong it will take years to erase the effects of this paper. A controlled trial in carefully matched groups could have given an unequivocal answer, though doubtless over a longer time.

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Lemuel Shattuck Hospital
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LIMITATIONS OF THE SCIENTIFIC METHOD

To the Editor: The editorial appearing in the February 15 issue of the *Journal* entitled "Editor's Choice: Wilson's disease" has touched upon problems that seem to be basic to clinical investigation. That medicine is not a science in the same sense as physics need hardly be mentioned, and trying to

2. Whitehead, A. N. *The Function of Reason.* Princeton: University Press, 1929.

CHINESE-RESTAURANT SYNDROME

To the Editor: For several years since I have been in this country, I have experienced a strange syndrome whenever I have eaten out in a Chinese restaurant, especially one that served Northern Chinese food. The syndrome, which usually begins 15 to 20 minutes after I have eaten the first dish, lasts for about two hours, without any hangover effect. The most prominent symptoms are numbness at the back of the neck, gradually radiating to both arms and the back, general weakness and palpitation. The symptoms simulate those that I have had from hypersensitivity to acetylsalicylic acid, but are milder. I had not heard of the syndrome until I received complaints of the same symptoms from Chinese friends of mine, both medical and nonmedical people, but all well educated.

The cause is obscure. After some discussion my colleagues and I at first speculated that it might be caused by some ingredient in the soy sauce, to which quite a few people are allergic. However, we use the same type of soy sauce in our home cooking, which does not result in the symptoms described above. Some have suggested that these symptoms may be caused by cooking wine, which is used generously in most Chinese restaurants, because the syndrome resembles to some extent the effects of alcohol. Others have suggested that it may be caused by the monosodium glutamate seasoning used to a great extent for seasoning in Chinese restaurants.

Another alternative is that the high sodium content of the Chinese food may produce temporary hypernatremia, which may consequently cause intracellular hypokalemia, resulting in numbness of the muscles, generalized weakness and palpitation. The Chinese food causes thirst, which would also be due to the high sodium content. The syndrome may therefore be due merely to the large quantity of salt in the food, and the high dissociation constant of the organic salt, monosodium glutamate, may make the symptoms more acute.

Because we lack personnel for doing research in this area, I wonder if my friends in the medical field might be interested in seeking more information about this rather peculiar syndrome.

I shall of course be more than happy to co-operate.

Robert Ho Man Kwok, M.D.
Senior Research Investigator
National Biomedical Research Foundation

Feb 21, 1969, Science

Monosodium L-Glutamate: Its Pharmacology and Role in the Chinese Restaurant Syndrome

Abstract. *Monosodium L-glutamate is the cause of the Chinese restaurant syndrome and can precipitate headaches. In appropriate doses it causes burning sensations, facial pressure, and chest pain. These are pharmacological effects obeying a dose-effect relationship. There is considerable variation in oral threshold doses among individuals.*

Monosodium L-glutamate (MSG) is a widely used food additive. Twenty thousand tons of MSG are manufactured and used in the United States each year (*1*). The labeling of a widely used brand states, "To wake up all the flavor nature put in your food, be sure to use at least the amounts . . . suggested below, adding more as desired." Amounts approximating 1 g per serving are the minimum amounts suggested.

Monosodium L-glutamate is not a wholly innocuous substance. It was proposed as the cause of the Chinese restaurant syndrome in July 1968 (*2*). We provoke an attack (*5, 6*). Although other foods caused the response, wonton soup was the simplest in composition.

The restaurant prepared soup without MSG and it failed to provoke an attack. The subjects then ingested each of the seven components of the wonton soup separately. Only MSG caused the symptoms. In a blind procedure, MSG was then given to four additional individuals who had symptoms in the same restaurant. It provoked an attack in all four in amounts of 3 g or less. Therefore, we concluded

A repeat trial with 5 g of L-glutamic acid, fully dissolved in 500 ml of water at 30°C, provoked an attack. In addition, to eliminate the possibility of an impurity in the commercially available L-glutamate, we synthesized monosodium DL-glutamate (*7*). The resultant product was identified from infrared spectra and by thin-layer chromatography. Five grams of this product were sufficient to provoke an attack.

The following substances did not provoke symptoms: monosodium D-glutamate (7 g), monosodium L-aspartate (5 g), NaCl (10 g), and glycine (5 g).

We next determined that the intensity and duration of the symptoms were related to the dosage of MSG. To define the temporal sequence and nature of the symptoms, we gave MSG, as Glutavene, intravenously to 13 subjects. After oral administration of this substance, the symptoms were perceived by our subjects in a less well-defined order because the onset was less abrupt and the increase in intensity

taurant syndrome in July 1968 (*2*). We report here some aspects of the acute human pharmacology of MSG and, in addition, present evidence that it causes headache.

Many symptoms have been suggested as components of the syndrome (*3*). On repeated observations, we find that three categories of symptoms can be elicited by MSG—burning, facial pressure, and chest pain. Headache is a consistent complaint in a minority of individuals. The MSG response and the syndrome are identical. The symptoms appear only if the meal is taken on an empty stomach by a susceptible individual (*4*).

The proof that MSG is the cause of the syndrome was arrived at with the cooperation of two subjects, both of whom had symptoms in the same restaurant. We found that 200 ml of wonton soup alone was sufficient to

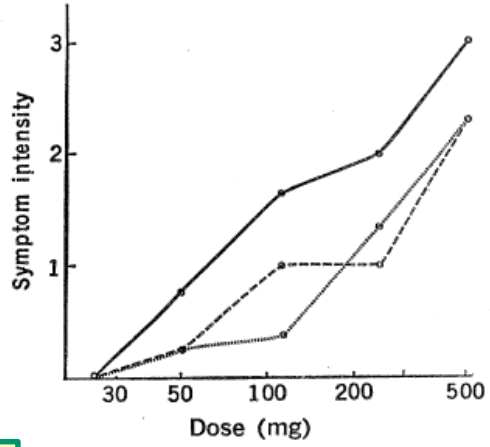
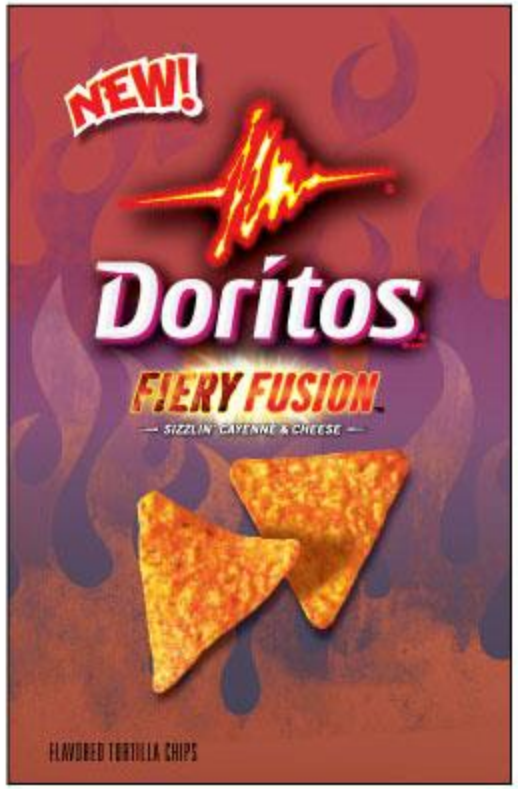


Fig. 1. Relation between intensity of burning (solid line), facial pressure (dashes), and chest pressure (dotted line) and intravenous dose of MSG. Each point represents a mean intensity from three or more responses. The data were obtained from four subjects.



Ingredients: Whole Corn, Vegetable Oil (Corn, Canola, Soybean, and/or Sunflower Oil), Maltodextrin (Made From Corn), Salt, Buttermilk, Onion Powder, Monosodium Glutamate, Cheddar Cheese (Milk, Cheese Cultures, Salt, Enzymes), Whey, Tomato Powder, Spices, Sour Cream (Cream, Skim Milk, Cultures), Sugar, Garlic Powder, Jalapeno Pepper Powder, Paprika, Natural Flavors, Citric Acid, Hot Sauce (Aged Cayenne Red Peppers, Vinegar, Salt, Garlic), and Malic Acid.
CONTAINS MILK INGREDIENTS.

Nutrition Facts

Serving Size 1 oz (28g/About 12 chips)

Amount Per Serving	1 oz.	Entire Pkg.
Calories	140	390
Calories from Fat	70	200
	% Daily Value*	
Total Fat 8g, 22g	**12%**	**34%**
Saturated Fat 1g, 3g	**5%**	**15%**
Trans Fat 0g, 0g		
Cholesterol 0mg, 0mg	**0%**	**0%**
Sodium 160mg, 470mg	**7%**	**20%**
Total Carbohydrate 16g, 46g	**5%**	**15%**
Dietary Fiber 1g, 3g	**4%**	**12%**
Sugars 0g, less than 1g		
Protein 2g, 5g		
Vitamin A	0%	4%
Vitamin C	0%	0%
Calcium	0%	2%
Iron	0%	4%
Thiamin	2%	4%
Vitamin B_6	2%	6%

* Percent Daily Values are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs:

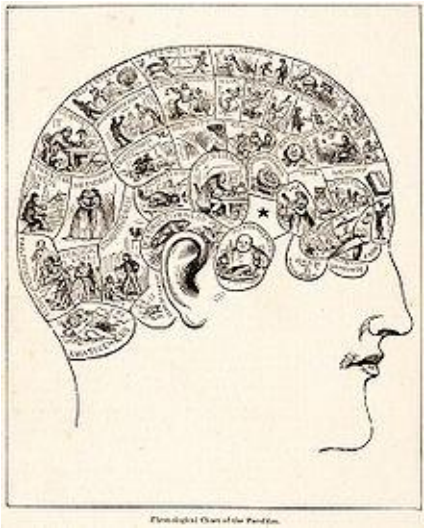
	Calories:	2,000	2,500
Total Fat	Less than	65g	80g
Sat Fat	Less than	20g	25g
Cholesterol	Less than	300mg	300mg
Sodium	Less than	2,400mg	2,400mg
Total Carbohydrate		300g	375g
Dietary Fiber		25g	30g

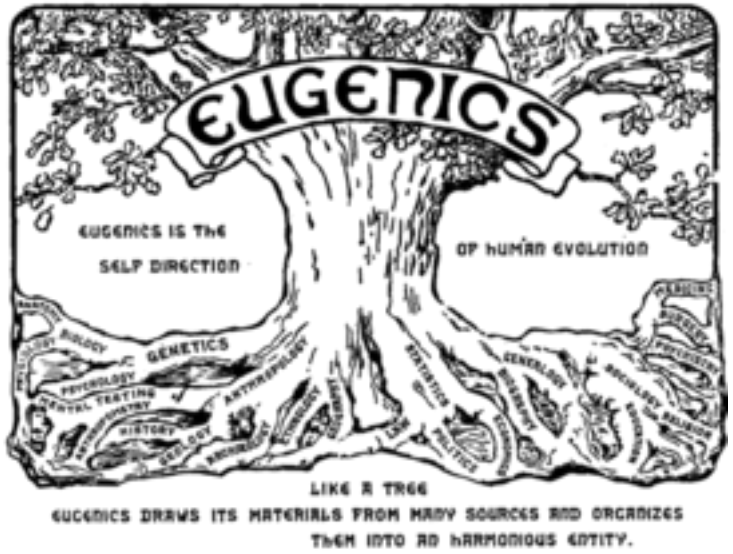
Calories per gram:
Fat 9 • Carbohydrate 4 • Protein 4

This normality bias is bigger than healthcare disparity

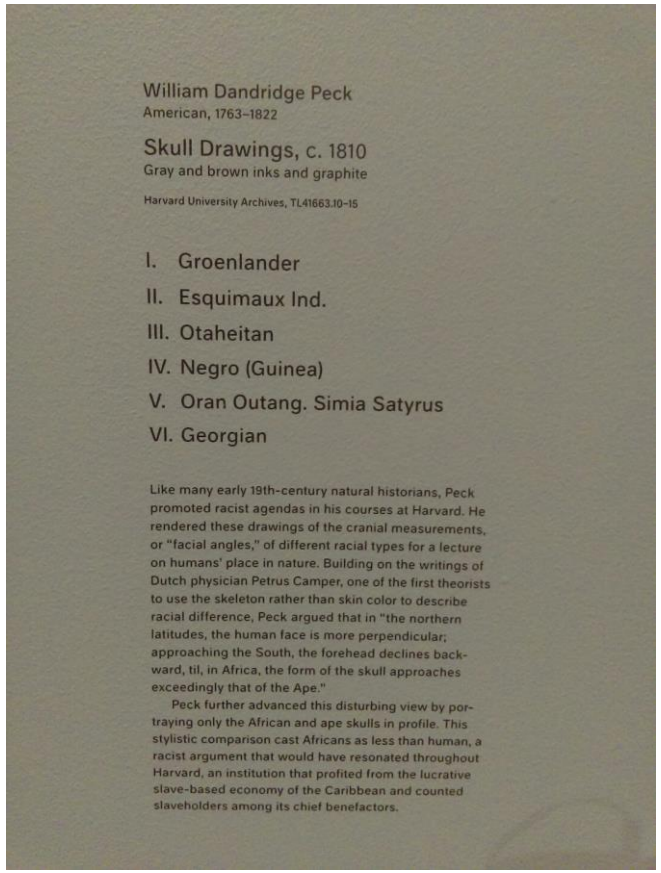
- May turn something into a “problem” when it really is not
  - People will subtly/unconsciously define “knowledge” in a way that is favorable to them
  - Because it is easier to describe and justify how things are
  - Majority / common => “normal” / “good”
    - What is “uncommon” becomes “bad” / “disease”
    - “Minority” traits then become synonymous with “bad” / “sick”
- **May simply mask biases**

Phrenology and eugenics





Harvard contributed to phrenology!



William Dandridge Peck
American, 1763–1822

Skull Drawings, c. 1810
Gray and brown inks and graphite

Harvard University Archives, TL41663.10–15

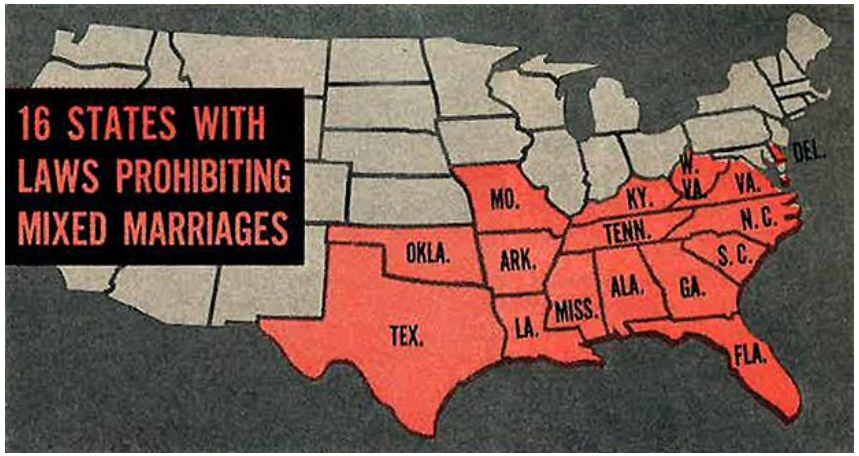
I. Groenlander
II. Esquimaux Ind.
III. Otaheitan
IV. Negro (Guinea)
V. Oran Outang. Simia Satyrus
VI. Georgian

Like many early 19th-century natural historians, Peck promoted racist agendas in his courses at Harvard. He rendered these drawings of the cranial measurements, or "facial angles," of different racial types for a lecture on humans' place in nature. Building on the writings of Dutch physician Petrus Camper, one of the first theorists to use the skeleton rather than skin color to describe racial difference, Peck argued that in "the northern latitudes, the human face is more perpendicular; approaching the South, the forehead declines backward, til, in Africa, the form of the skull approaches exceedingly that of the Ape."

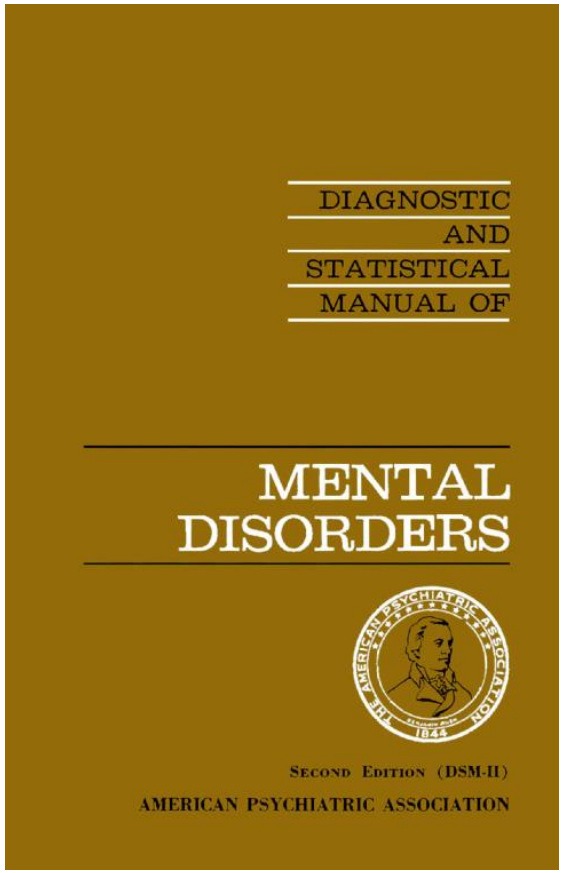
Peck further advanced this disturbing view by portraying only the African and ape skulls in profile. This stylistic comparison cast Africans as less than human, a racist argument that would have resonated throughout Harvard, an institution that profited from the lucrative slave-based economy of the Caribbean and counted slaveholders among its chief benefactors.

Interracial marriage

Loving vs State of Virginia, 1967



Homosexuality

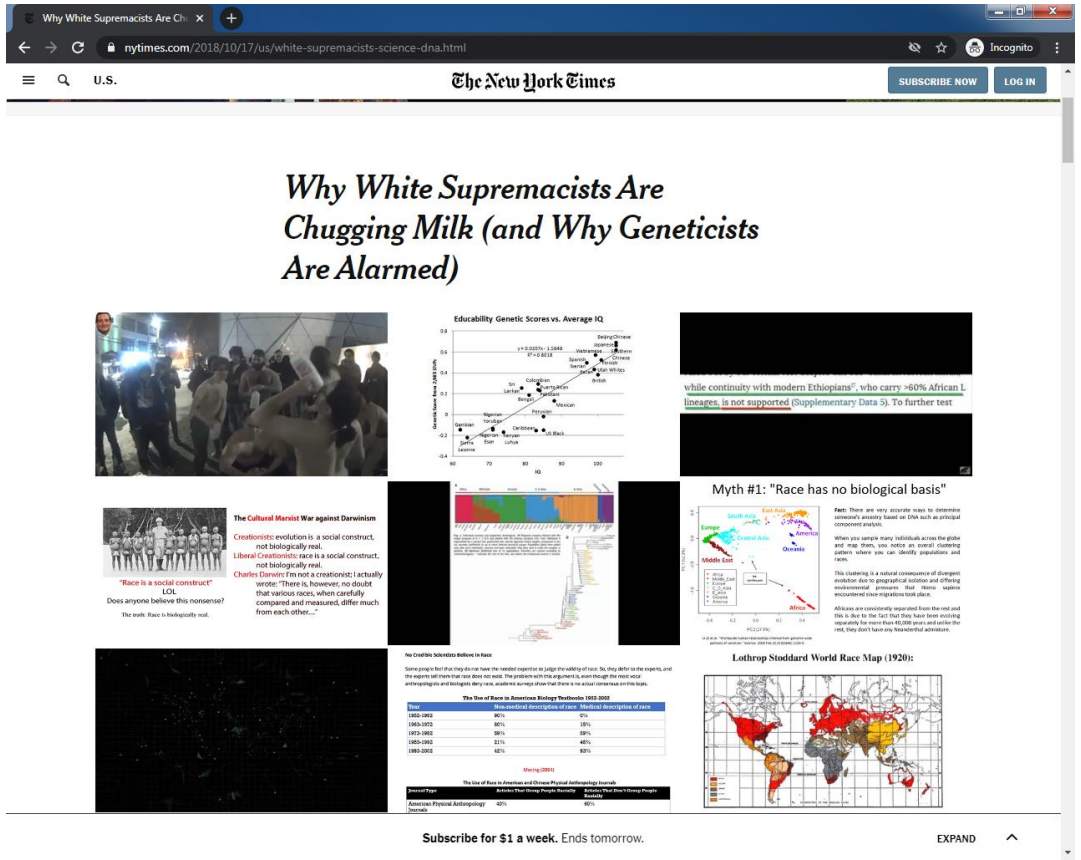


“Hugs” is healthy?

- Lower blood pressure
- Improve memory
- Reduce stress

- What about bowing?

The normality bias in science is not only leading to worse patient outcomes for women and minority…



- It is subtly being used to justify discriminatory beliefs about women and non-European cultures
- Discriminatory beliefs are much more difficult to debunk when linked to "health"

This problem happens in many other industries, with dire consequences for our children

See the problem

Be the solution

Solutions

- For readers
- For researchers

For the readers: Be aware of common errors

- Non-representative sample
- Dilution effect
- “Numbers by themselves, without comparison, don’t say good or bad”
- “A difference is just that, a difference
- “X is good”, vs “X is better/best”

Be aware of non-representative sample

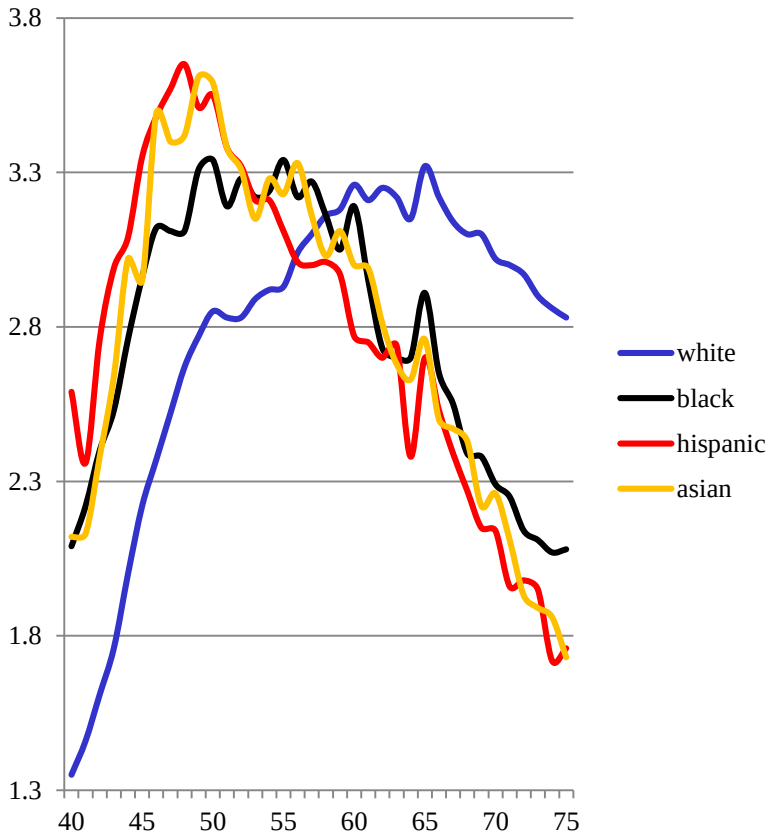
ORIGINAL ARTICLE

Racially Conscious Cancer Screening Guidelines

A Path Towards Culturally Competent Science

Numa P. Perez, MD,†‡ Yefri A. Baez, BA,‡§ Sahael M. Stapleton, MD, MBA,*‡ Ashok Muniappan, MD,*
Tawakalitu S. Oseni, MD,* Robert N. Goldstone, MD,* and David C. Chang, PhD, MPH, MBA‡✉*

Be aware of dilution effect



- Whites peak in the 60s
- Hispanics, blacks, Asians all peak in the 40s
- Raising screening age to 50 will negatively affect non-white women in US

Numbers by themselves, without comparison, don't say good or bad

Risk Factors for Morbidity After Lobectomy for Lung Cancer in Elderly Patients

Mark F. Berry, MD, Jennifer Hanna, MD, Betty C. Tong, MD, William R. Burfeind, Jr, MD, David H. Harpole, MD, Thomas A. D'Amico, MD, and Mark W. Onaitis, MD

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Background. Studies evaluating risk factors for complications after lobectomy in elderly patients have not adequately analyzed the effect of using minimally invasive approaches.

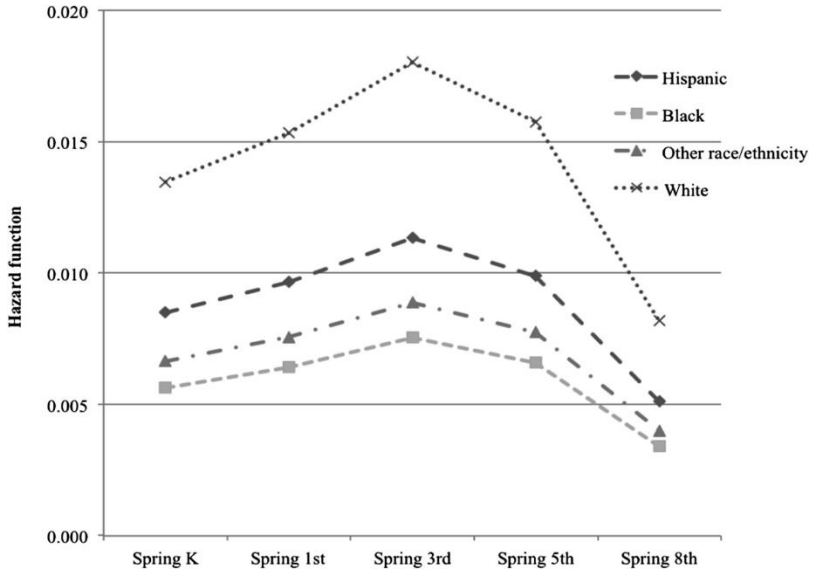
Methods. A model for morbidity including published preoperative risk factors and surgical approach was developed by multivariable logistic regression. All patients aged 70 years or older who underwent lobectomy for primary lung cancer without chest wall resection or airway procedure between December 1999 and October 2007 at a single institution were reviewed. Preoperative, histopathologic, perioperative, and outcome variables were assessed using standard descriptive statistics. Morbidity was measured as a patient having any perioperative complication. The impact of bias in the selection of surgical approach was assessed using propensity scoring.

Results. During the study period, 338 patients older than 70 years (mean age, 75.7 ± 0.2) underwent lobectomy (219 thoracoscopy, 119 thoracotomy). Operative mortality was 3.8% (13 patients) and morbidity was 47% (159 patients). Patients with at least one complication had increased length of stay (8.3 ± 0.6 versus 3.8 ± 0.1 days; $p < 0.0001$) and mortality (6.9% [11 of 159] versus 1.1% [2 of 179]; $p = 0.008$). Significant predictors of morbidity by multivariable analysis included age (odds ratio, 1.09 per year; $p = 0.01$) and thoracotomy as surgical approach (odds ratio, 2.21; $p = 0.004$). Thoracotomy remained a significant predictor of morbidity when the propensity to undergo thoracoscopy was considered (odds ratio, 4.9; $p = 0.002$).

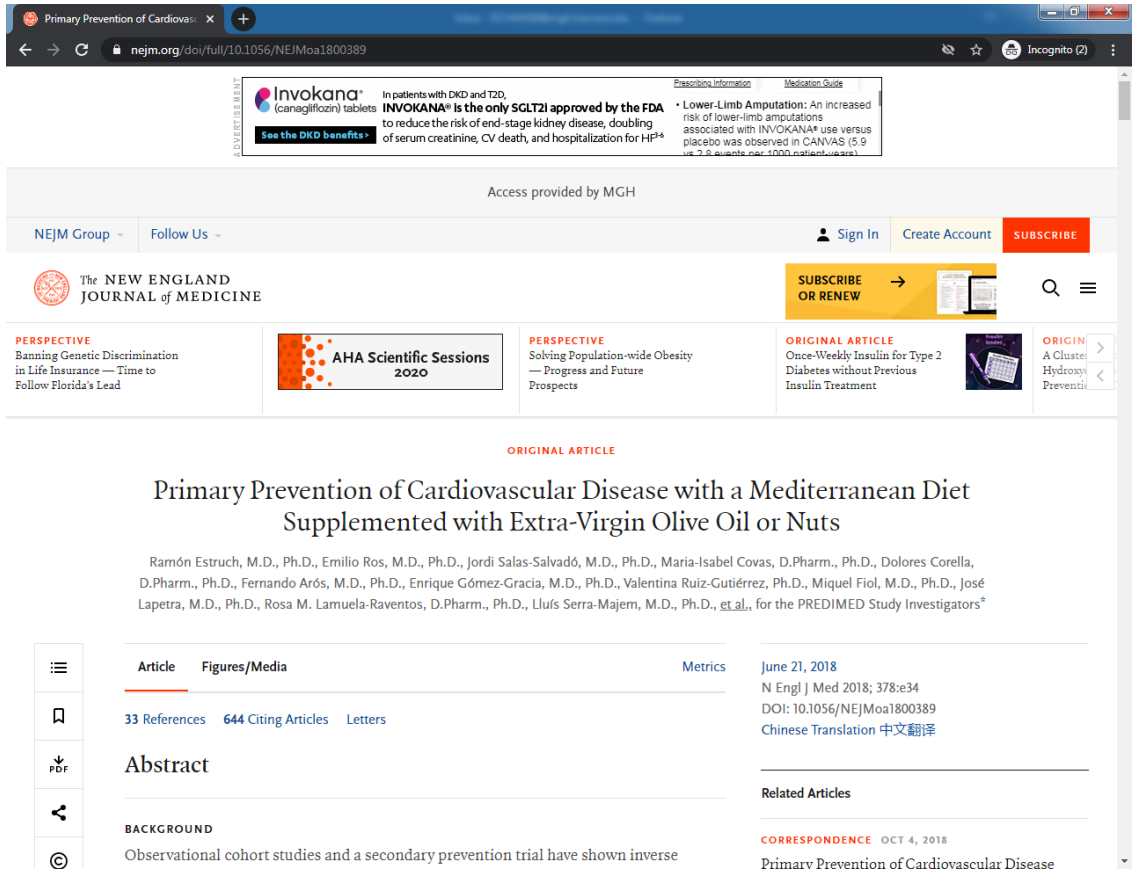
Conclusions. Patients older than 70 years of age can undergo lobectomy for lung cancer with low morbidity and mortality. Advanced age and the use of a thoracotomy increased the risk of complications in this patient population.

(Ann Thorac Surg 2009;88:1093–9)

A difference is just that, a difference



“X is good”, vs “X is better/best”



For the readers: Where to look?

- Demographics
  - Generalizability?
  - Dilution effect?
- Comparison:
  - Is it saying X is good? (descriptive, or compare to no intervention / no exposure)
  - Or is it saying X is better/best? (compare to another intervention/exposure)
- Problem is probably not in the stats – you don’t need fancy training to pick up on these problems

For the researchers: What to do?

- Improved study designs
  - Enrollment
  - Analysis
  - Interpretation

Increase enrollment

Program Director/Principal Investigator (Last, First, Middle):

Inclusion Enrollment Report

This report format should NOT be used for data collection from study participants.

Study Title: _____

Total Enrollment: _____ **Protocol Number:** _____

Grant Number: _____

PART A. TOTAL ENROLLMENT REPORT: **Number of Subjects Enrolled to Date (Cumulative) by Ethnicity and Race**				
Ethnic Category	**Females**	**Males**	**Sex/Gender Unknown or Not Reported**	**Total**
Hispanic or Latino				**
Not Hispanic or Latino				
Unknown (individuals not reporting ethnicity)				
Ethnic Category: Total of All Subjects*				*
Racial Categories				
American Indian/Alaska Native				
Asian				
Native Hawaiian or Other Pacific Islander				
Black or African American				
White				
More Than One Race				
Unknown or Not Reported				
Racial Categories: Total of All Subjects*				*

Increase enrollment not enough

- Dilution effect: Minority patients will still be a minority in the study population, with their impact overwhelmed by the majority population
- Need to actively consider the generalizability question in analysis and interpretation
  - Need to consider the possibility that there may not be ONE answer; there may be multiple answers, different for different populations

Improved analysis

- Not helpful to know that women and non-whites have different outcomes
  - Very depressing
- More important to know if the risk factors are different among non-whites
- Stratify on non-modifiable risk factors
  - Adjust for modifiable risk factors

Improved analysis

- “Heterogeneity of treatment effects”
- Statistical “interaction”
- Synergistic / antagonistic effect / effect modification
- “Clinical indications”: We know it works, but does it work equally well in everyone?

Interpretation

- Consider alternate “reference” group
  - Statistical “reference” group often subtly becomes the “normal” group

VIEWPOINT

Culturally Competent Science

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Although social norms have eliminated many forms of overt discrimination, more subtle forms of bias persist. Unfortunately, the scientific community, and particularly those of us in the health sciences, may be unintentionally contributing to many of these biases. The study of population differences is important for the understanding of health outcomes. However, studies of population differences can be, and have been, negatively influenced by subjective value judgments. This has historically taken the form of the majority population being ascribed as having "normal" traits and being used to set norms for disease definitions and treatment standards. We hypothesize that this subtle "majority is normal" bias has resulted from a lack of broad-based participation in the scientific process. Although there have been great efforts to promote culturally competent care, less has been done to encourage culturally competent science. The former focuses on practicing physicians delivering

donor race negatively affects patient survival among white patients when kidneys from black donors are transplanted to white recipients; however, outcome differences by donor ethnicity did not exist when organs from black or white donors were transplanted to patients from other racial groups, suggesting that the original findings may be limited to the pairing of black donors and white recipients. This finding should raise the question of whether the negative association with survival is attributable to issues related to black organ donors, or to the immunotolerance of white recipients.[5] In the revised US Preventive Services Task Force breast cancer screening guidelines, the screening age was raised to 50 years to reflect the finding that the majority of women in the United States who develop breast cancer receive a diagnosis in their 60s. However, it was recently noted that this incidence pattern is only applicable to white women; among nonwhite women,

- Flawed science hurts more patients than flawed care
- Culturally competent care begins with culturally competent science

Exercise

- Read the abstract of NEJM article, and a NY Times article, about the Mediterranean diet
- ~5 People in each breakout room
- Introduce yourselves by stating your name and birthday (just month and day)
- Whoever's birthday is closest to today will be the reporter

- **How might you have written (or re-write) the NY Times article?**