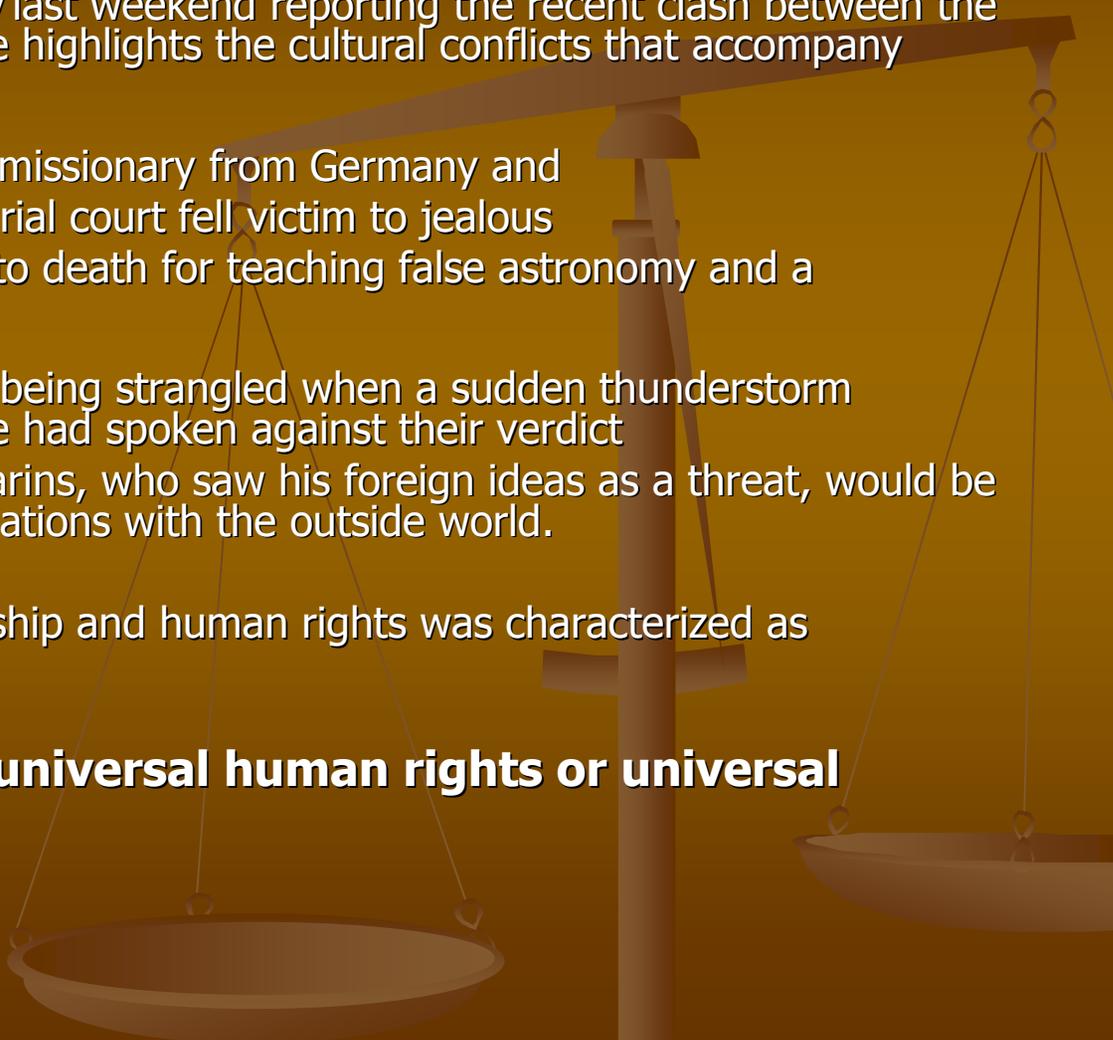


Ethical considerations for the role of a statistician in international survey research



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Battling the information Barbarians



An article in *The Wall Street Journal* last weekend reporting the recent clash between the Chinese government and Google highlights the cultural conflicts that accompany international ventures

"In 1661, Adam Schall, a Jesuit missionary from Germany and astronomer at the Chinese imperial court fell victim to jealous mandarins, and was sentenced to death for teaching false astronomy and a superstitious faith."

As it turned out he was saved from being strangled when a sudden thunderstorm convinced his judges that nature had spoken against their verdict
The defensiveness of the mandarins, who saw his foreign ideas as a threat, would be a recurring theme in Chinese relations with the outside world.

Google's pronouncement on censorship and human rights was characterized as "information imperialism."

So are there such things as universal human rights or universal ethical standards?

Clash of concepts

Individual v. group rights

HIV/AIDS reporting

Medicare reform

Free speech

Vaccinations

Affirmative action

Privacy v. transparency, need to know

Obedience to authority v. freedom to dissent

Respect for individuals

Parental authority

Respect for standards

Head covering

Soles of feet

Eye contact

Gender roles



Ethical frameworks

Utilitarian

Social justice

Non-interference

Virtual certainty

Who chooses and why?

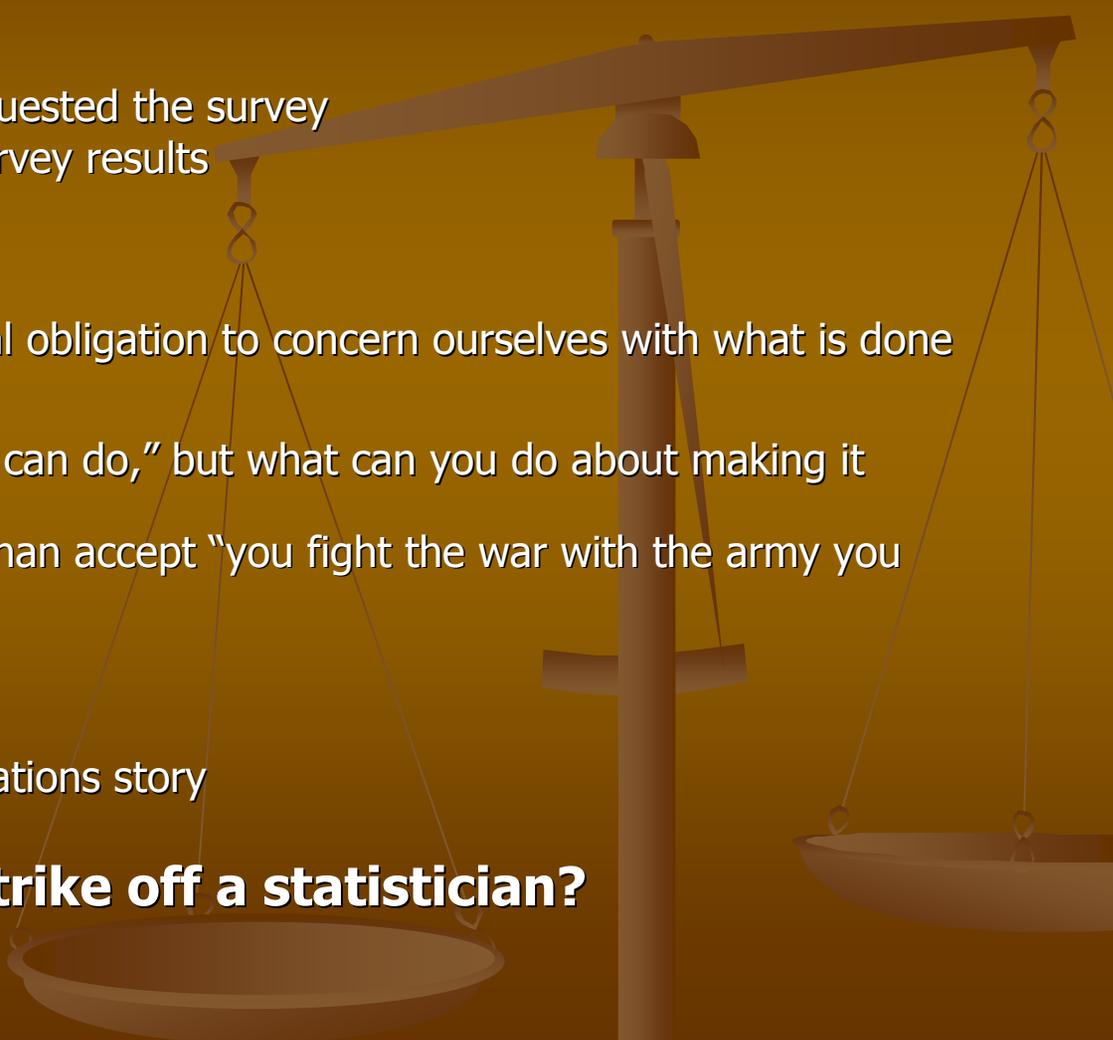


Contexts for ethical considerations

1. Clinical trials
2. Surveys
 - Medicine
 - Economics
 - Education
 - Social welfare
 - Politics
3. Epidemiological and other observational studies
4. Planning
 - Financial markets
 - World Bank
 - Healthcare
 - Public health and safety
5. Teaching and training
6. Risk assessment under uncertainty



Ethical obligations



Ethical obligations to whom?

- those surveyed
- those who sponsored/requested the survey
- those who will use the survey results
- policy-makers
- the public

Moreover, do we not have an ethical obligation to concern ourselves with what is done with our work?

Perhaps "you can only do what you can do," but what can you do about making it possible to do more?

Surely we can do better than accept "you fight the war with the army you have"

Follow-up

- SIDS
- The recent autism/vaccinations story

Can we strike off a statistician?

Surveys and policy

What is the role of statisticians?

Design

Sample: who, where, how many

Questions

Language: is there an equivalent?

Sensitivity: ethnic, religious, gender, other local cultural considerations

Privacy: varying notions of privacy

Do you want to carry an ID card? Where do you work?

How much money do you make? How old are you?

questioning in the presence of others

Legality: "5th amendment" equivalencies

Questioners

Who can question whom? Who is supervising the surveyors?

Data

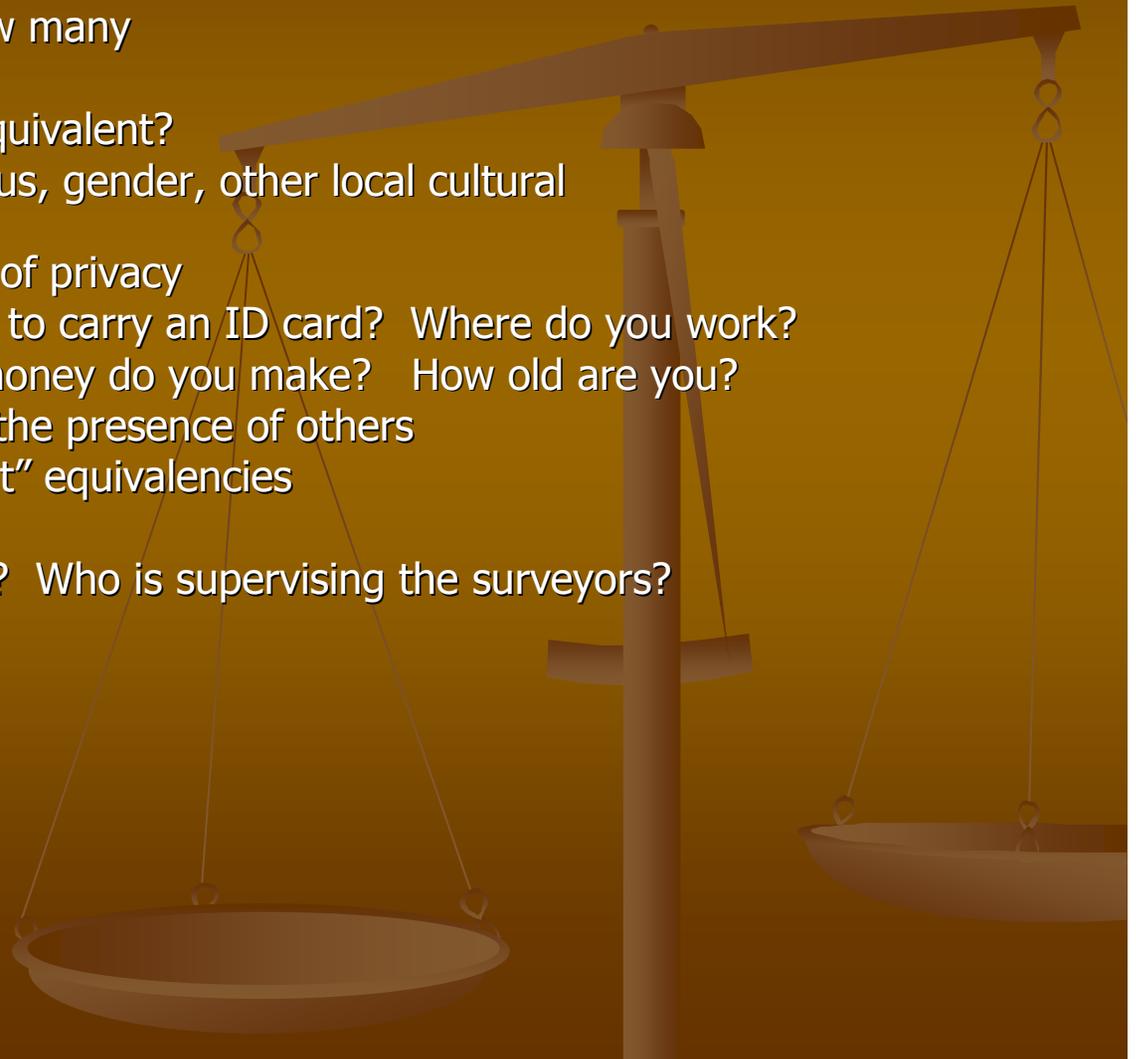
Access

Use

Analysis

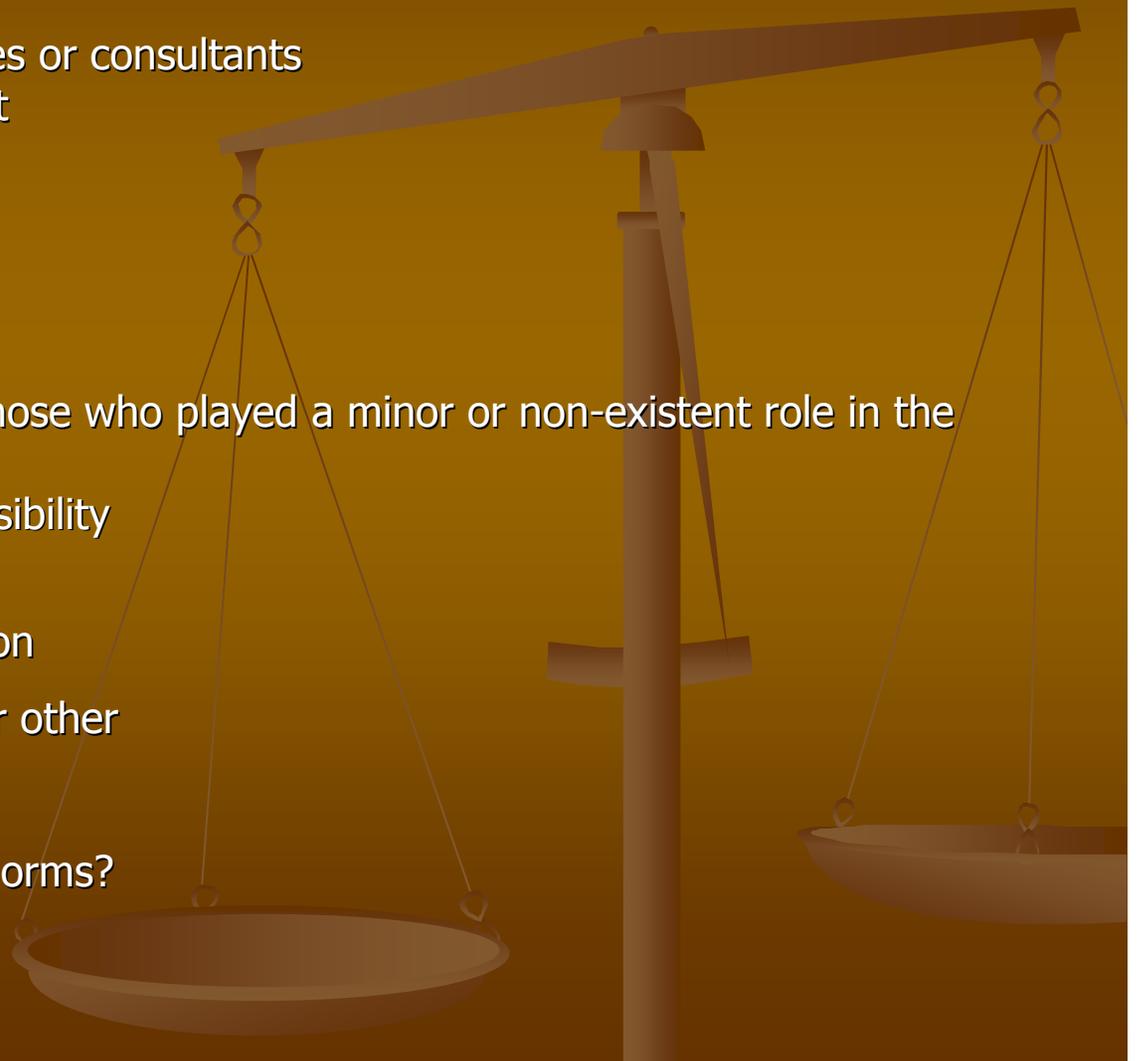
Methods

Limitations



Ethical issues

1. "Hired guns"—who produce any results for enough money or other incentives (such as political gain)
 - Drug company employees or consultants
 - Expert witnesses in court
 - Government agencies
2. Suppression of results
 - By employers or funders
 - Self-censorship
3. Credit falsely assigned to those who played a minor or non-existent role in the research
 - Failure to assume responsibility
 - Lack of accountability
4. Coercive or paid participation
5. Failure to protect privacy or other individual rights
6. Failure to respect cultural norms?



Recognition of ethical concerns

In the middle of the Merck crisis of several years ago, a headline appeared:

“Vioxx Kept Trial Going In Spite of Concerns”

Some of my undergraduate statistics students saw the headline and, observing the words “statistically significant” farther down the page read the article (online, I should mention—I sometimes think no one under 25 reads print media).

The story related how concerns arose regarding possible increased risk of certain heart problems after as little as four months’ use of Vioxx, but the trial continued until the adverse events became statistically significant.

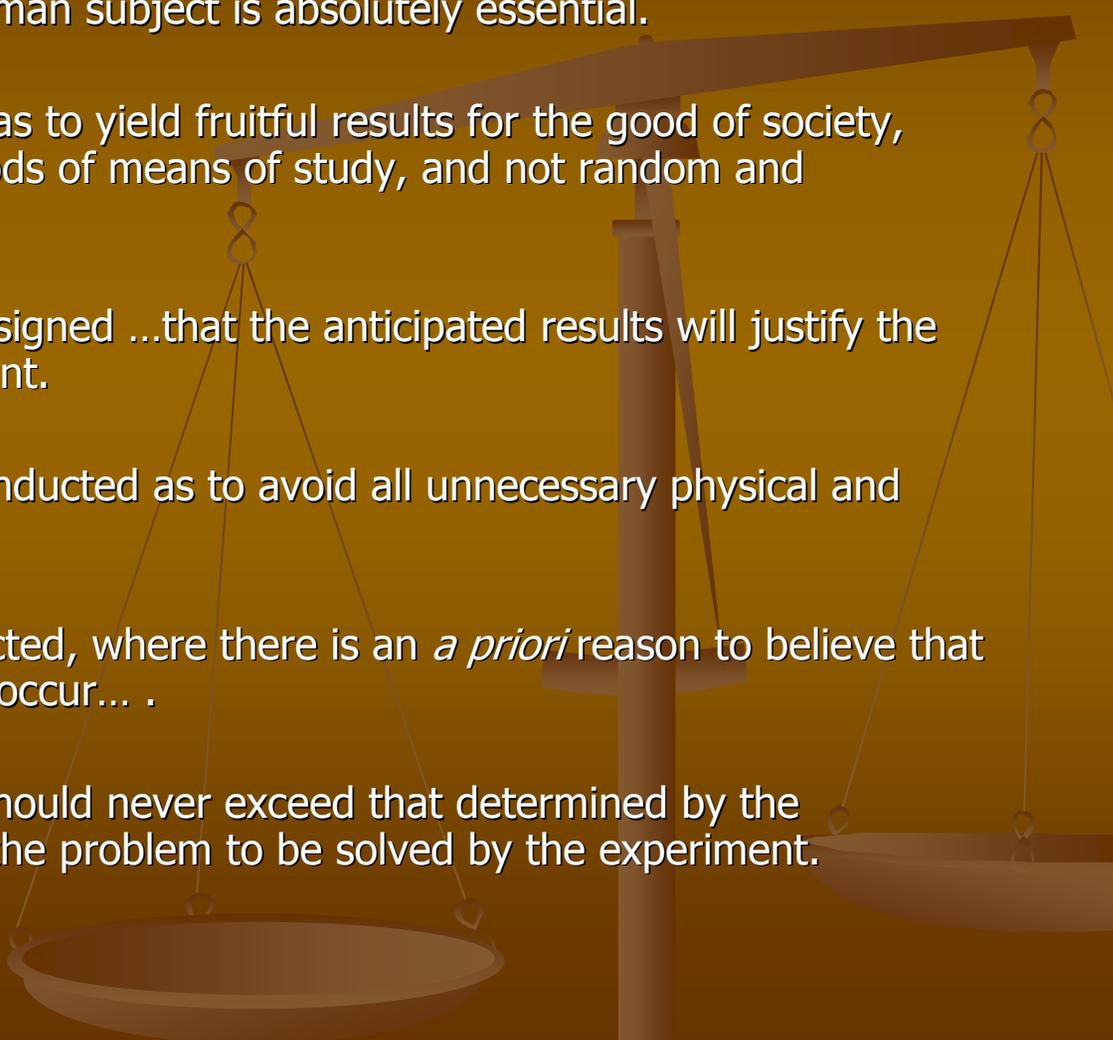
Does this mean, asked my students, that more people had to die just to get statistical significance?

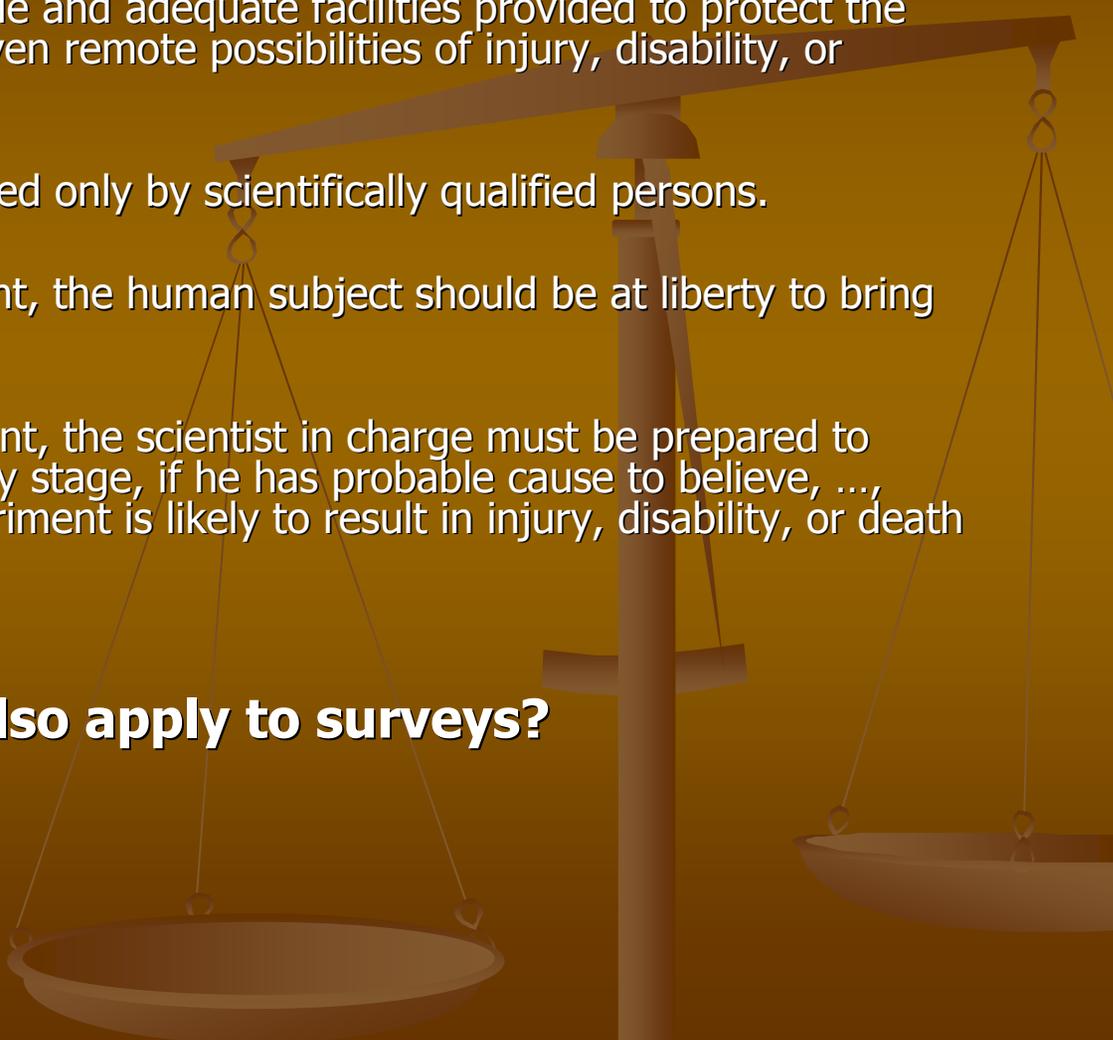
Not, perhaps, how we would put it, but that **THEY** did is a bit unsettling.

So do we keep on surveying?

The pervasiveness of headlines regarding the ethics of researchers—in clinical trials, in political polling, in investigation of possible war crimes—has actually become more than a bit unsettling.

The Nuremberg Code

1. The voluntary consent of the human subject is absolutely essential.
 2. The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods of means of study, and not random and unnecessary in nature.
 3. The experiment should be so designed ...that the anticipated results will justify the performance of the experiment.
 4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.
 5. No experiment should be conducted, where there is an *a priori* reason to believe that death or disabling injury will occur... .
 6. The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.
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7. Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.
 8. The experiment should be conducted only by scientifically qualified persons.
 9. During the course of the experiment, the human subject should be at liberty to bring the experiment to an end.
 10. During the course of the experiment, the scientist in charge must be prepared to terminate the experiment at any stage, if he has probable cause to believe, ..., that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject.

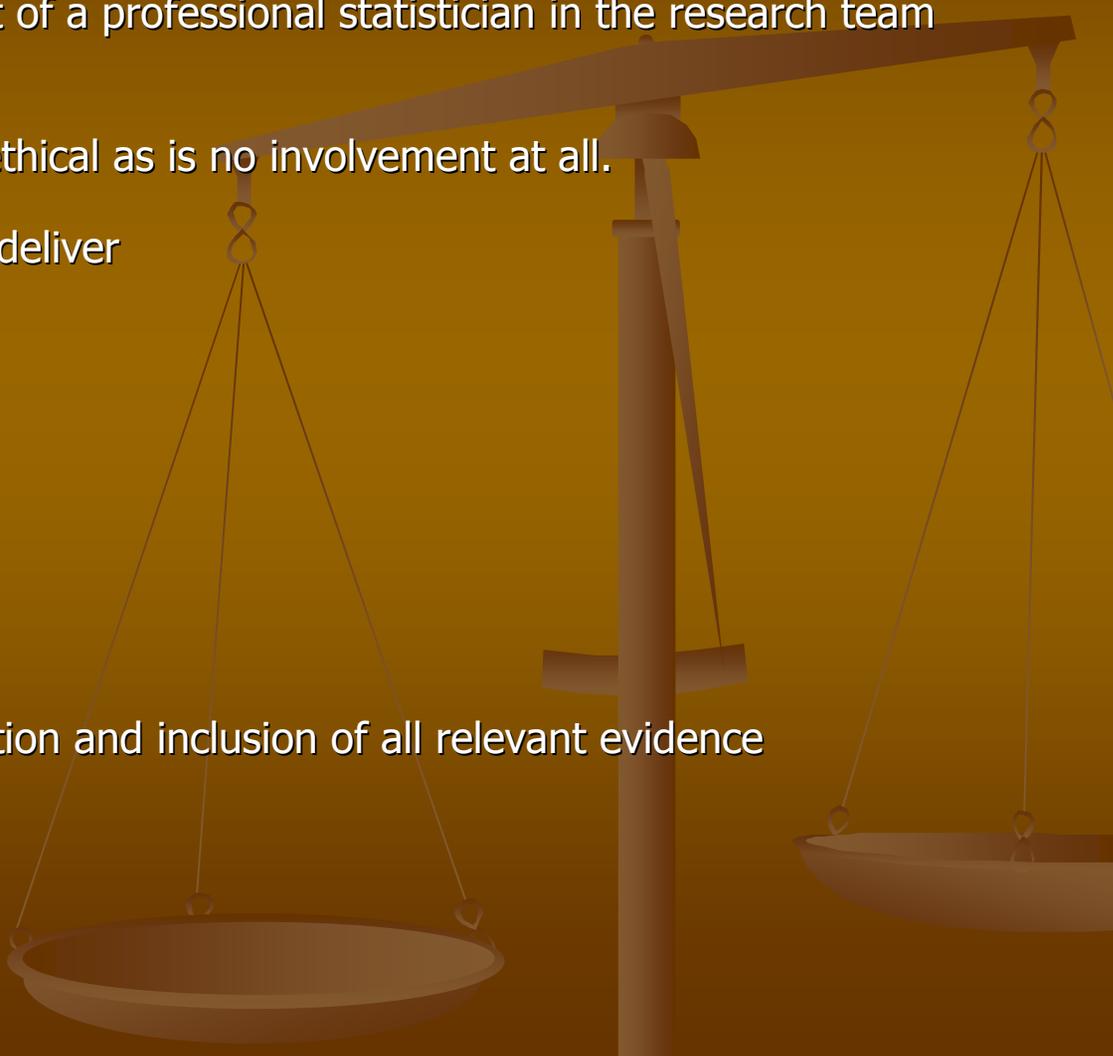
Does this also apply to surveys?

International Statistical Institute Code of Ethics

1. Obligations to society
 - Considering conflicting interests
 - Widening the scope of statistics
 - Pursuing objectivity
2. Obligations to funders and employers
 - Clarifying obligations and roles
 - Assessing alternatives impartially
 - Not pre-empting outcomes
 - Guarding privileged information
3. Obligations to colleagues
 - Maintaining confidence in statistics
 - Exposing and reviewing methods and findings
 - Communicating ethical principles



Basic principles



There should be formal involvement of a professional statistician in the research team from the beginning.

Informal involvement can be as unethical as is no involvement at all.

Do not promise more than you can deliver

- To those surveyed

- To surveyors

- To sponsors

- To policy makers

- To the public

Address uncertainty and variability

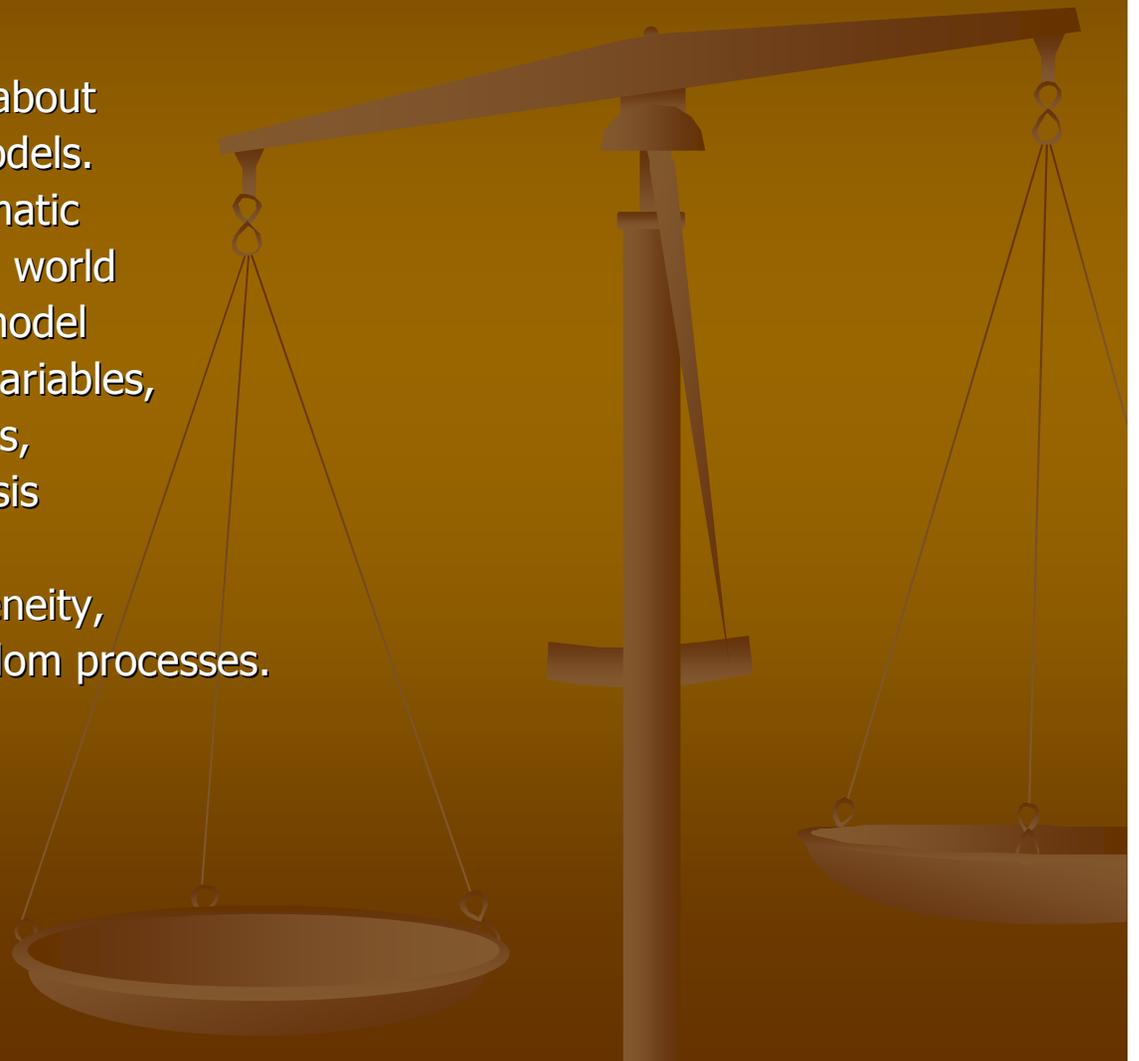
Demonstrate respect for randomization and inclusion of all relevant evidence

Guard against conflicts of interest

Uncertainty and variability

Uncertainty is a lack of knowledge about specific factors, parameters, models. measurement, sampling, systematic errors, oversimplification of real world processes, misspecification of model structure, inappropriate proxy variables, descriptive or aggregation errors, misjudgment, incomplete analysis

Variability arises from real heterogeneity, diversity, results of natural random processes.



Further considerations

Focus on areas of greatest uncertainty

Responsibility to include many perspectives from stakeholders to bring up issues that otherwise would not be considered and to expose underlying forces

Avoid advocacy

SEEPT—social, economic, environmental, political and technological factors

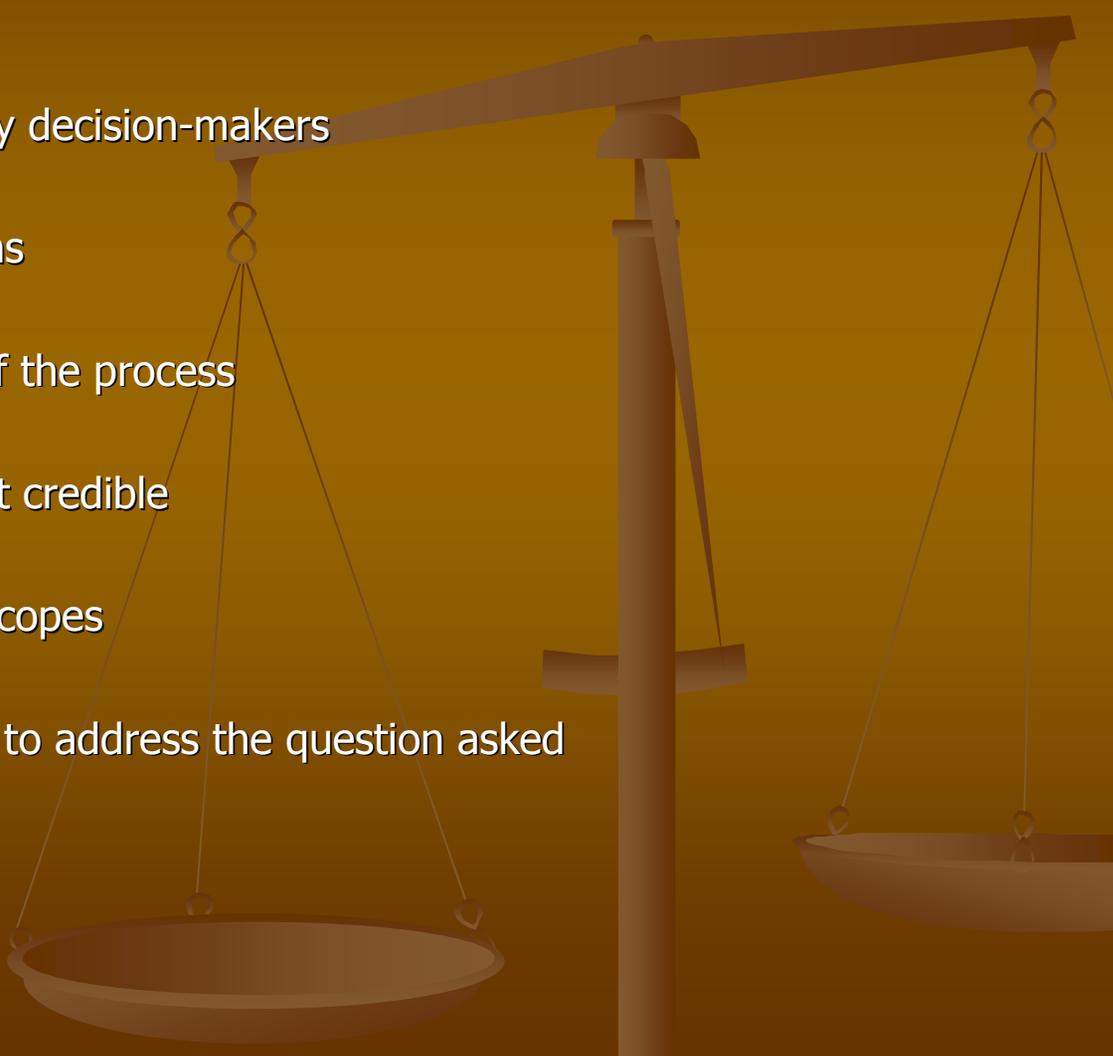
Build accountability system

Monitor progress and test results

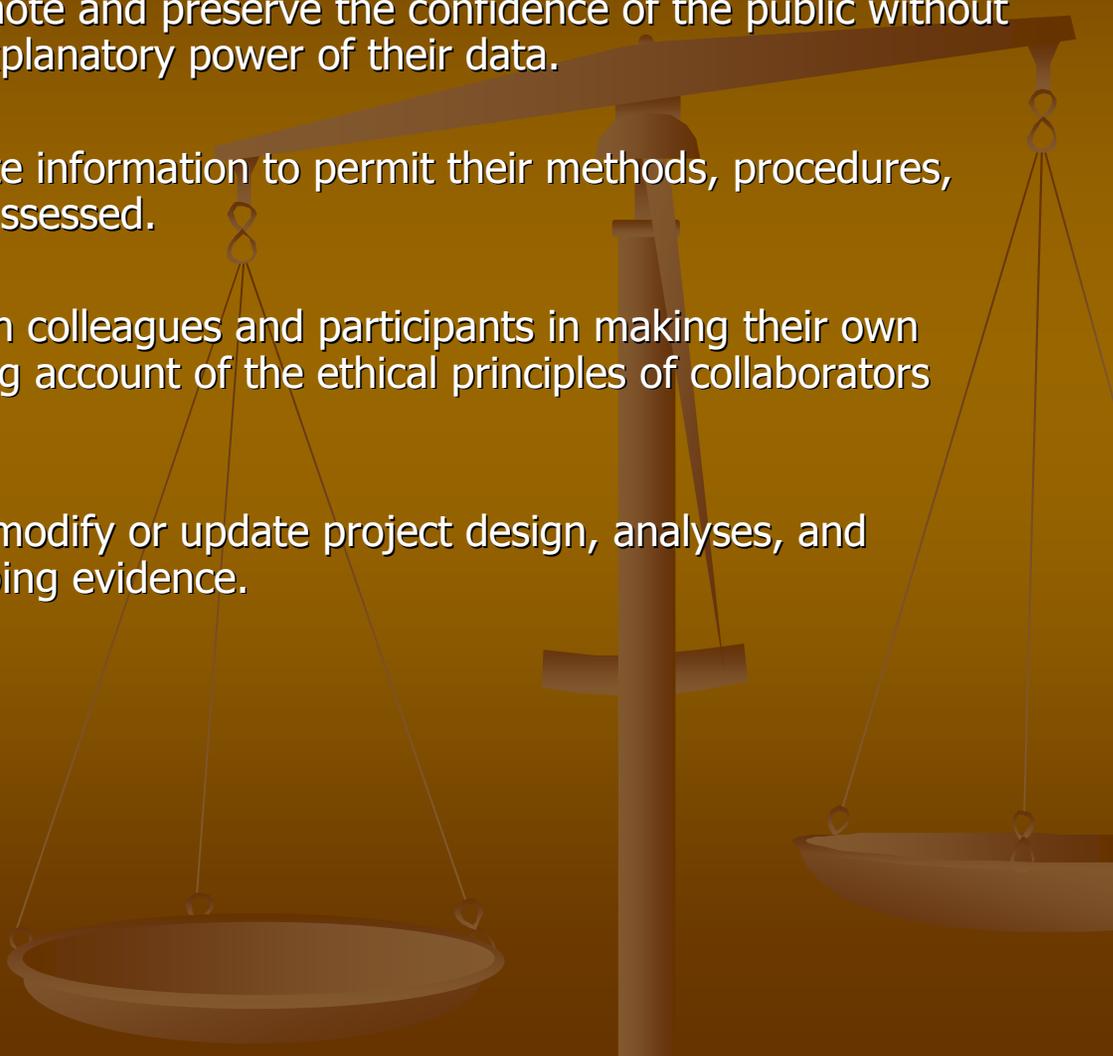
Re-examine environment and strategy



Pitfalls for which statisticians may share responsibility

1. Failure to gain the support of key decision-makers
 2. Unrealistic goals and expectations
 3. Failure to develop a clear map of the process
 4. Building of scenarios that are not credible
 5. Inappropriate time frames and scopes
 6. Failure to design survey process to address the question asked
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Communication



Statisticians should attempt to promote and preserve the confidence of the public without exaggerating the accuracy or explanatory power of their data.

Statisticians should provide adequate information to permit their methods, procedures, techniques, and findings to be assessed.

Statisticians need to collaborate with colleagues and participants in making their own ethical principles clear and taking account of the ethical principles of collaborators and participants.

Statisticians should be prepared to modify or update project design, analyses, and conclusions based upon developing evidence.