What's Ethics Got to Do with Big Data?

WHO-University of Miami
Ethics Consultation
October 12, 2017

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President & CEO
Council of Canadian Academies

“The more the data banks record about each one of us, the less we exist.”

- Marshall McLuhan
Playboy Interview (1969)

MARK SIEGLER

Confidentiality in Medicine—A Decrepit Concept

Medical confidentiality, as it has traditionally been understood by patients and doctors, no longer exists. This ancient medical principle, which has been included in every physician's oath and code of ethics since Hippocratic times, has become old, worn-out, and useless; it is a decrepit concept. Efforts to preserve it appear

consultant, and others); 12 house officers (medical, surgical, intensive-care unit, and "covering" house staff); 20 nursing personnel (on three shifts); 6 respiratory therapists; 3 nutritionists; 2 clinical pharmacists; 15 students (from medicine, nursing, respiratory therapy, and clinical pharmacy); 4 unit secretaries; 4 hospital financial

rs; and 4 chart reviewers (utilization review, qual-

surance review, tissue review,

t is of interest that this pati

ntforward, and he therefore di

technical and support servic

al provides. For example, he

onsultants and fellows, such

as dialysis, or social workers,

ists, occupational therapists,

on completing my survey I

tient that I estimated that at least 75

als and hospital personnel had acc

record. I suggested to the patient tha

all involved in providing or suppor

services. They were, I assured him

Despite my reassurances the patient

tressed and retorted, "I always bel

confidentiality was part of a docto

Perhaps you should tell me just wha

by 'confidentiality'!"

fer, the patient saw a respiratory therapist writing in his medical chart (the therapist was recording the results of an arterial blood gas analysis) and became concerned about the confidentiality of his hospital records. The patient threatened to leave the hospital prematurely unless I could guarantee that the confidentiality of his hospital record would be respected.

This patient's complaint prompted me to enumerate the number of persons who had both access to his hospital record and a reason to examine it. I was amazed to learn that at least 25 and possibly as many as 100 health professionals and administrative personnel at our university hospital had access to the patient's record and that all of them had a legitimate need, indeed a professional responsibility, to open and use that

TWO ASPECTS OF MEDICAL CONFIDENTIALITY

CONFIDENTIALITY AND THIRD-PARTY INTERESTS

Previous discussions of medical confidentiality usually

"I was amazed to learn that at least 25 and possibly as many as 100 health professionals and administrative personnel…had access to the patient's hospital record and a reason to examine it."

"[A]t some point most patients should have an opportunity to review their medical record and to make informed choices about whether their entire record is to be available to everyone or whether certain portions of the record are privileged and should only be accessible to their principal physician or to others explicitly designated by the patient."

“These issues – [are] perhaps best framed as ethical, legal, and social issues (ELSI)”

-- Concept Note

The Current "Ethics" Menu
(borrowed from the human genome project)

Mapping – find and name the ethical issues

Sequencing – unpack and describe their parts

Function – explain how they work

Proteomic – recognize that they are non-linear, "folded", complex

Mapping and Sequencing Ethical Issues

Consent
- direct, broad, dynamic, presumed

Commercialization
- pub/pvt, priority-setting, commodification

Justice and fairness
- access to products, services; globalization, exploitation

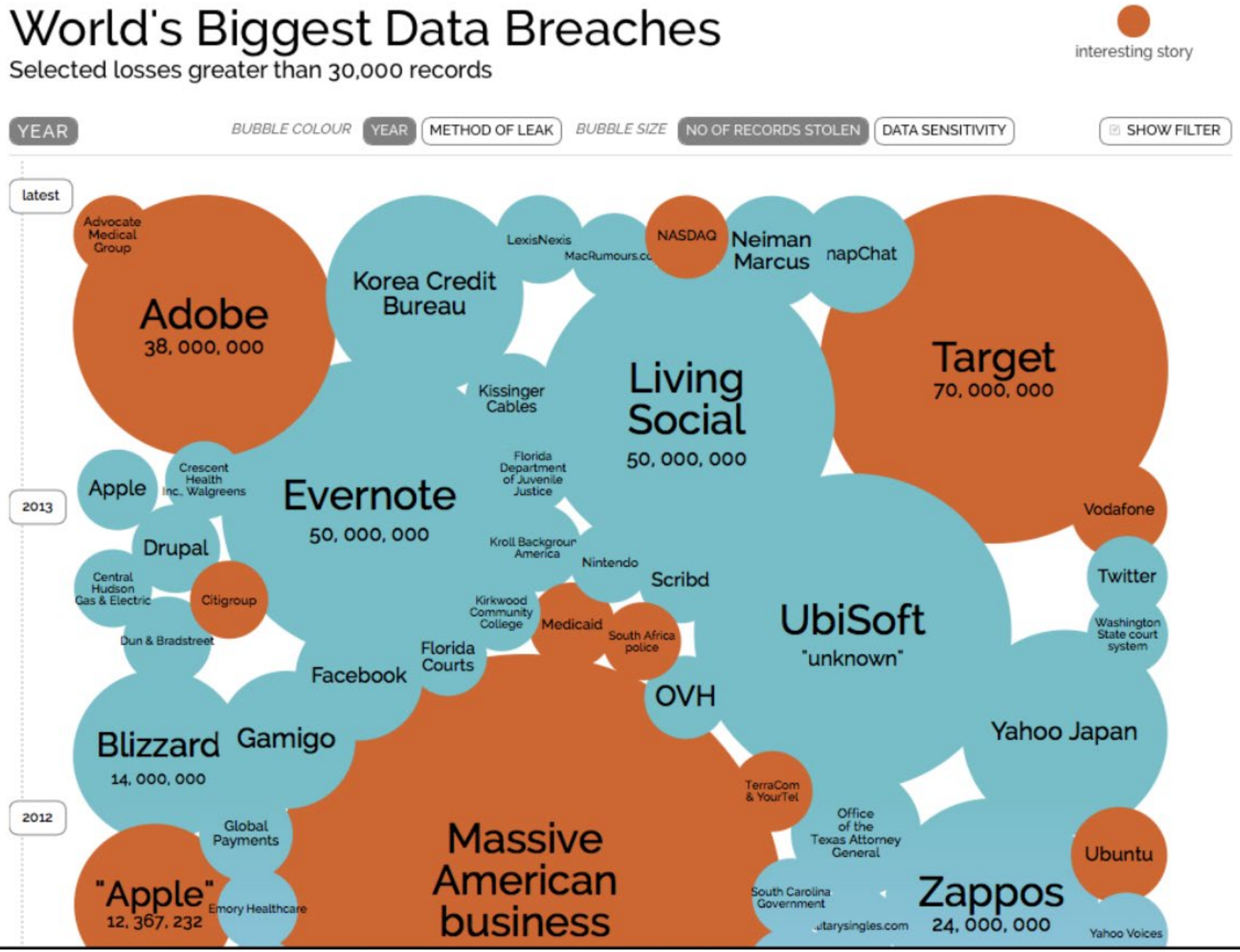
Privacy
- data security, discrimination, identity

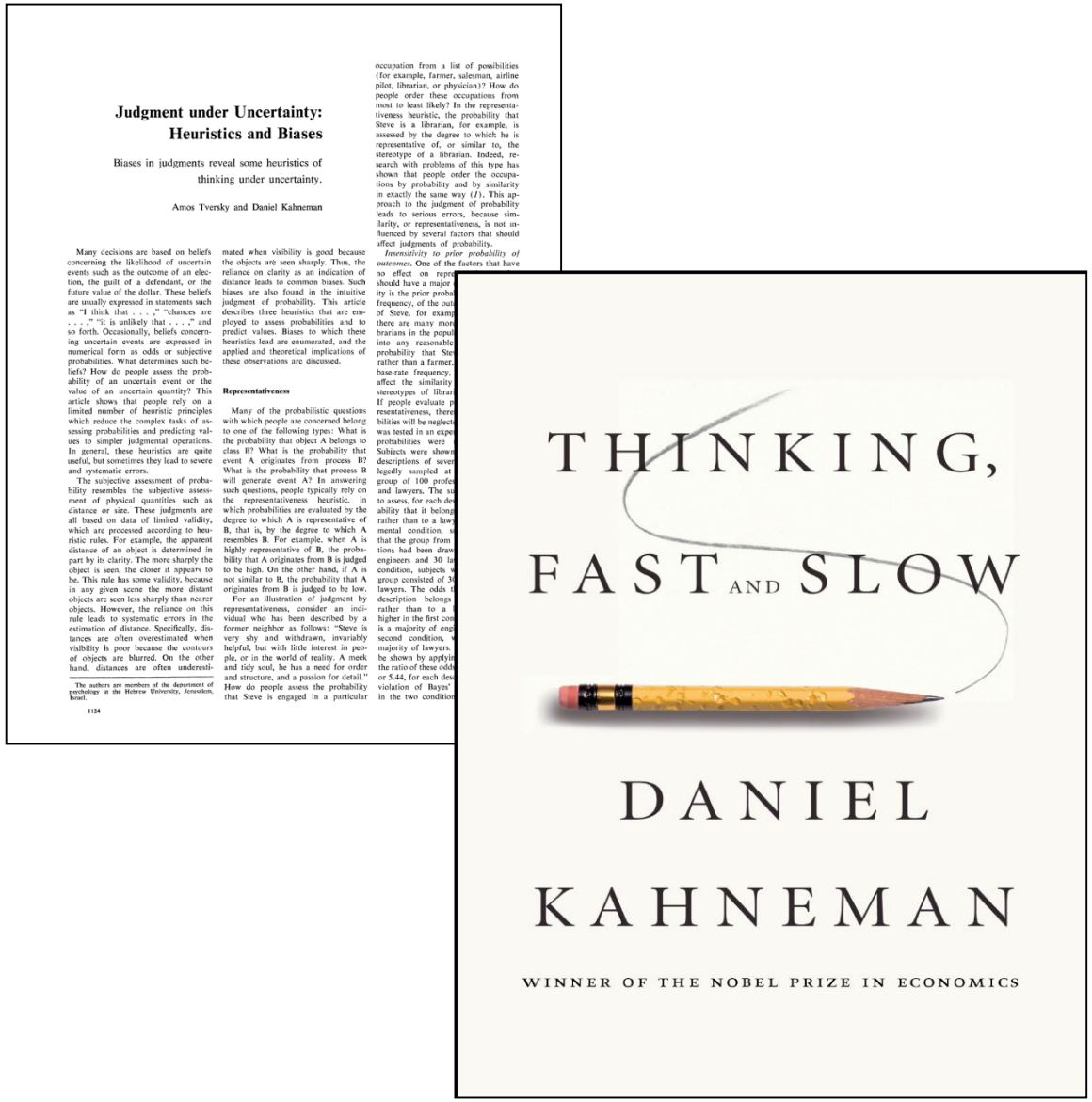
Regulatory authority
- to intervene prohibit, restrict, encourage

Governance
- public engagement, deliberative approaches

World's Biggest Data Breaches

Selected losses greater than 30,000 records





Judgment under Uncertainty: Heuristics and Biases

Biases in judgments reveal some heuristics of thinking under uncertainty.

Amos Tversky and Daniel Kahneman

Many decisions are based on beliefs concerning the likelihood of uncertain events such as the outcome of an election, the guilt of a defendant, or the future value of the dollar. These beliefs are usually expressed in statements such as "I think that . . . ," "chances are . . . ," "it is unlikely that . . . ," and so forth. Occasionally, beliefs concerning uncertain events are expressed in numerical form as odds or subjective probabilities. What determines such beliefs? How do people assess the probability of an uncertain event or the value of an uncertain quantity? This article shows that people rely on a limited number of heuristic principles which reduce the complex tasks of assessing probabilities and predicting values to simpler judgmental operations. In general, these heuristics are quite useful, but sometimes they lead to severe and systematic errors.

The subjective assessment of probability resembles the subjective assessment of physical quantities such as distance or size. These judgments are all based on data of limited validity, which are processed according to heuristic rules. For example, the apparent distance of an object is determined in part by its clarity. The more sharply the object is seen, the closer it appears to be. This rule has some validity, because in any given scene the more distant objects are seen less sharply than nearer objects. However, the reliance on this rule leads to systematic errors in the estimation of distance. Specifically, distances are often overestimated when visibility is poor because the contours of objects are blurred. On the other hand, distances are often underestimated when visibility is good because the objects are seen sharply. Thus, the reliance on clarity as an indication of distance leads to common biases. Such biases are also found in the intuitive judgment of probability. This article describes three heuristics that are employed to assess probabilities and to predict values. Biases to which these heuristics lead are enumerated, and the applied and theoretical implications of these observations are discussed.

The authors are members of the department of psychology at the Hebrew University, Jerusalem, Israel.

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Representativeness

Many of the probabilistic questions with which people are concerned belong to one of the following types: What is the probability that object A belongs to class B? What is the probability that event A originates from process B? What is the probability that process B will generate event A? In answering such questions, people typically rely on the representativeness heuristic, in which probabilities are evaluated by the degree to which A is representative of B, that is, by the degree to which A resembles B. For example, when A is highly representative of B, the probability that A originates from B is judged to be high. On the other hand, if A is not similar to B, the probability that A originates from B is judged to be low.

For an illustration of judgment by representativeness, consider an individual who has been described by a former neighbor as follows: "Steve is very shy and withdrawn, invariably helpful, but with little interest in people, or in the world of reality. A meek and tidy soul, he has a need for order and structure, and a passion for detail." How do people assess the probability that Steve is engaged in a particular occupation from a list of possibilities (for example, farmer, salesman, airline pilot, librarian, or physician)? How do people order these occupations from most to least likely? In the representativeness heuristic, the probability that Steve is a librarian, for example, is assessed by the degree to which he is representative of, or similar to, the stereotype of a librarian. Indeed, research with problems of this type has shown that people order the occupations by probability and by similarity in exactly the same way (1). This approach to the judgment of probability leads to serious errors, because similarity, or representativeness, is not influenced by several factors that should affect judgments of probability.

Insensitivity to prior probability of outcomes. One of the factors that have no effect on repres
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ity is the prior proba
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into any reasonable
probability that Ste
rather than a farmer.
base-rate frequency,
affect the similarity
stereotypes of librar
If people evaluate p
resentativeness, there
bilities will be neglect
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probabilities were
Subjects were shown
descriptions of sever
legedly sampled at
group of 100 profes
and lawyers. The su
to assess, for each de
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mental condition, s
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condition, subjects w
group consisted of 3
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description belongs
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higher in the first con
is a majority of engi
second condition, w
majority of lawyers.
be shown by applyi
the ratio of these odd
or 5.44, for each des
violation of Bayes'
in the two condition

"[The availability bias is] the tendency to assess the relative importance of issues by the ease with which they are retrieved from memory…which is largely determined by the extent of coverage in the media".

The Nobel Prize in Economics 2017

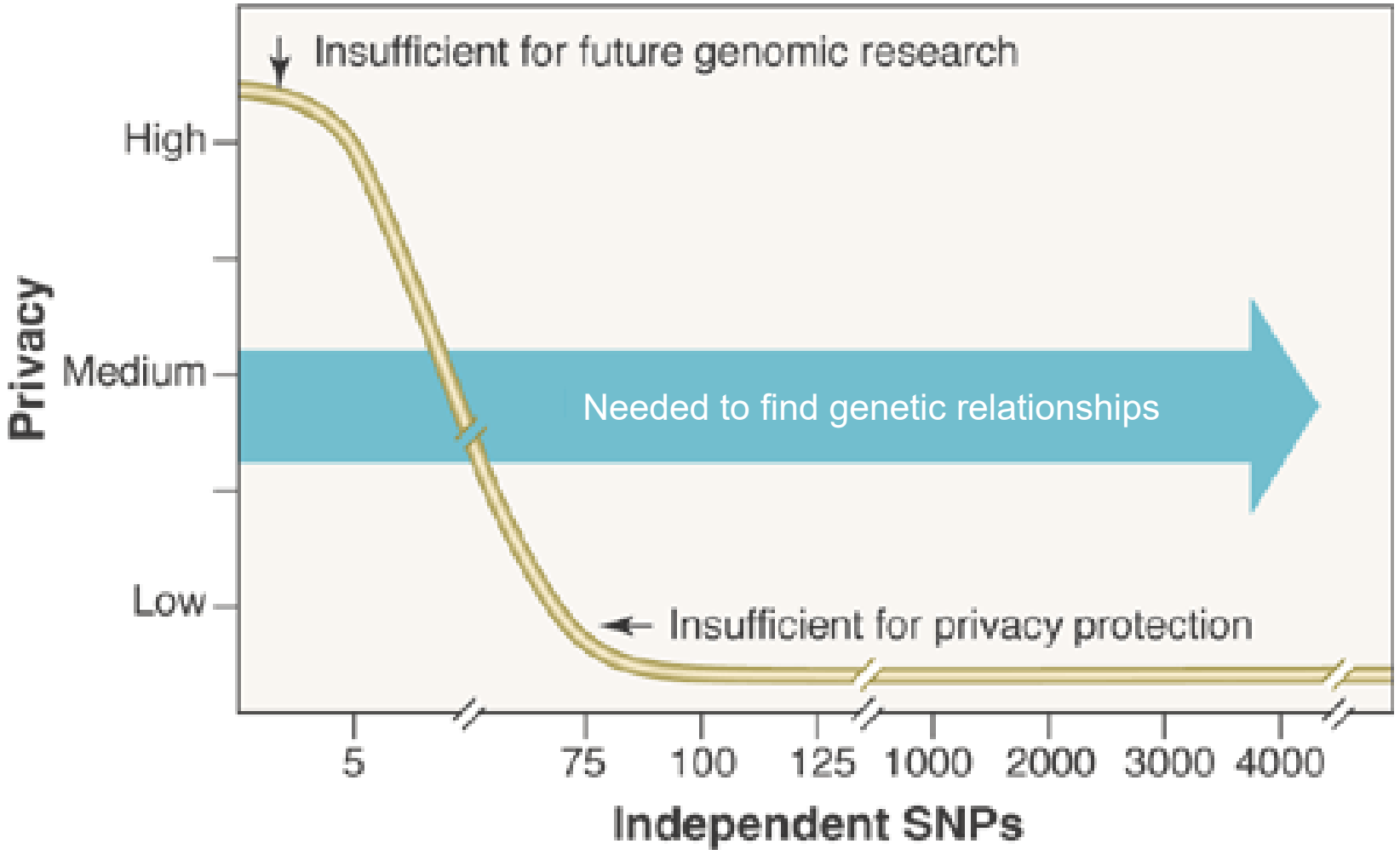
Richard Thaler

The Sveriges Riksbank Prize in Economic Sciences in Memory of Alfred Nobel 2017 was awarded to Richard Thaler of the University of Chicago.

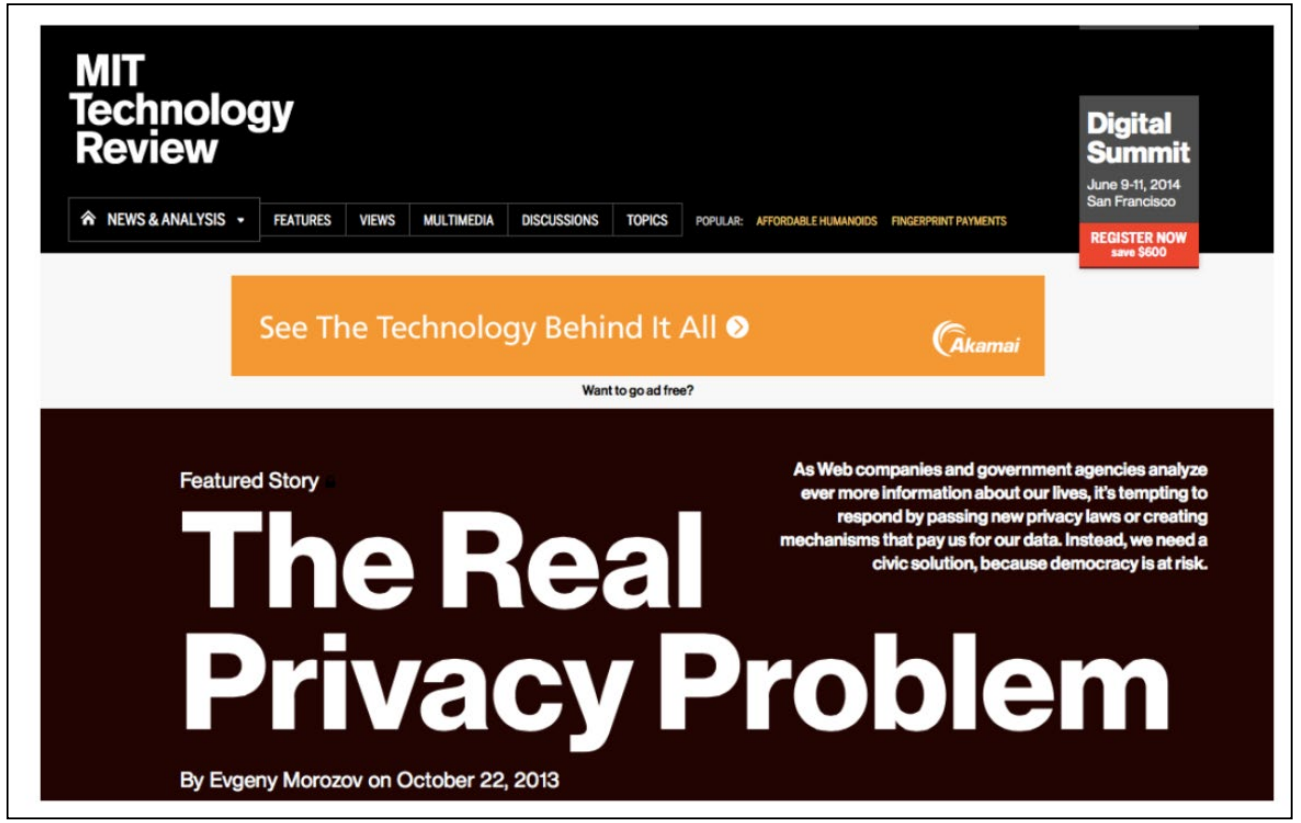
Richard Thaler's work combining the economics and the psychology of decision-making yielded unique insights into the actions of markets and individuals. His research was instrumental in creating the field of behavioral economics, and the National Science Foundation is proud to have supported it.

Image credit: © Nobel Media. Ill. N. Elmehed

A “reminder” from genomics about privacy



(R. Altman, Science)



"Too little privacy can endanger democracy.
But so too can too much privacy."

-- Evgeny Morozov (2013)

"Big data refers to datasets whose size is beyond the ability of typical database software tools to capture, store, manage and analyze."

"If US healthcare were to use big data creatively and effectively to drive efficiency and quality, the sector could create more than $300 billion in value every year."

- McKinsey (2011)

"In the next five to 10 years, AI is going to deliver so many improvements in the quality of our lives."

LEXUS
EXPERIENCE AMAZING

SEIZE THE DRIVE.

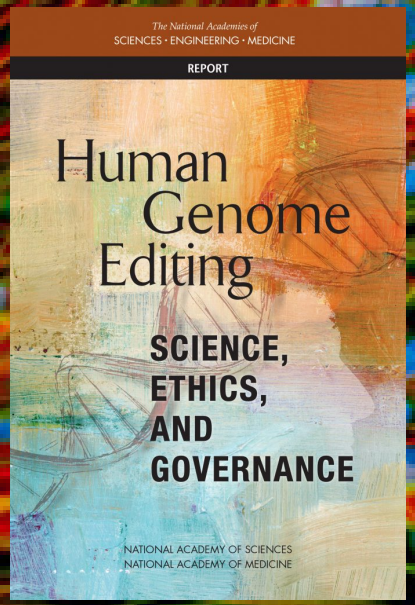
BEFORE AUTONOMOUS CARS DO.

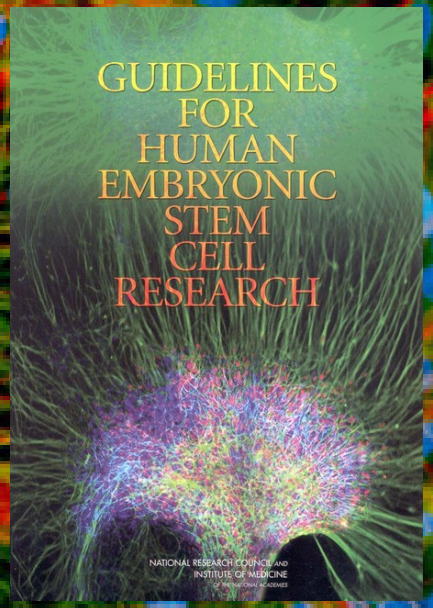
re not concerned
AI safety, you should
stly more risk than
Korea.

PLANNING

Innovation is fueled by imagination that asks:
what could we do?

Ethics, as the systematic study of morality, asks:
what should we do?





ENABLING

Ethics has, traditionally been seen as a brake on progress.

But it can be an accelerant (or at least, a lubricant).

EDITORIALS

Australia needs a better system for health care evaluation

Fiona J Stanley and Eric M Meslin

Is it unethical to avoid using all available information to monitor drug safety?

Adverse effects of health care have recently been in the news, from the worrying unexpected cardiovascular risks associated with use of the cyclooxygenase-2 inhibitor rofecoxib (Vioxx) to reports of high percentages of complications following routine surgery.[1,2] As medical care becomes more complex, sophisticated and expensive in Australia, it is paramount that we have the best systems in place to monitor its impact and

other health problems.[3-5] As a result, the WA Data Linkage Unit and the researchers it serves have considerable experience in linking, analysing and interpreting the complexities of such data, and have developed best practice in relation to privacy concerns. These analyses have had a major impact on improving health services in the state (see Brook et al[5] for examples). If all Australian health care data were linked to drug exposure data (from the

"If society has the capability to better monitor the safety of new drugs, it may be unethical not to do so – avoiding the use of information that would help reduce risk to individuals suggests a willingness to allow people to be harmed".

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journal homepage: www.ijmijournal.com

Giving patients granular control of personal health information: Using an ethics 'Points to Consider' to inform informatics system designers☆

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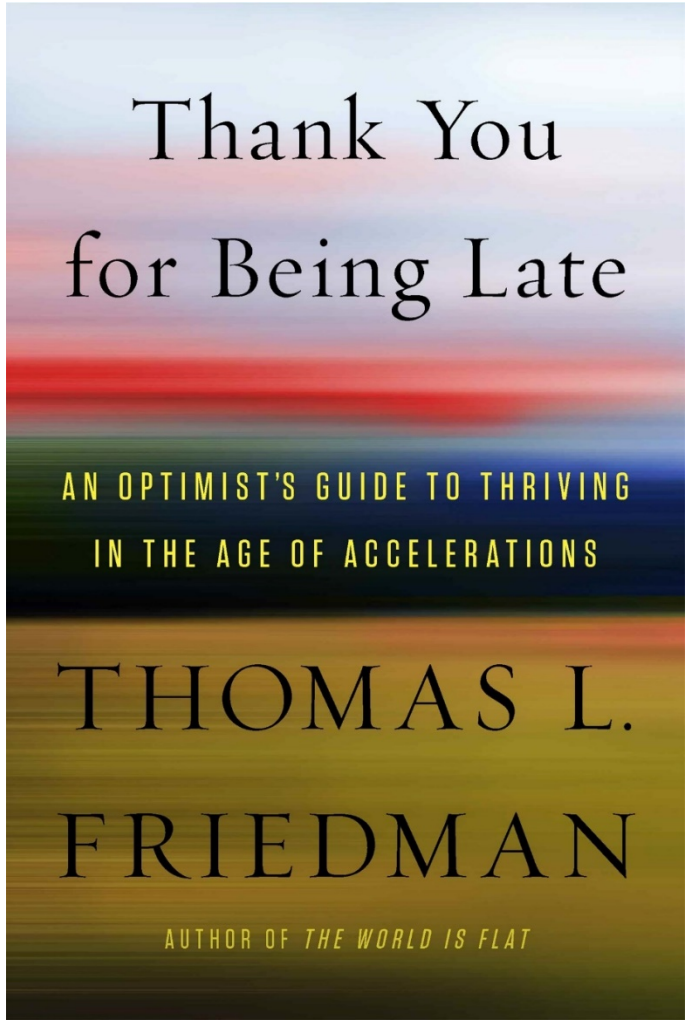
DEVELOPING POLICY INNOVATION INSTRUMENTS

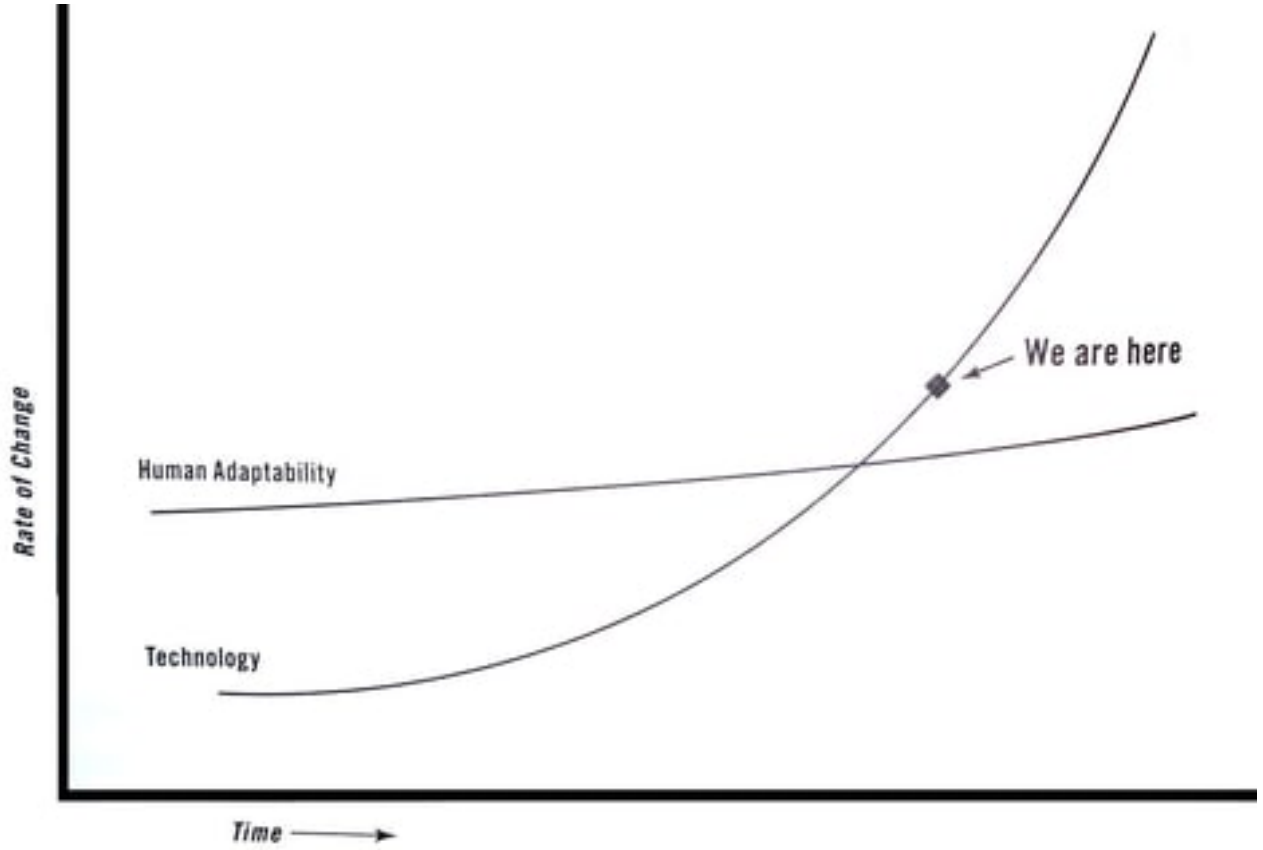
Ethics can help traverse the "policy valley of death"



"If it is true that it now takes ten to fifteen years to understand a new technology, and then build out new laws and regulations to safeguard society, how do we regulate when the technology has come and gone in five to seven years?"

"This is a problem."

“This is a problem.”



Astro Teller’s Curve

“That is dizzying for many people, because they hear about advances such as robotic surgery, **gene editing, cloning**, or artificial intelligence but have no idea where these developments will take us.”

-Friedman

The Role of Evidence, The Place of the Public

What does the law say?

What rules apply at university research labs?

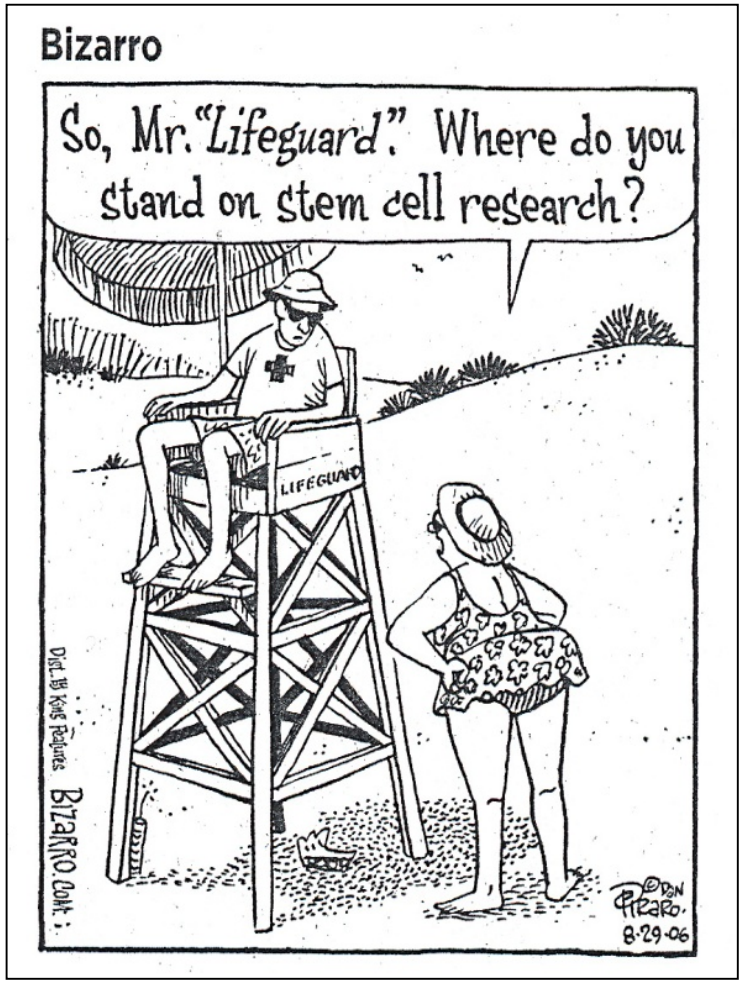
Who has decision making authority?

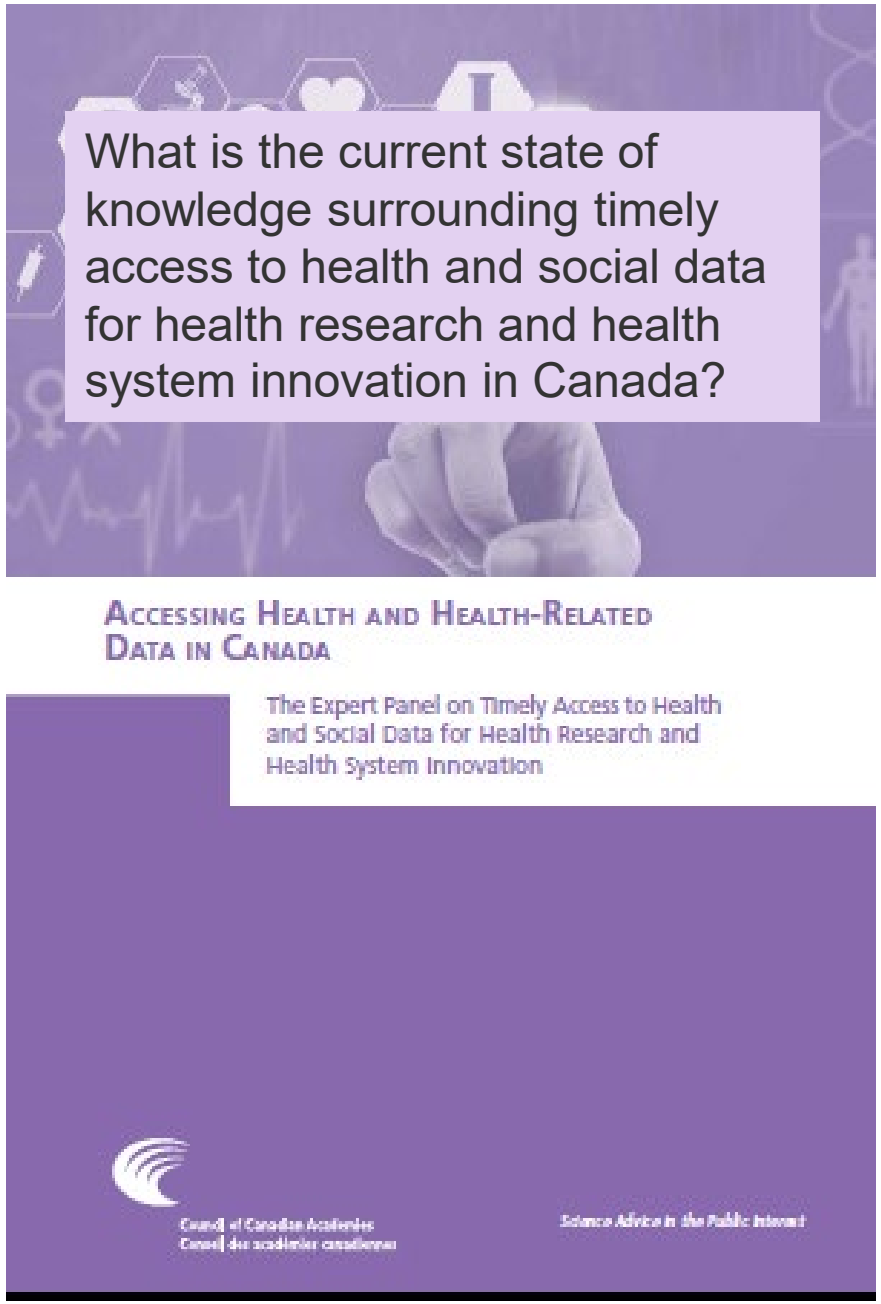
What ethical requirements are imposed by the funders?

What does the public think?

What do religious institutions say?

What are the economic costs?





Key Findings: Council of Canadian Academies (2014)

• For effective research with health and health-related data, disparate sources of data must be brought together.

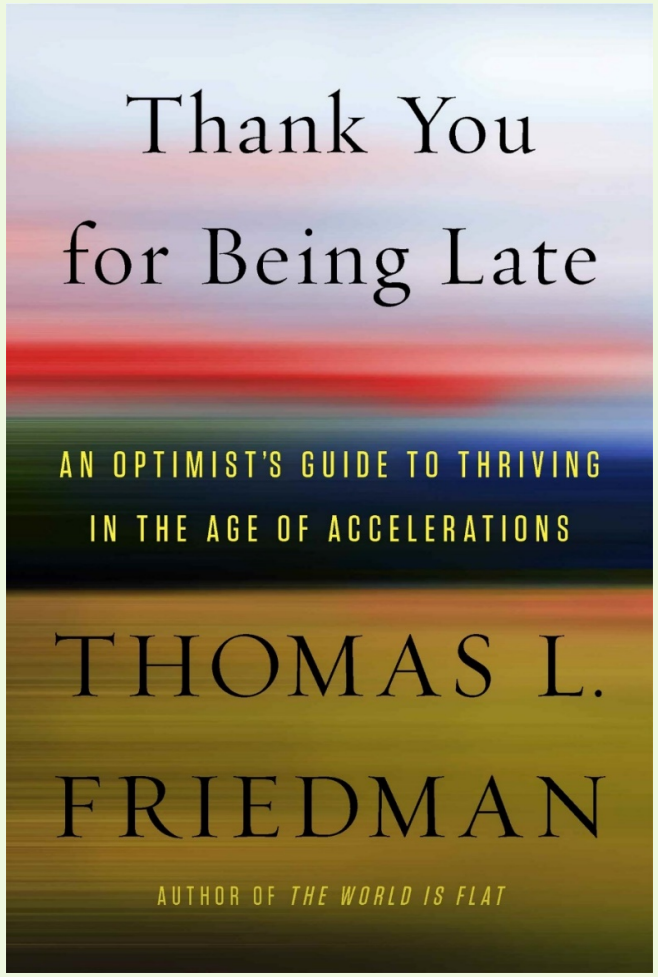
• Providing these data in an "analysis-ready" format, allowing statistical relationships or patterns to be derived, is a central methodological challenge.

• Timely access to data enables high-quality research with far-reaching effects for health care and the overall health of Canadians.

•The risk of harm from access to data is tangible but low; can be further lowered through effective governance mechanisms.

•Timely access to data is hindered by variable legal structures and differing interpretations of "identifiable" and "de-identified"

• A shift is occurring from a "data custodianship" model to a "data stewardship" model.



LEADERSHIP

"Therefore, properly exercising the powers that have been uniquely placed in the hands of our generation will require a **degree of moral innovation** that we have barely begin to explore…and a **degree of grounding in ethics** that most leaders lack." (emphasis added)

What do Governments Want?

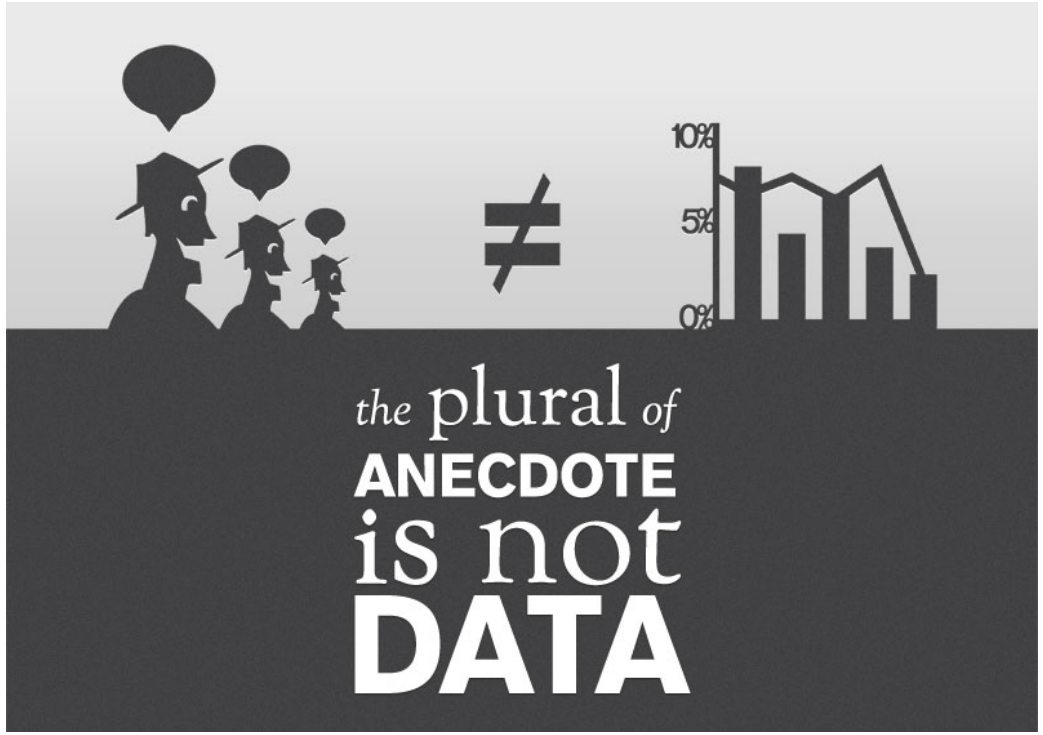
- *Assistance* in framing a policy problem
- *Context* for decision making, policy construction
- *Support* for a position to be adopted
- *Support* for a position to be rejected
- *Understanding* of similar activity elsewhere
- *"Proof"* of what "works" (or doesn't)

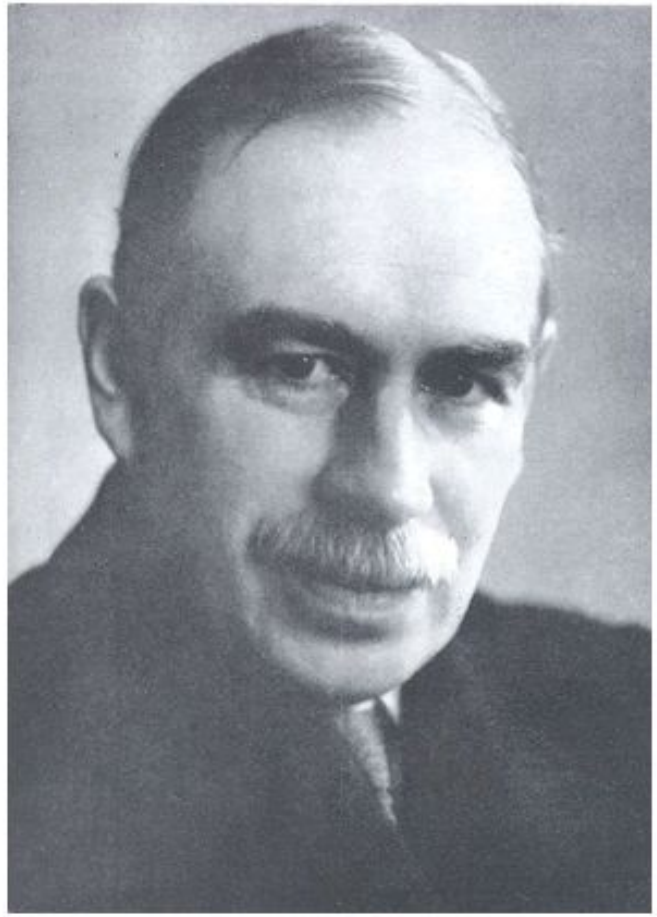
Why do they Want it?

- *Confidence* in areas of unfamiliarity
- *Feeling* of thoroughness, due diligence
- *Desire* for objectivity in decision making
- *Belief* that facts should inform decisions that affect the public welfare, to avoid perception of arbitrary whim

What do they Need?: It depends

- Anecdote
- Case Study
- Valid, powerful data/knowledge
- Leak-proof ethical arguments
- Comprehensive legal/regulatory analysis
- Economic impact assessment





'There is nothing a government hates more than to be well-informed; for it makes the process of arriving at decisions much more complicated and difficult.'

John Maynard Keynes
(1883-1946)

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