De-Identification or Real Identification?

Do the HIPAA De-Identification Provisions Protect Privacy and Security in the Current World?

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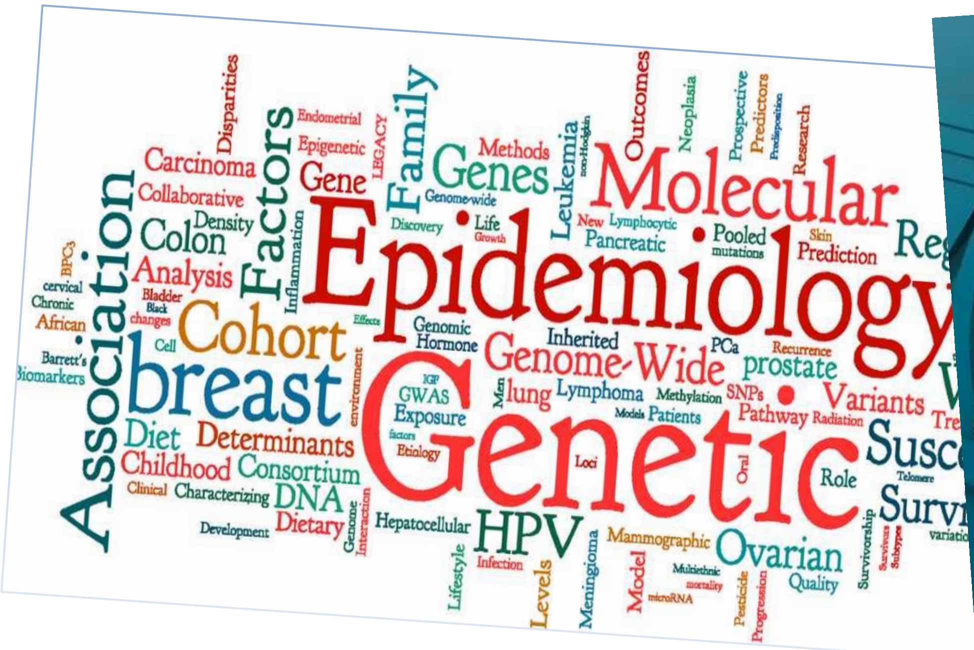
A Historic and Important Societal Debate is underway…



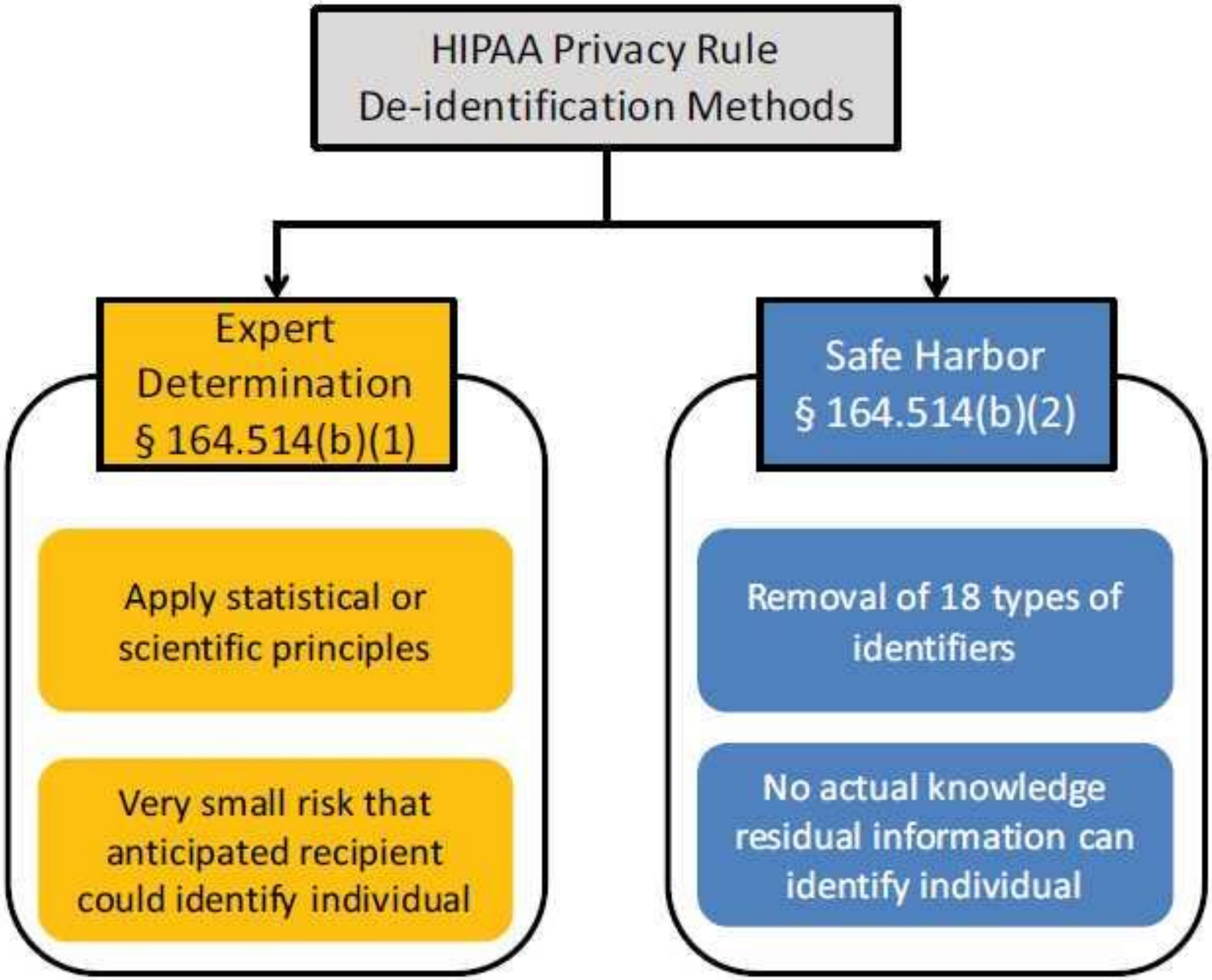
Public Policy Collision Course

The Research Value of De-identified Health Data

The Societal Value of De-identified Data

- Properly de-identified health data is an ***invaluable "public good"***. *The broad availability of de-identified data is an essential tool for society supporting scientific innovation and health system improvement and efficiency.*
- De-identified data does and can serve as the engine driving forward innumerable essential health systems improvements: quality improvement, health systems planning, healthcare fraud, waste and abuse detection, and medical/public health research (e.g. comparative effectiveness research, adverse drug event monitoring, patient safety improvements and reducing health disparities).
- De-identified health data greatly benefits our society and provides strong privacy protections for the individuals. As the promise of EHRs and Health IT yields richer de-identified clinical data, the progress of our nation's healthcare reform will likely be built on a foundation of such de-identified health data.

Two Methods of HIPAA De-identification



HIPAA §164.514(b)(2)(i) -18 “Safe Harbor” Exclusions

All of the following must be **removed in order** for the information **to be** considered **de-identified.**

(2)(i) The **following identifiers of the individual or of relatives, employers, or household members** of the individual, are removed:

(A) Names;

(B) All **geographic subdivisions smaller than a State**, including street address, city, county, precinct, zip code, and their equivalent geocodes, **except for the initial three digits of a zip code** if, according to the current publicly available data from the Bureau of the Census: (*1*) The geographic unit formed by combining all zip codes with the same three initial digits contains **more than 20,000 people**; and (*2*) The initial three digits of a zip code for all such geographic units containing 20,000 or fewer people is changed to 000.

(C) **All elements of dates (except year)** for dates directly related to an individual, including **birth date**, **admission date**, **discharge date, date of death**; and **all ages over 89** and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older;

(D) Telephone numbers;

(E) Fax numbers;

(F) Electronic mail addresses;

(G) Social security numbers;

(H) **Medical record numbers**;

(I) **Health plan beneficiary numbers**;

(J) Account numbers;

(K) Certificate/license numbers;

(L) Vehicle identifiers and serial numbers, including license plate numbers;

(M) **Device identifiers and serial numbers**;

(N) Web Universal Resource Locators (URLs);

(O) Internet Protocol (IP) address numbers;

(P) Biometric identifiers, including finger and voice prints;

(Q) Full face photographic images and any comparable images; and

(R) **Any other unique identifying number, characteristic, or code** except as permitted in §164.514(c)

Limits of Safe Harbor De-identification

- Full Dates and detailed Geography are often critical
- Challenging in complex data sets
  - Safe Harbor rules prohibiting Unique codes (§164.514(2)(i)(R)) unless they are not “derived from or related to information about the individual”(§164.514(c)(1)) can create significant complications for:
    - Preserving referential integrity in relational databases
    - Creating longitudinal de-identified data
- Encryption does not equal de-identification
  - Encryption of PHI, rather than its removal - as required under safe harbor, will not necessarily result in de-identification
- Not suitable for “Data Masking”
  - Removal requirement in 164.514(b)(2)(i)
  - Software development requires realistic “fake” data which can pose re-identification risks if not properly managed

Expert Determination Data Set (EDDS) = Statistical De-identification Data Set (SDDS)

- *Expert Determination* (or *Statistical De-identification)* often can be used to release some of the safe harbor "prohibited identifiers" provided that the risk of re-identification is ***"very small"***.
- For example, more detailed *geography*, *dates of service* or *encryption* codes could possibly be used within statistical de-identified data sets based on statistical disclosure analyses showing that the risks are very small.
- However, disclosure analyses must be conducted to assess risks of re-identification

  (e.g., encrypted data with strong statistical associations to unencrypted data can pose important re-identification risks)

HIPAA Expert Determination Conditions

- “Risk is ***very small…”***
  - “that the ***information could be used***”…
  - “alone or ***in combination with other reasonably available information***”…,
  - “***by an anticipated recipient***”…
  - “***to identify an individual***”…

Permissible “Very Small” Risk

- HIPAA Privacy Rule permits a covered entity or its business associate to use and disclose information that it *does not provide a reasonable basis to identify* an individual.
- Even when de-identification is properly applied, it will yield data that retains some risk of identification. Although the risk is very small, it is not zero.
- There is some possibility that de-identified data could be linked back to the identity of the patient.

57 UCLA LAW REVIEW 1701 (2010)

BROKEN PROMISES OF PRIVACY: RESPONDING TO THE SURPRISING FAILURE OF ANONYMIZATION

Paul Ohm*

Computer scientists have recently undermined our faith in the privacy-protecting power of anonymization, the name for techniques that protect the privacy of individuals in large databases by deleting information like names and social security numbers. These scientists have demonstrated that they can often "reidentify" or "deanonymize" individuals hidden in anonymized data with astonishing ease. By understanding this research, we realize we have made a mistake, labored beneath a fundamental misunderstanding, which has assured us much less privacy than we have assumed. This mistake pervades nearly every information privacy law, regulation, and debate, yet regulators and legal scholars have paid it scant attention. We must respond to the surprising failure of anonymization, and this Article provides the tools to do so.

Misconceptions about HIPAA De-identified Data:

"It doesn't work…" "easy, cheap, powerful re-identification" (Ohm, 2009 "*Broken Promises of Privacy*")

****Pre-HIPAA*** Re-identification Risks {Zip5, Birth date, Gender} able to identify 87%?, 63%, 28%? of US Population (Sweeney, 2000, Golle, 2006, Sweeney, 2013)

- Reality: HIPAA compliant de-identification provides important privacy protections
  - Safe harbor re-identification risks have been estimated at 0.04% (4 in 10,000) (Sweeney, NCVHS Testimony, 2007)
- Reality: Under HIPAA de-identification requirements, re-identification is expensive and time-consuming to conduct, requires substantive computer/mathematical skills, is rarely successful, and usually uncertain as to whether it has actually succeeded

Misconceptions about HIPAA De-identified Data:

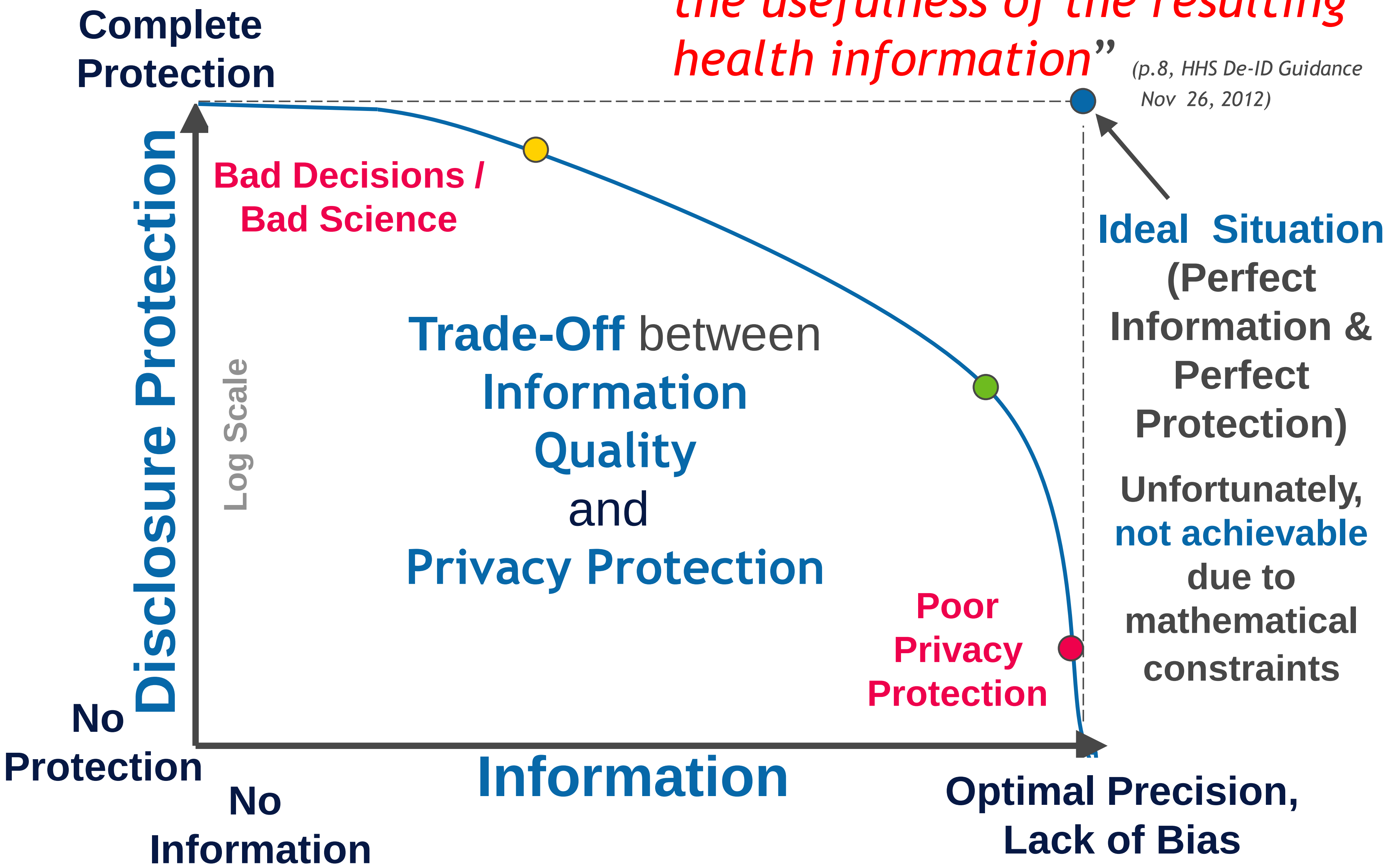
"It works perfectly and permanently…"

- Reality:
  - Perfect de-identification is not possible.
  - De-identifying does not free data from all possible subsequent privacy concerns.
  - Data is never permanently "de-identified"…

    There is no 100% guarantee that de-identified data will remain de-identified regardless of what you do with it after it is de-identified.

The Inconvenient Truth:

"*De-identification leads to information loss which may limit the usefulness of the resulting health information*" *(p.8, HHS De-ID Guidance Nov 26, 2012)*



Essential Re-identification Concepts

- Essential Re-identification and Statistical Disclosure Concepts
  - Record Linkage
  - Linkage Keys (Quasi-identifiers)
  - *Sample Uniques* and *Population Uniques*
- Straightforward Methods for Controlling Re-identification Risk
  - Decreasing Uniques:
    - by Reducing Key Resolutions
    - by Increasing Reporting Population Sizes

Quasi-identifiers

While individual fields may not be identifying by themselves, the contents of several fields in combination may be sufficient to result in identification, the set of fields in the Key is called the set of ***Quasi-identifiers***.

Name	Address	Gender	Age	Ethnic Group	Marital Status	Geo-graphy

^------- Quasi-identifiers ---------^

Fields that should be considered part of a Quasi-identifier are those variables which would be likely to exist in "reasonably available" data sets along with actual identifiers (names, etc.).

Note that this includes even fields that are not "PHI".

Key Resolution

Key “*resolution*” increases with:

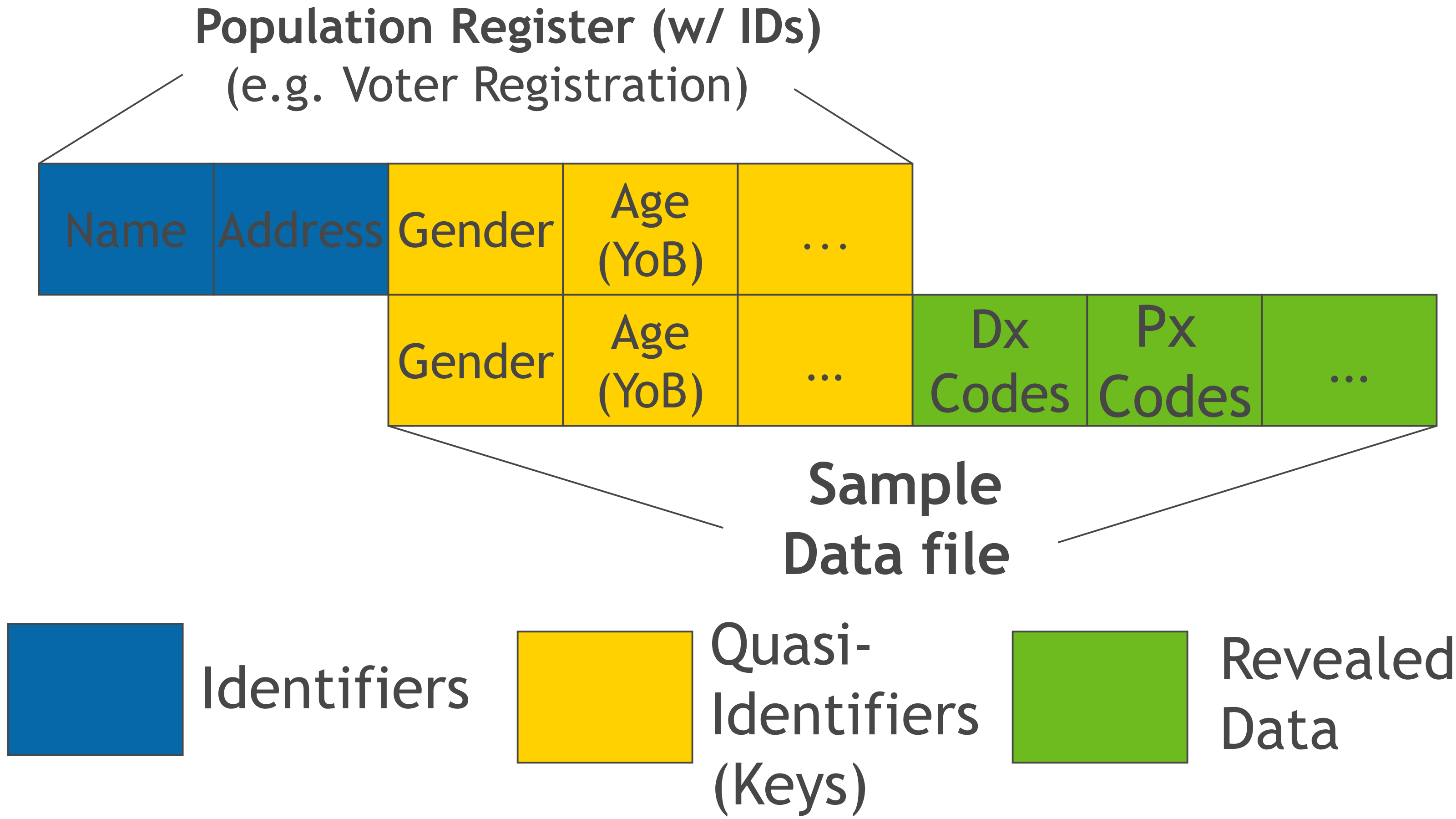
1) the number of matching fields available

2) the level of detail within these fields. (e.g. Age in Years versus complete Birth Date: Month, Day, Year)

Name	Address	Gender	Full DoB	Ethnic Group	Marital Status	Geo-graphy		
		Gender	Full DoB	Ethnic Group	Marital Status	Geo-graphy	Dx Codes	Px Codes

Record Linkage

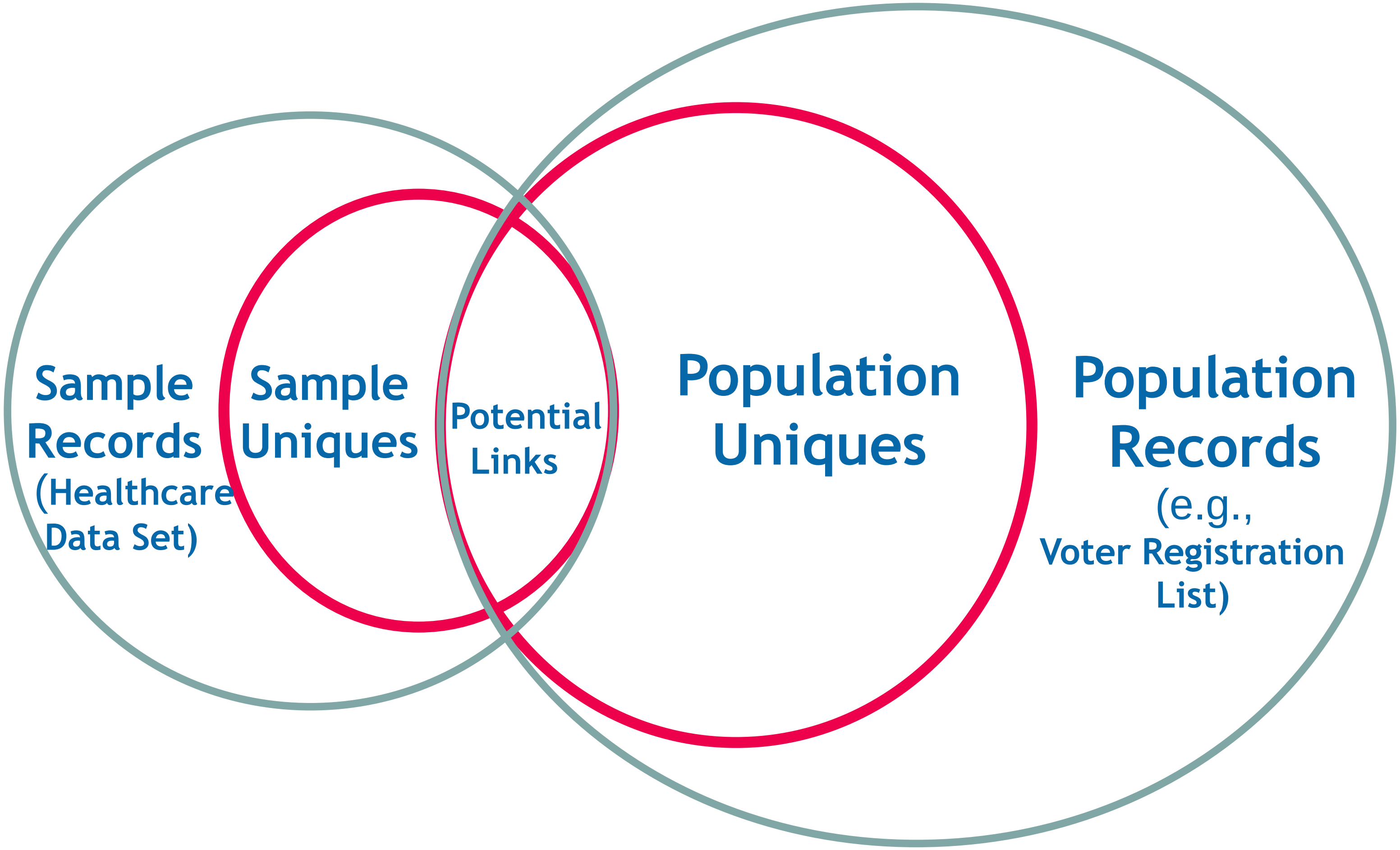
Record Linkage is achieved by matching records in separate data sets that have a common "Key" or set of data fields.



Sample and *Population Uniques*

- When only one person with a particular set of characteristics exists within a given data set (typically referred to as the ***sample*** data set), such an individual is referred to as a "***Sample Unique***".
- When only one person with a particular set of characteristics exists within the entire population or within a defined area, such an individual is referred to as a "***Population Unique***".

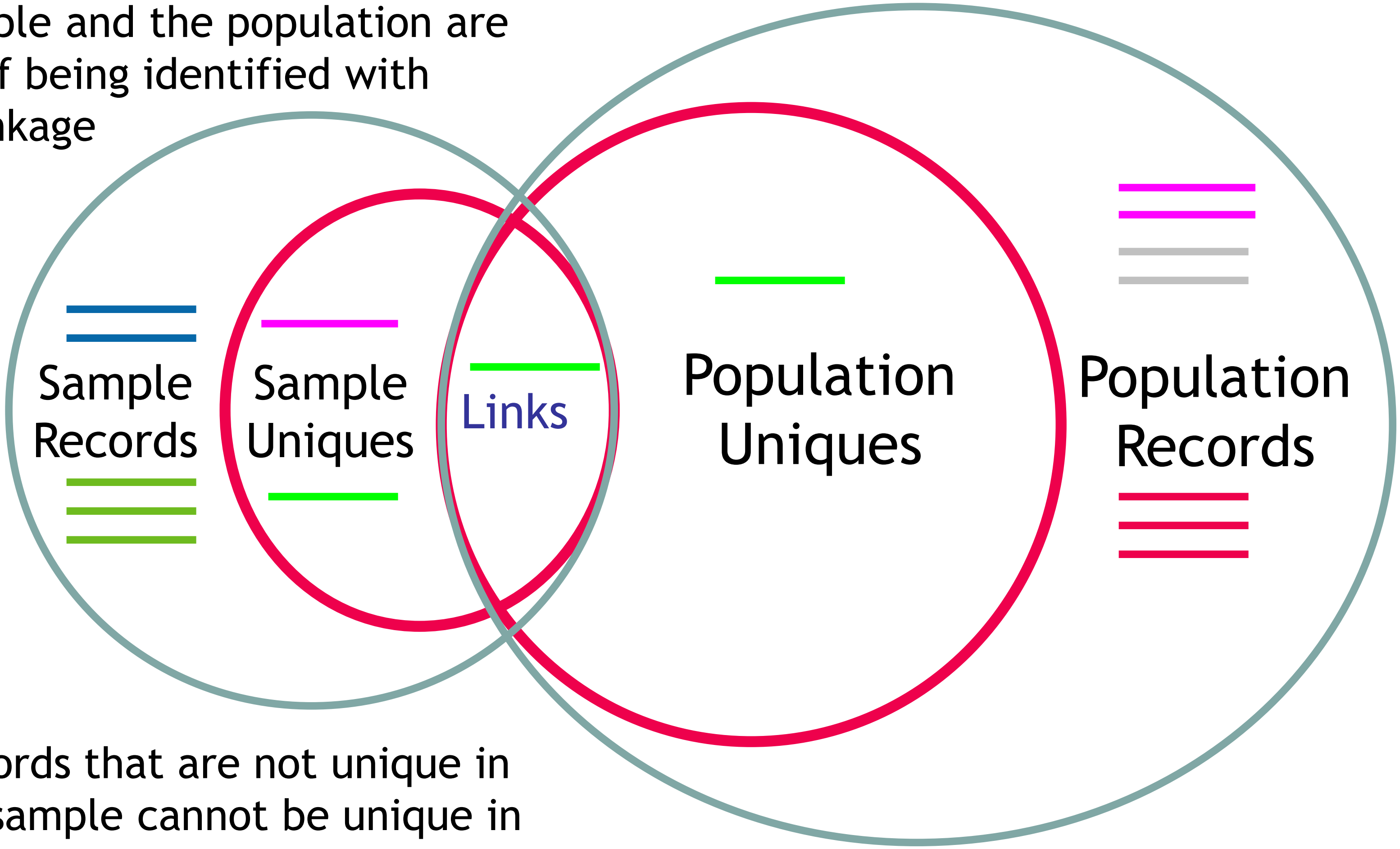
Measuring Disclosure Risks



Linkage Risks

Records that are unique in the sample but which aren't unique in the population, would match with more than one record in the population, and only have a probability of being identified

Only records that are unique in the sample and the population are at risk of being identified with exact linkage

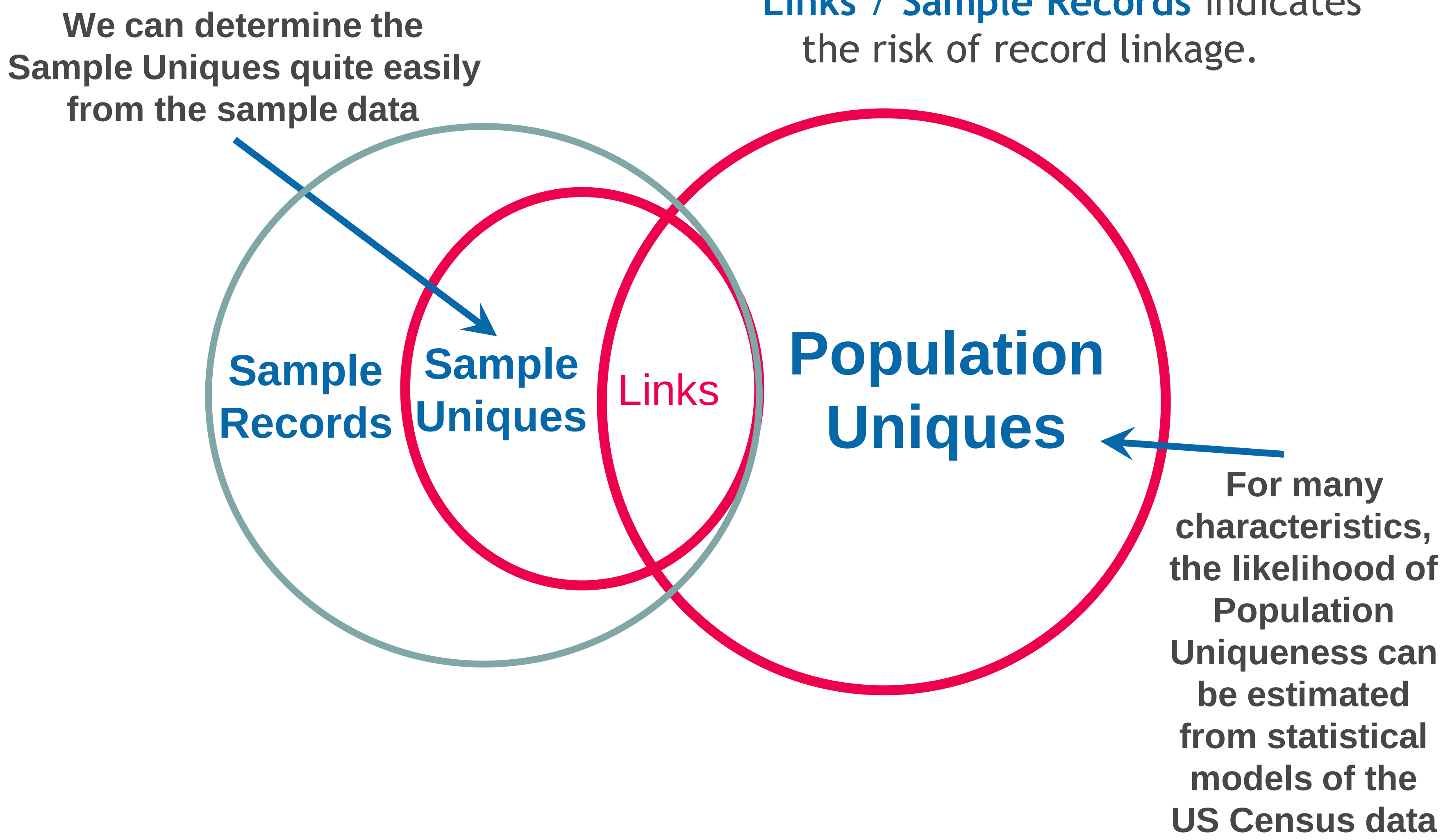


Records that are not unique in the sample cannot be unique in the population and, thus, aren't at definitive risk of being identified

Records that are not in the sample also aren't at risk of being identified

Estimating Disclosure Risks

Links / Sample Records indicates the risk of record linkage.



Reducing Disclosure Risks

- Application of distortion based methods in frequently updated data sets is non-trivial, and, therefore, typically expensive and logistically complicated to implement, requiring complex data management operations to assure proper application.
- Because of such logistic complications, the two simplest methods for reducing disclosure risks are also the most practical when protecting privacy in data streams.
- The two most basic methods of reducing disclosure risks involve:
  - Reducing Key Resolution
  - Increasing Reporting Unit Populations

Basic Solutions: *Reducing Key Resolutions*

- Reducing *Key Resolution* will both reduce the proportion of Sample Uniques in the data set (or data stream) and the probability that an individual is Population Unique with regard to the re-identification key.
- Key Resolution can be reduced either by:
  – Reducing the number of Quasi-identifiers that are released (i.e., restrict number of variables reported),

  or by

  – Reducing the number of categories or values within a Quasi-Identifier (e.g., report Year of Birth rather than complete birth date).

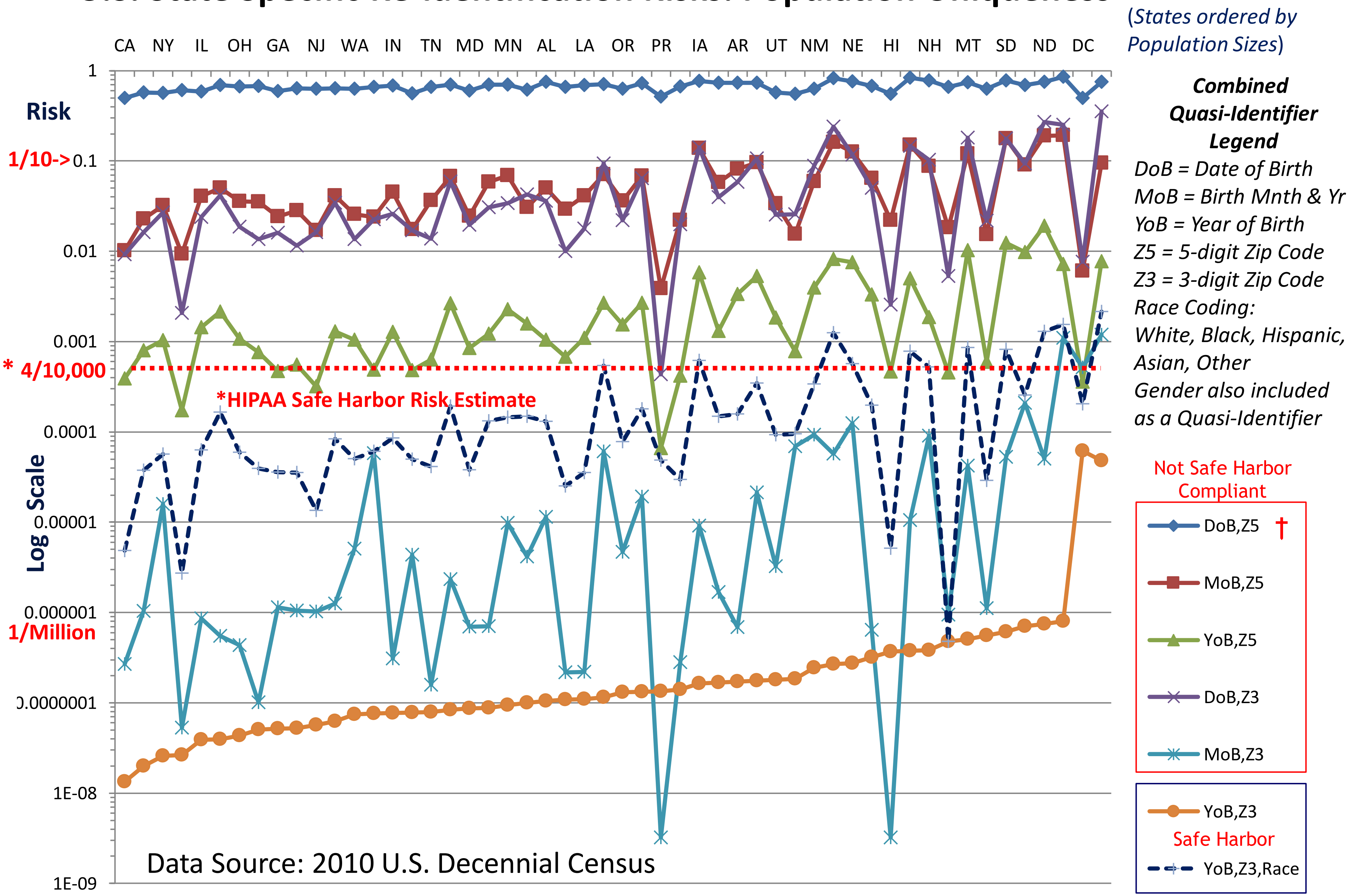
Basic Solutions: *Increasing the Population Sizes of Geographic Reporting Units*

- Another easily implemented solution for reducing disclosure risks is simply to impose a requirement for minimum population sizes within any geographic reporting units.
- Example: the Safe Harbor provision specifies that the only geographic units smaller than the State that are reportable under safe harbor de-identification are 3-digit Zip Codes containing populations of more than 20,000 individuals.
- However, statistical disclosure ***risk analyses should be conducted*** in order to assure that appropriate thresholds have been selected and that these thresholds will result in very small disclosure risks ***for the specific key resolutions*** of the set of variables which are to be reported.

Basic Solutions:
Increasing Sizes of Reporting Units, cont'd.

- Using larger population sizes for geographic reporting areas is an important method of controlling disclosure risks because increasing the reporting population size decreases the probability of an individual being unique within the reporting area and, thus, the risk of re-identification.
- Ideally, any method for restricting the reporting of geographic information should allow reporting on all (or most) of the population, but the level of geographic resolution would be scaled to the underlying population density to control disclosure risks.

U.S. State Specific Re-identification Risks: Population Uniqueness



Graph © DB-J 2013

† HIPAA Safe Harbor does not permit any Dates more specific than the year, or Geographic Units smaller than 3-digit Zip Codes (Z3).

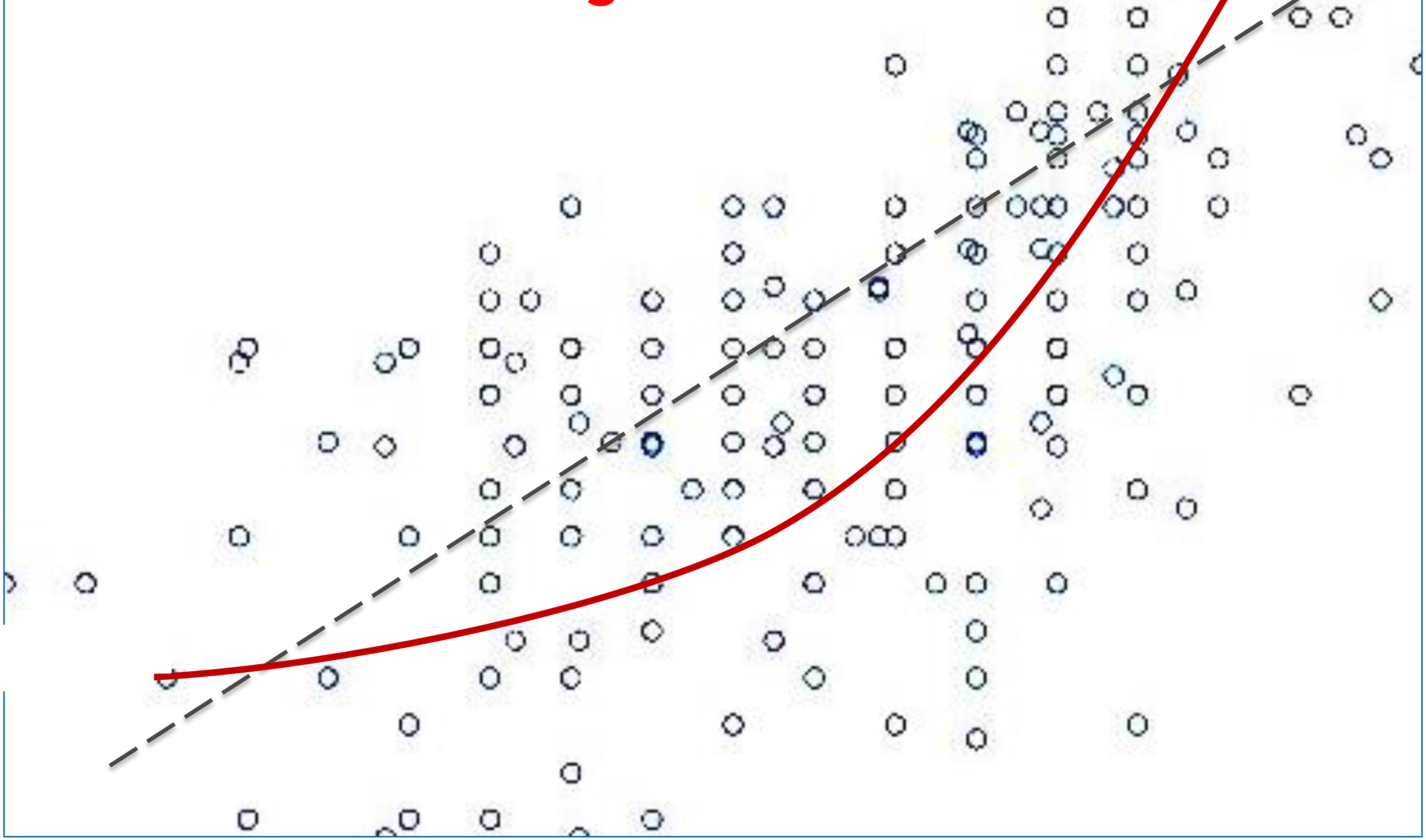
Balancing Disclosure Risk/Statistical Accuracy

- Balancing disclosure risks and statistical accuracy is essential because some popular de-identification methods (e.g. k-anonymity) can unnecessarily, and often undetectably, degrade the accuracy of de-identified data for multivariate statistical analyses or data mining (distorting variance-covariance matrixes, masking heterogeneous sub-groups which have been collapsed in generalization protections)
- This problem is well-understood by statisticians, but not as well recognized and integrated within public policy.
- Poorly conducted de-identification can lead to "bad science" and "bad decisions".

Reference: C. Aggarwal http://www.vldb2005.org/program/paper/fri/p901-aggarwal.pdf

Separating the Signal from the Noise

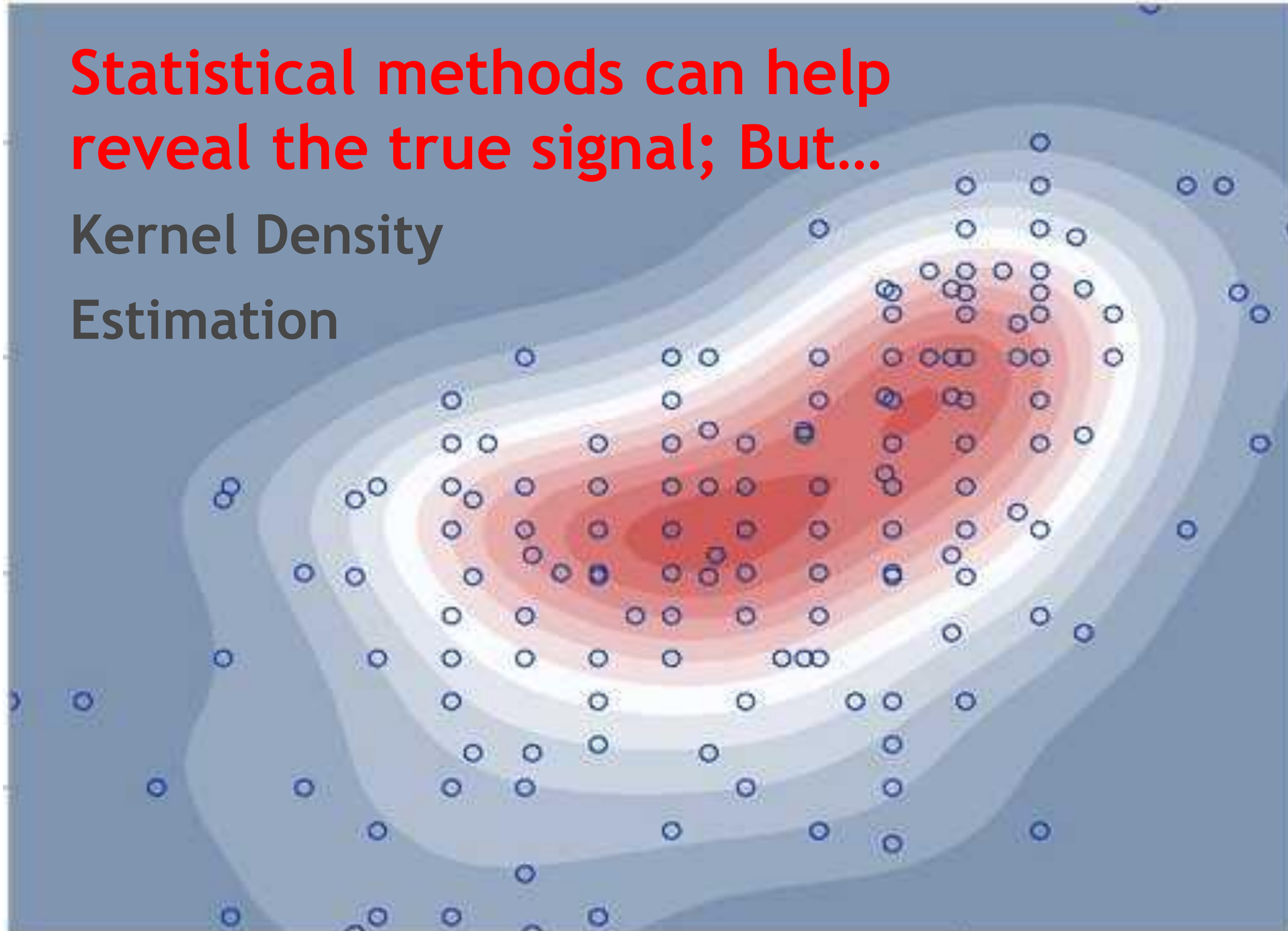
Which is the true signal here?



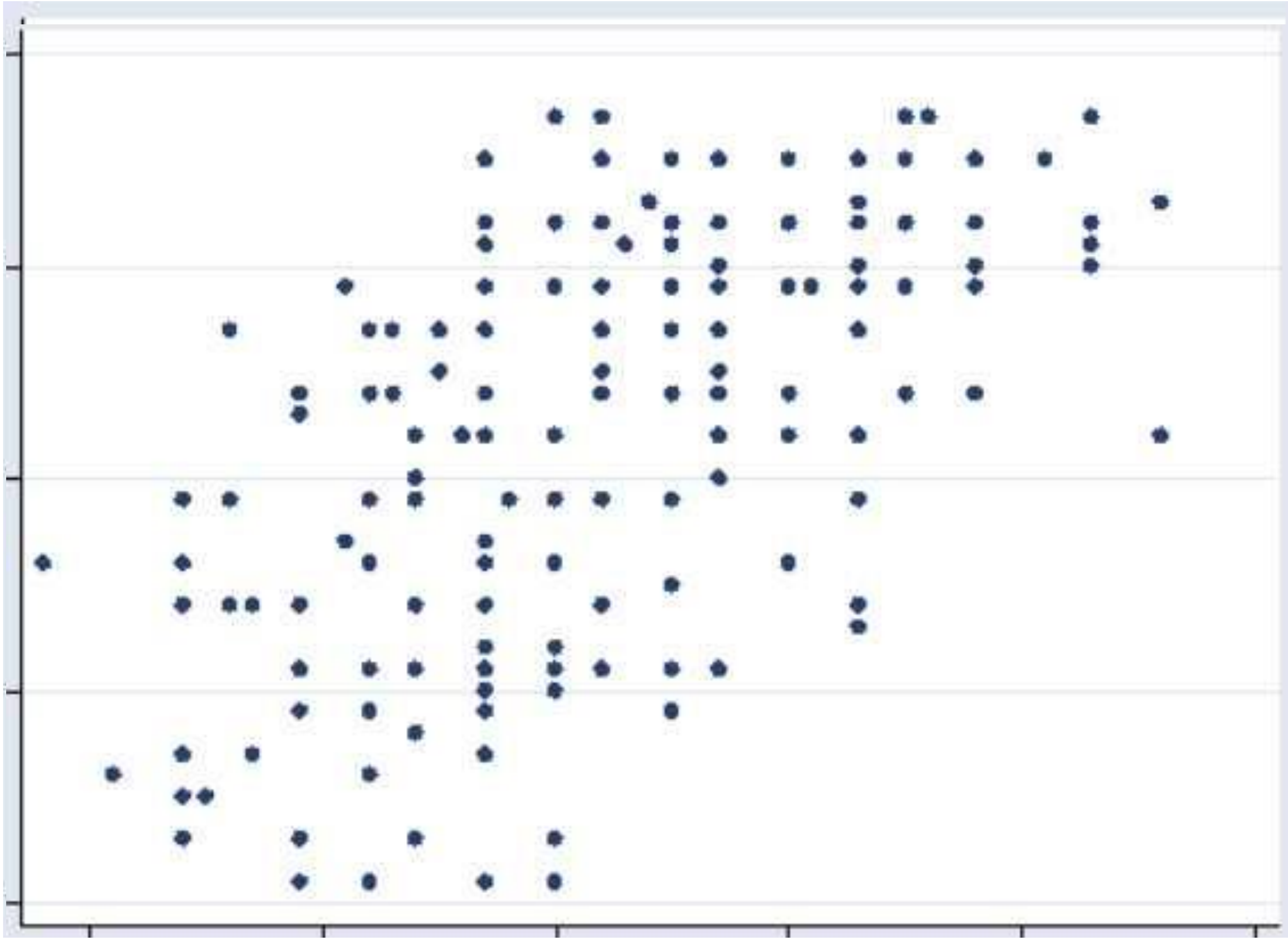
Statistical methods can help reveal the true signal; But…

Kernel Density

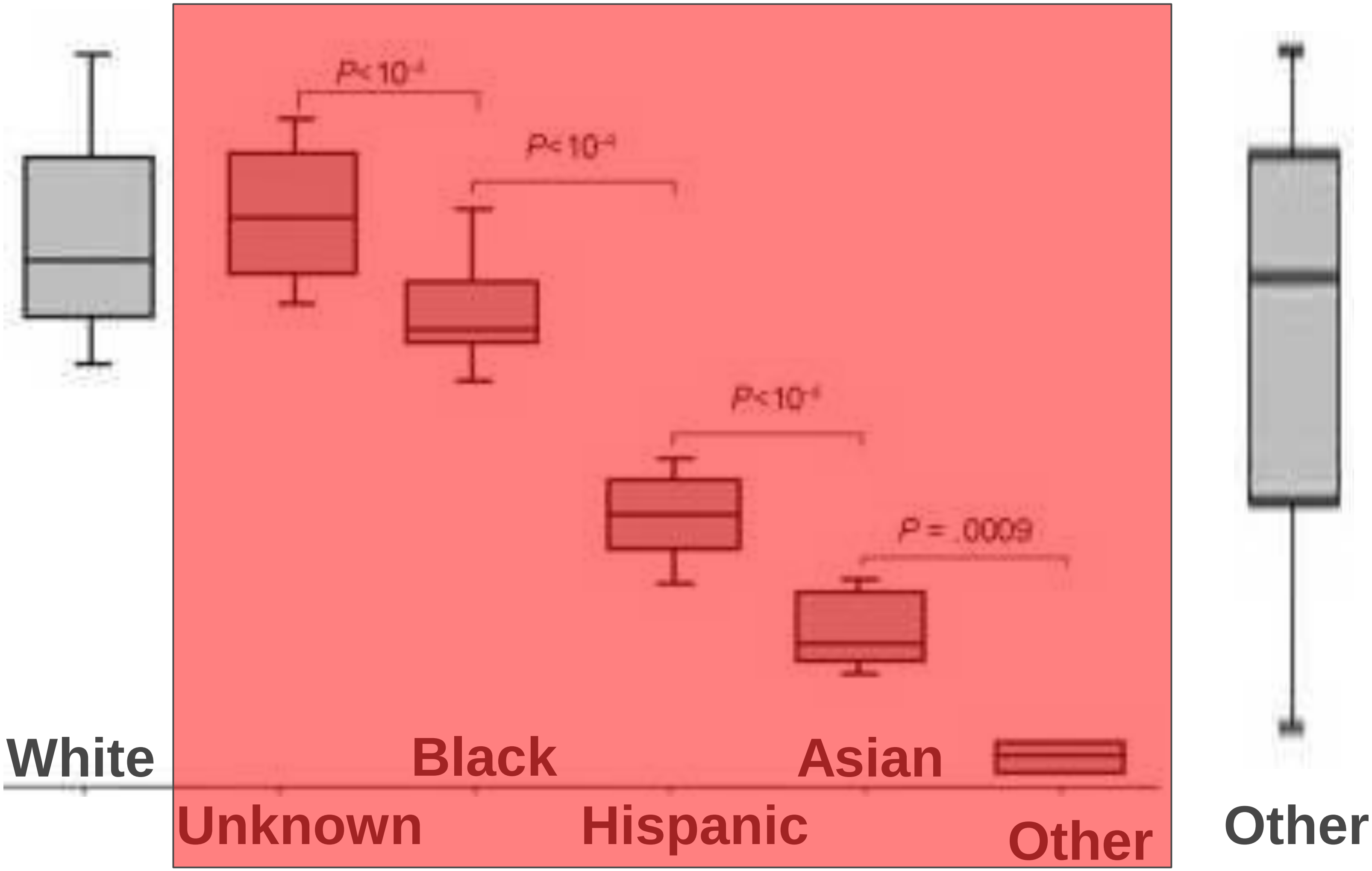
Estimation



K-anonymity Can Distort Multivariate Relationships



De-identification Can Hide Important Differences



Percent of Regression Coefficients which changed Significance:

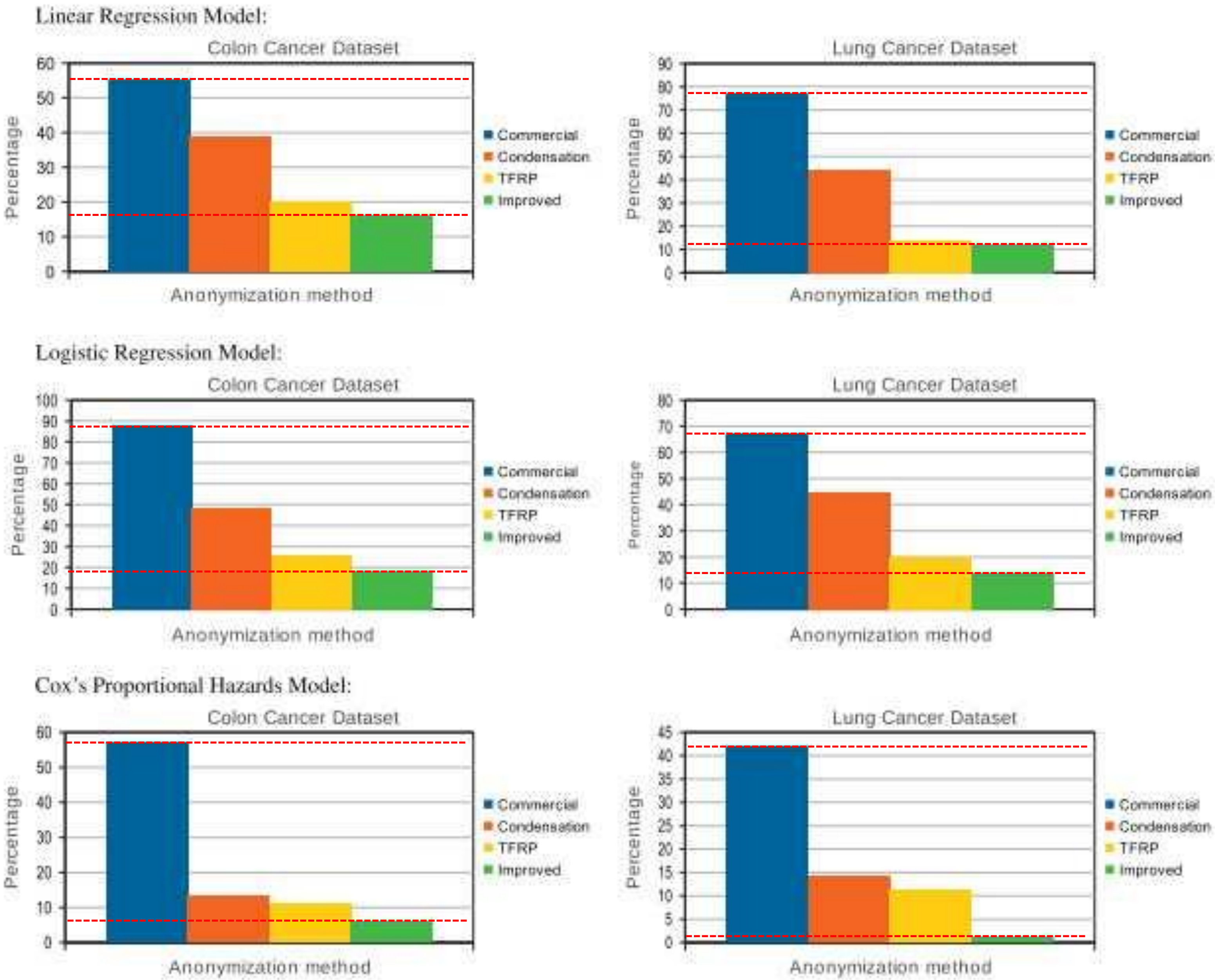
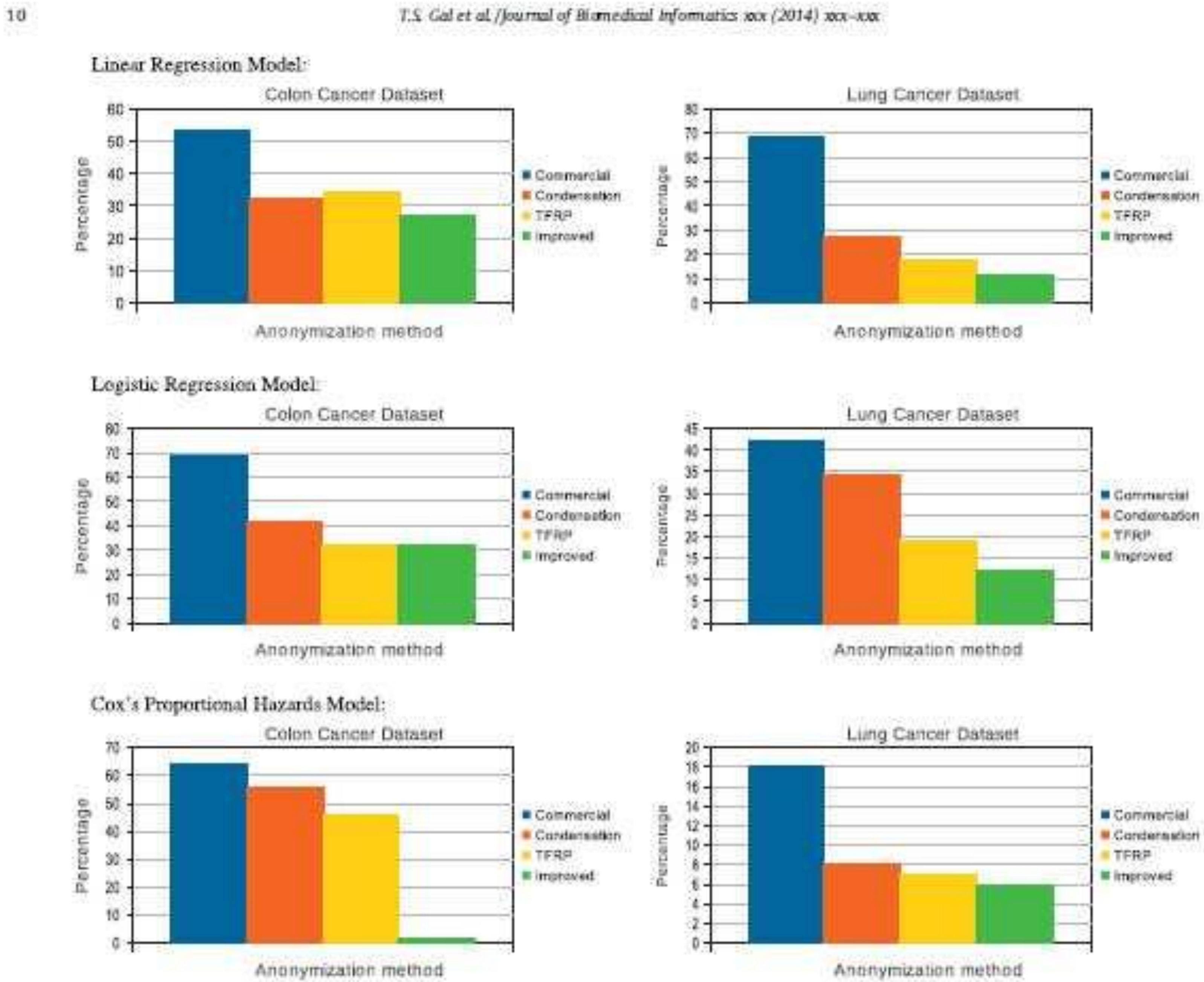


Fig. 1. Coefficients changed significance.



Significant Coefficients changed Direction

If this is what we are going to do to our ability to conduct accurate research - then… we should all just give up and go home.

- Although poorly conducted de-identification can distort our ability to learn what is true leading to “bad science/decisions”, this does not need to be an inevitable outcome.
- Well-conducted de-identification practice always carefully considers both the re-identification risk context and examines and controls the possible distortion to the statistical accuracy and utility of the de-identified data to assure de-identified data has been appropriately and usefully de-identified.
- But doing this requires a firm understanding/grounding in the extensive body of the statistical disclosure control/limitation literature.

Successful Solutions:
Balancing Disclosure Risk and Statistical Accuracy

- When appropriately implemented, statistical de-identification seeks to protect and balance two vitally important societal interests:
  - 1) Protection of the privacy of individuals in healthcare data sets, (Disclosure or Identification Risk), and
  - 2) Preserving the utility and accuracy of statistical analyses performed with de-identified data (Loss of Information).
- Limiting disclosure inevitably reduces the quality of statistical information to some degree, but the appropriate disclosure control methods result in small information losses while substantially reducing identifiability.

Data Privacy Concerns are Far Too Important (and Complex) to be summed up with Catch Phrases or "Anecdata"

Eye-catching headlines and twitter-buzz announcing "*There's No Such Thing as Anonymous Data*" might draw the public's attention to broader and important concerns about data privacy in this era of "Big Data",

but such statements are essentially meaningless, even misleading, for further generalization without consideration of the specific de/re-identification contexts -- including the precise data details (e.g., number of variables, resolution of their coding schemas, special data properties, such as spatial/geographic detail, network properties, etc.) de-identification methods applied, and associated experimental design for re-identification attack demonstrations.

Good Public Policy demands reliable scientific evidence…

57 UCLA LAW REVIEW 1701 (2010)

BROKEN PROMISES OF PRIVACY: RESPONDING TO THE SURPRISING FAILURE OF ANONYMIZATION

Paul Ohm*

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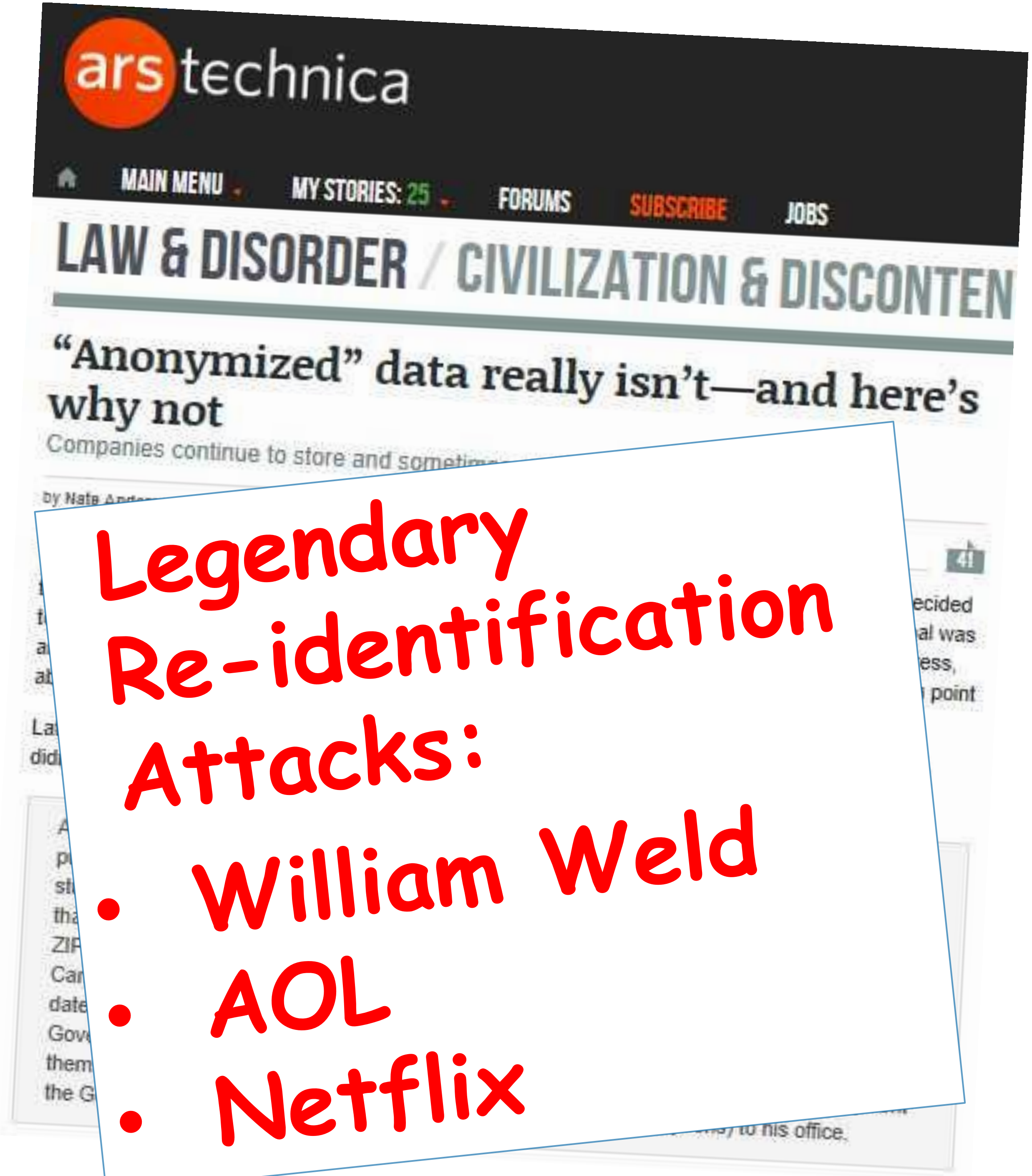


Legendary Re-identification Attacks:

- William Weld
- AOL
- Netflix

Unfortunately, de-identification public policy has often been driven by largely anecdotal and limited evidence, and re-identification demonstration attacks targeted to particularly vulnerable individuals, which fail to provide reliable evidence about real world re-identification risks

Re-identification Demonstration Attack Summary

Re-identification Attacks	Quasi-Identifers (w/ HIPAA Safe Harbor exclusion data in Red)	Vulnerable Subgroup Targeted?	Used Stat. Sampling	Individuals w/ Alleged/Verified Re-identification	At-Risk Sample Size	Notable Headlines & Quotes	Attack Against HIPAA Compliant (or SDL Protected) Data?	Demonstrated Re-identification Risk
Governor Weld [1,2]	Zip5, Gender, DoB	Yes	No	n=1	99,500	*"Anonymized" Data Really Isn't* [27]	No	0.00001
AOL [3]	Free Text from Search Queries w/ Name, Location, etc	Yes	No	n=1	657,000	*A Face is Exposed* [3]	No	0.0000015
Netflix [4]	Movie Ratings & Dates	Yes	No	n=2	500,000	*"…successfully identified 99% of people in Netflix database"* [28]	No	0.000004
ONC Safe Harbor [5]	Zip3, YoB, Gender, Marital Status, Hispanic Ethnicity	No	N/A	n=2	15,000	[Press Did Not Cover This Study]	Yes	0.00013
Heritage Health Prize [6,7,8,9]	Age, Sex, Days in Hospital, Physician Specialty, Place of Service, CPT Code, Days Since First Claim, ICD-9 Diagnosis	Yes	No	n=0	113,000	*To best of my judgment, reidentification is within realm of possibility* [8] *El Emam estimated < 1% of Pts could be re-identified. Narayanan estimated > 12% of Pts were identifiable.* [29]	Yes	0.0
Y-Chromosome STR Surname Inference [10,11] - Simulation Study Part	Y-STR DNA Sequences* Age in Years & State	No	N/A, Simulation	Not Attempted: Simulated Results	~150 Million US Males	*"nice example of how simple it is to re-identify de-identified samples"* [30]	*No? (Safe Harbor vs. Expert Determination)	.12 (For Males Only), after accounting for 30% False Positive Rate
- CEU Attack Part	Age, Utah State, Genealogy Pedigrees & Mormon Ancestry	Yes, Highly Targeted	No	n=5 w/ Y-STR Alone, (but w/ Geneology Amplification n=50)	?	*DNA Hack Could Make Medical Privacy Impossible* [31]	**Safe Harbor Excludes: Any unique identifying #, characteristic or code*	Not Clearly Calculable for CEU Attack
Personal Genome Project [12,13,14]	Zip5, Gender, DoB	No	N/A	n=161	579	*"…re-identified names of > 40% anonymous participants"* [32] *re-identified 84 to 97% of sample of PGP volunteers* [33]	No	0.28 (w/ Embedded Names Excluded)
Washington St. Hospital Discharge [15,16]	Hospital Data w/ Diagnoses, Zip5, Month/Yr of Discharge	Yes	No	n=40 (8 verified) from 81 News Reports	648,384	*"…how new stories about hospital visits in Washington State leads to identifying matching health record 43% of the time"* [34]	No	0.000062
Cell Phone "Unicity" [17]	High Resolution Time (Hours) and Cell Tower Location	No	N/A	Not Attempted	1.5 Million	*"four spatio-temporal points enough to uniquely identify 95%"* [17]	No	0.0
NYC Taxi [18,19]	High Resolution Time (Minutes) and GPS Locations	Yes	No	n=11	173 Million Rides	*How Big Brother Watches You With Metadata* [35]	No	0.0000001
Credit Card "Unicity" [20,21,22,23,24,25,26]	High Resolution Time (Days), Location and Approx. Price	No	N/A	Not Attempted	1.1 Million	*With a Few Bits of Data, Researchers Identify 'Anonymous' People* [36]	No	0.0

- *Publicized attacks are on data without HIPAA/SDL de-identification protection.*
- *Many attacks targeted especially vulnerable subgroups and did not use sampling to assure representative results.*
- *Press reporting often portrays re-identification as broadly achievable, when there isn't any reliable evidence supporting this portrayal.*

Re-identification Demonstration Attack Summary

- For Ohm's famous "Broken Promises" attacks (Weld, AOL, Netflix) a total of n=4 people were re-identified out of 1.25 million.
- For attacks against HIPAA de-identified data (ONC, Heritage*), a total of n=2 people were re-identified out of 128 thousand.
  - ONC Attack Quasi-identifers: Zip3, YoB, Gender, Marital Status, Hispanic Ethnicity
  - Heritage Attack Quasi-identifiers*: Age, Sex, Days in Hospital, Physician Specialty, Place of Service, CPT Procedure Codes, Days Since First Claim, ICD-9 Diagnoses (*not complete list of data available for adversary attack)
  - Both were "adversarial" attacks.
- For all attacks listed, a total of n=268 were re-identified out of 327 million opportunities.

Let's get some perspective on this…

Obviously, This slide is **BLACK**

So clearly, De-identification Doesn't Work.

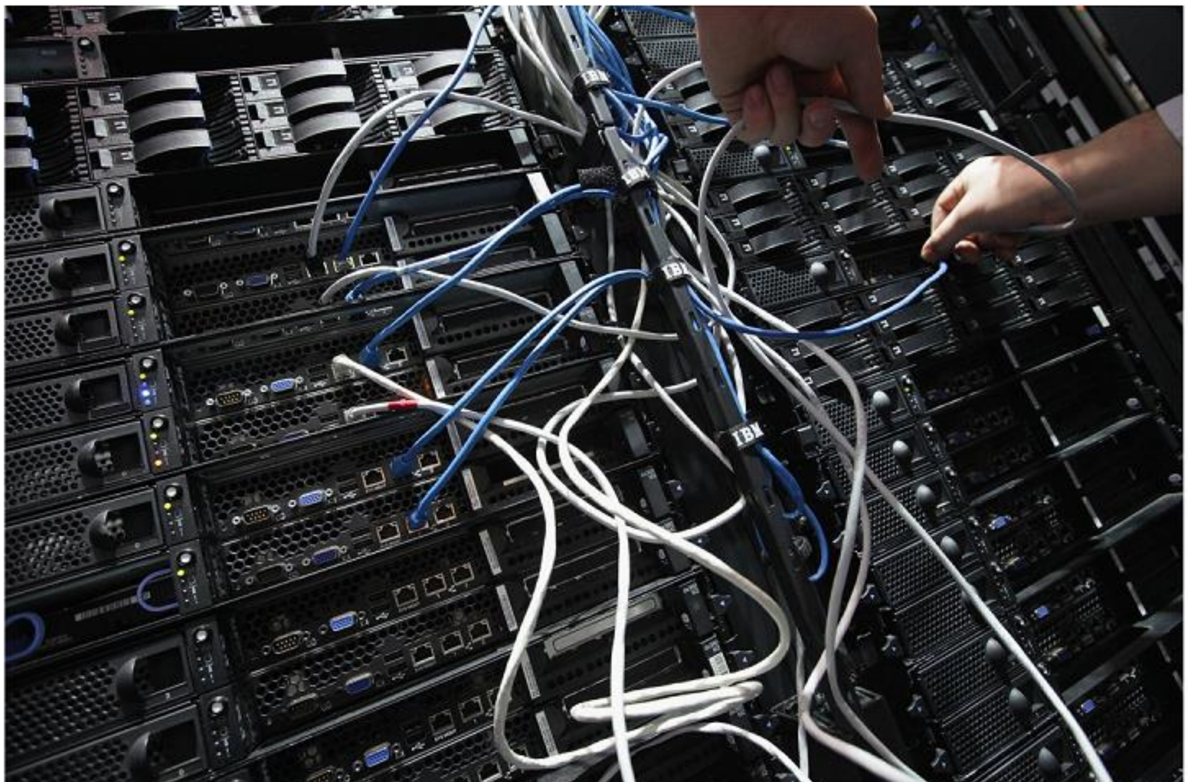
The New York Times

Your Data Were 'Anonymized'? These Scientists Can Still Identify You

By Gina Kolata

July 23, 2019

Computer scientists have developed an algorithm that can pick out almost any American in databases supposedly stripped of personal information.



Scientists have found a way to identify virtually any American from any data set with just 15 attributes, like gender, ZIP code or marital status. Sean Gallup/Getty Images

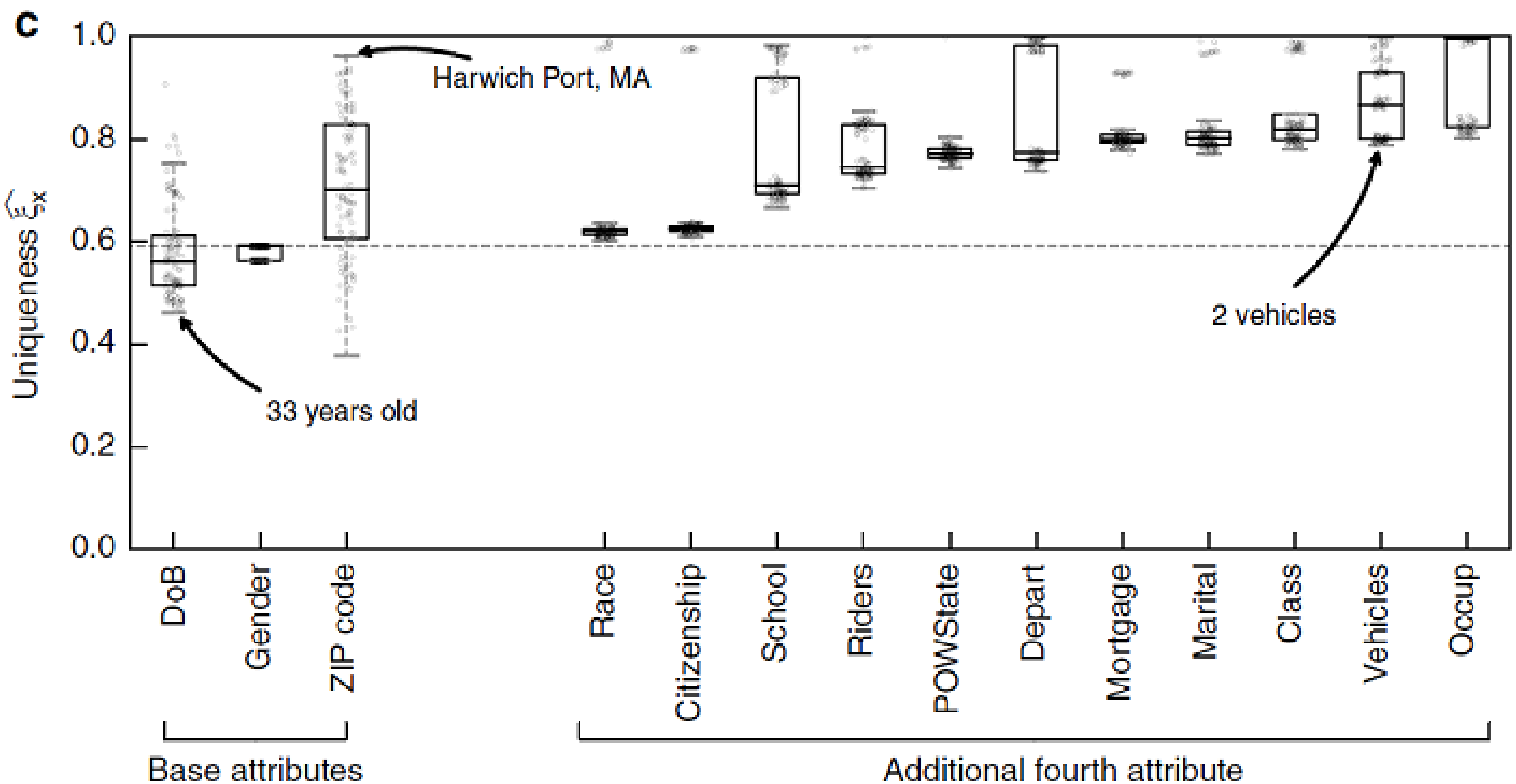
nature COMMUNICATIONS

ARTICLE

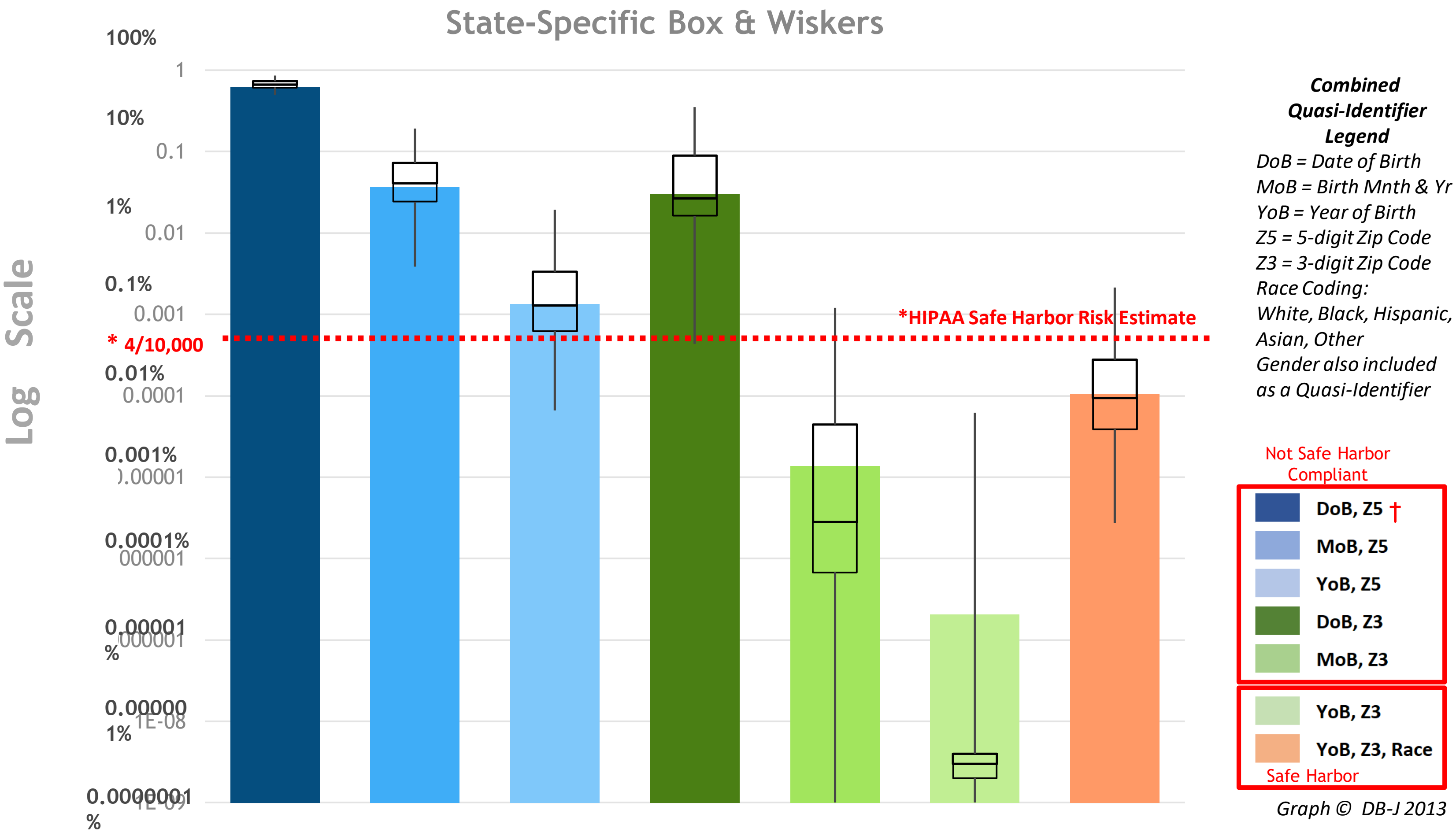
https://doi.org/10.1038/s41467-019-10933-3 OPEN

Estimating the success of re-identifications in incomplete datasets using generative models

Luc Rocher[1,2,3], Julien M. Hendrickx[1] & Yves-Alexandre de Montjoye[2,3]



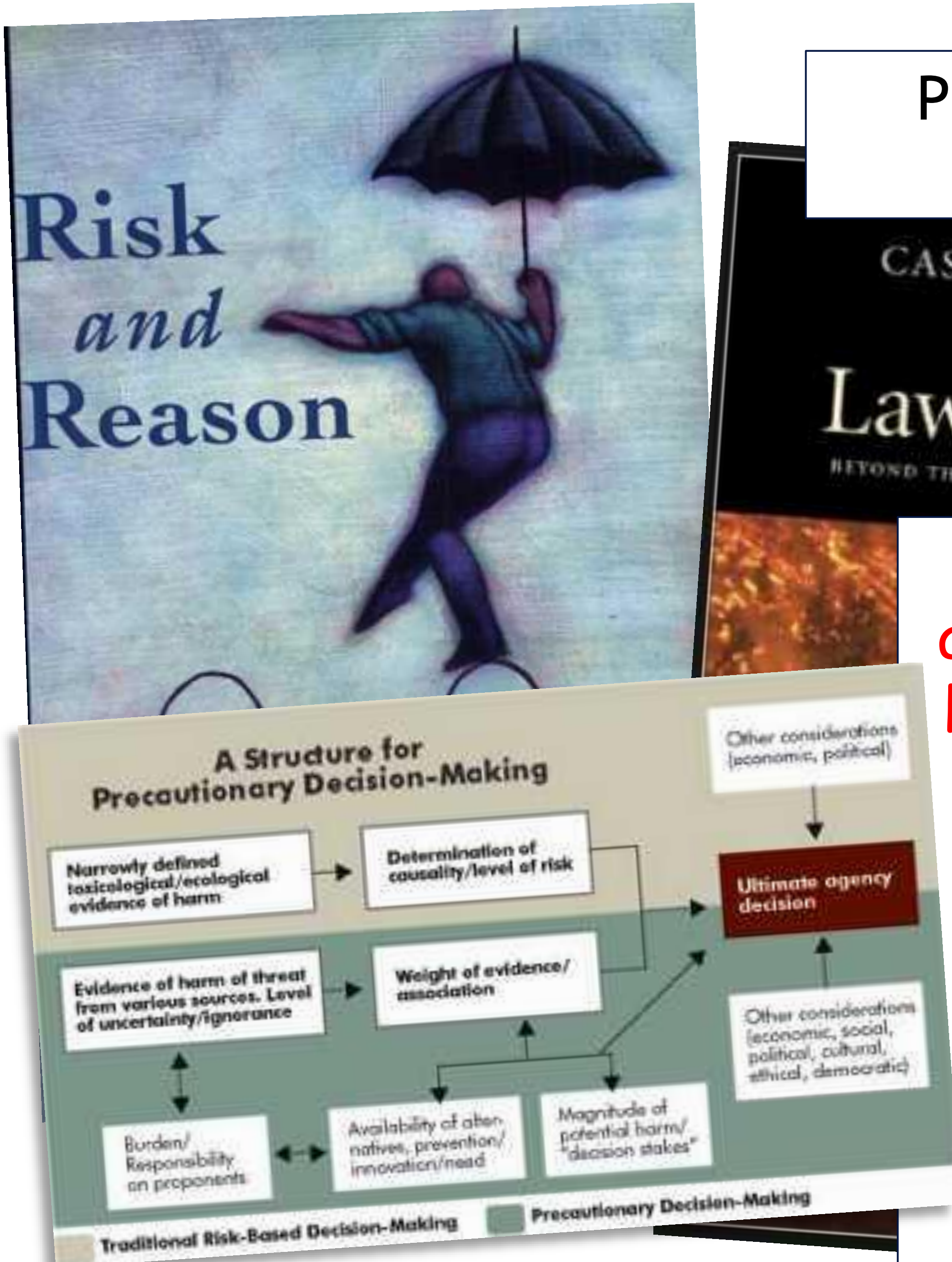
Re-identification Risks: Population Uniqueness



Data Source: 2010 U.S. Decennial Census

† *HIPAA Safe Harbor does not permit any Dates more specific than the year, or Geographic Units smaller than 3-digit Zip Codes (Z3).*

Precautionary Principle or Paralyzing Principle?



"When a re-identification attack has been brought to life, our assessment of the probability of it actually being implemented in the real-world may subconsciously become 100%, which is highly distortive of the true risk/benefit calculus that we face." – DB-J

Re-identification Demonstration Attack Summary

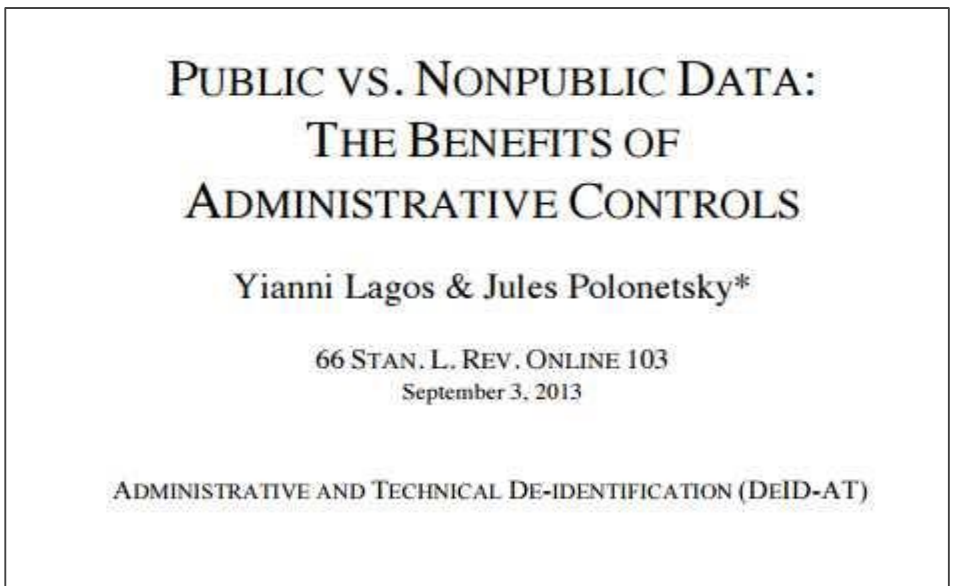
What can we conclude from the empirical evidence provided by these 11 highly influential re-identification attacks?

- The proportion of *demonstrated* re-identifications is extremely small.
- Which ***does not imply data re-identification risks are necessarily very small*** (*especially if the data has not been subject to Statistical Disclosure Limitation methods*).
- But with only 268 re-identifications made out of 327 million opportunities, Ohm's "Broken Promises" assertion that "*scientists have demonstrated they can often re-identify with astonishing ease*" seems rather dubious.
- It also seems clear that the state of "re-identification science", and the "evidence", it has provided needs to be dramatically improved in order to better support good public policy regarding data de-identification.

So, How Do We Move Beyond Anecdotes to a Rigorous, Scientific, Evidence-Based Risk Management Approach for Dealing with Re-identification Risks?

Supplementing Technical Data De-identification with Legal/Administrative Controls

However, in many cases, because of the possibility of highly-targeted demonstration attacks, arriving at solutions which will appropriately preserve the statistical accuracy and utility will also require that we supplement our statistical disclosure limitation "technical" data de-identification methods with additional legal and administrative controls.



PUBLIC VS. NONPUBLIC DATA:
THE BENEFITS OF
ADMINISTRATIVE CONTROLS

Yianni Lagos & Jules Polonetsky*

66 STAN. L. REV. ONLINE 103
September 3, 2013

ADMINISTRATIVE AND TECHNICAL DE-IDENTIFICATION (DEID-AT)

Recommended De-identified Data Use Requirements

Recipients of De-identified Data should be required to:

1) Not re-identify, or attempt to re-identify, or allow to be re-identified, any patients or individuals within the data, or their relatives, family or household members.
2) Not link any other data elements to the data without obtaining determination that the data remains de-identified.
3) Implement and maintain appropriate data security and privacy policies, procedures and associated physical, technical and administrative safeguards to assure that it is accessed only by authorized personnel and will remain de-identified.
4) Assure that all personnel or parties with access to the data agree to abide by all of the foregoing conditions

We also need…

Comprehensive, Multi-sector Legislative Prohibitions Against Data Re-identification

A BILL

To protect the privacy of potentially identifiable personal information by establishing accountability for the use and transfer of potentially identifiable personal information. [Version 4.4]

SECTION 1. SHORT TITLE.

This Act may be cited as the "Personal Data Deidentification Act".

SEC. 2. DEFINITIONS.

As used in this Act:

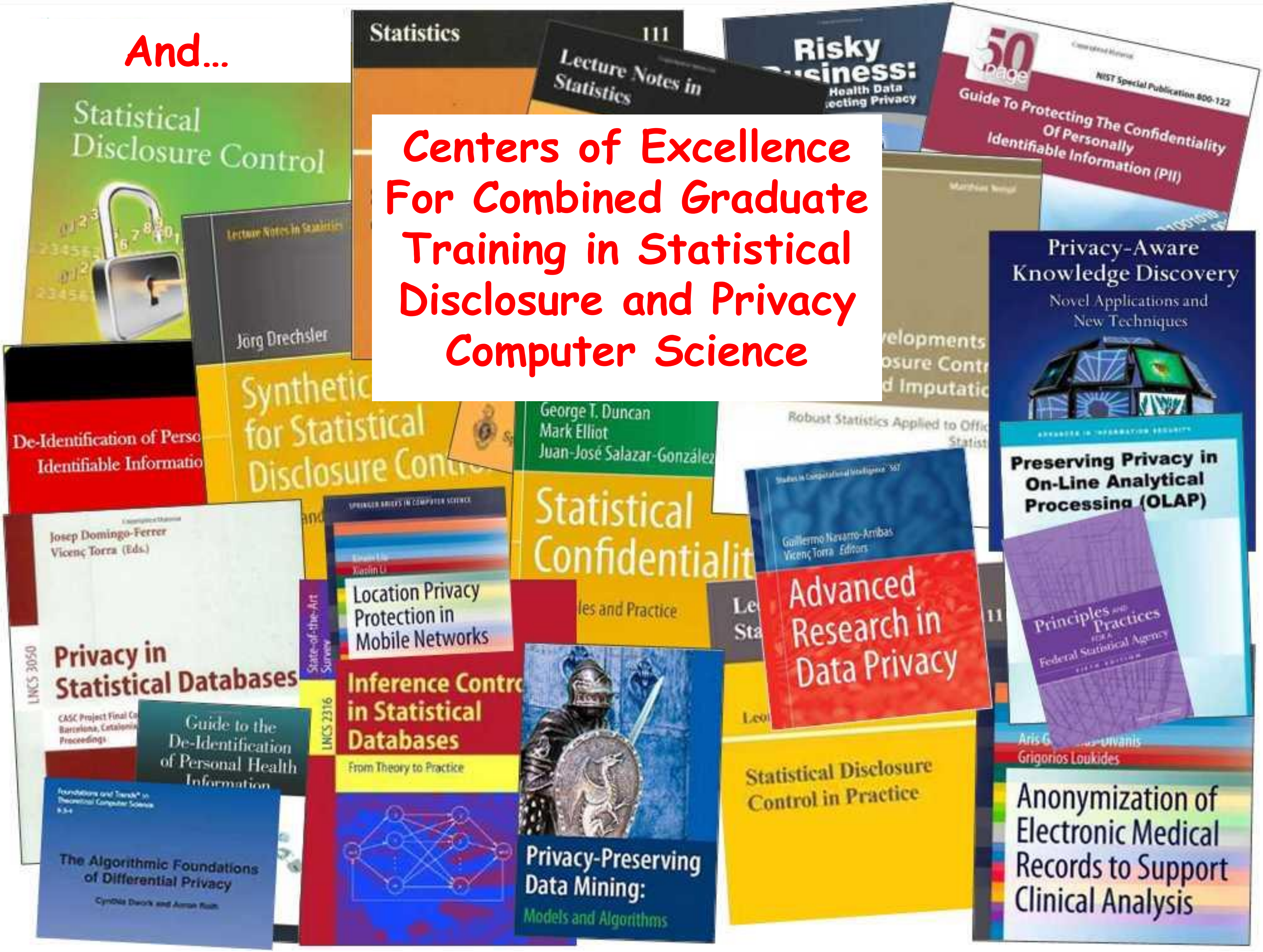
(1) DATA AGREEMENT.—The term "data agreement" means a contract, memorandum of understanding, data use agreement, or similar agreement between a discloser and a recipient relating to the use of personal information.

(2) DATA AGREEMENT SUBJECT TO THIS ACT.—The term "data

Robert Gellman, 2010

https://fpf.org/wp-content/uploads/2010/07/The_Deidentification_Dilemma.pdf

And…



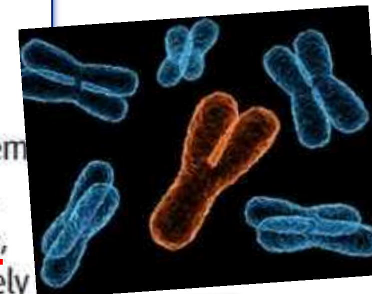
Centers of Excellence For Combined Graduate Training in Statistical Disclosure and Privacy Computer Science

Reserve Slides for Questions

Identifying Personal Genomes by Surname Inference

Science
AAAS

Melissa Gymrek,[1,2,3,4] Amy L. McGuire,[5] David Golan,[6] Eran Halperin,[7,8,9] Yaniv Erlich[1]*



Sharing sequencing data sets without identifiers has become a common practice in genomics. Here, we report that surnames can be recovered from personal genomes by profiling short tandem repeats on the Y chromosome (Y-STRs) and querying recreational genetic genealogy databases. We show that a combination of a surname with other types of metadata, such as age and state, ca... the identity of the target. A key feature of this technique is that it entirely re... es. We quantitatively analyze the ... id... w...

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Archive > Volume 497 > Issue 7448 > News Feature > Article

NATURE | NEWS FEATURE

Privacy protections: The genome hacker

Yaniv Erlich shows how research participants can be identified from 'anonymo...

Erika Check Hayden

08 May 2013

PDF | Rights & Permissions

Our analysis projects a success rate of ~12% (SD = 2%) in recovering surnames of U.S. Caucasian males (Fig. 1B and fig. S2). This rate can be accomplished with a conservative threshold that would return a wrong surname in 5% of cases and label 83% of cases as unknown. Higher success rates of up to 18% can be achieved at the price of increased probability to recover an incorrect surname. Because our input cohort is based

TG
TG
ACTACTACTACTACTACTA
7 repeats

"Y-STR Surname" Attack Headlines

CSO | SECURITY AND RISK Newsletters Dashboard RSS Research Centers White Pap

Identity & Access

News | Blogs | Tools & Templates | Security Jobs | Basics | Data Protection | Identity & Access | Business C

"Your Biggest Genetic Secrets Can Now Be Hacked, Stolen, and Used for Target Marketing"

Home » Identity

IN DEPTH

DNA hack could make medical privacy impossible

Researchers could find your name by taking samples from a distant cousin

» 1 Comment Share 17 +1 Like 33 More

By Kevin Fogarty

March 11, 2013 — CSO —

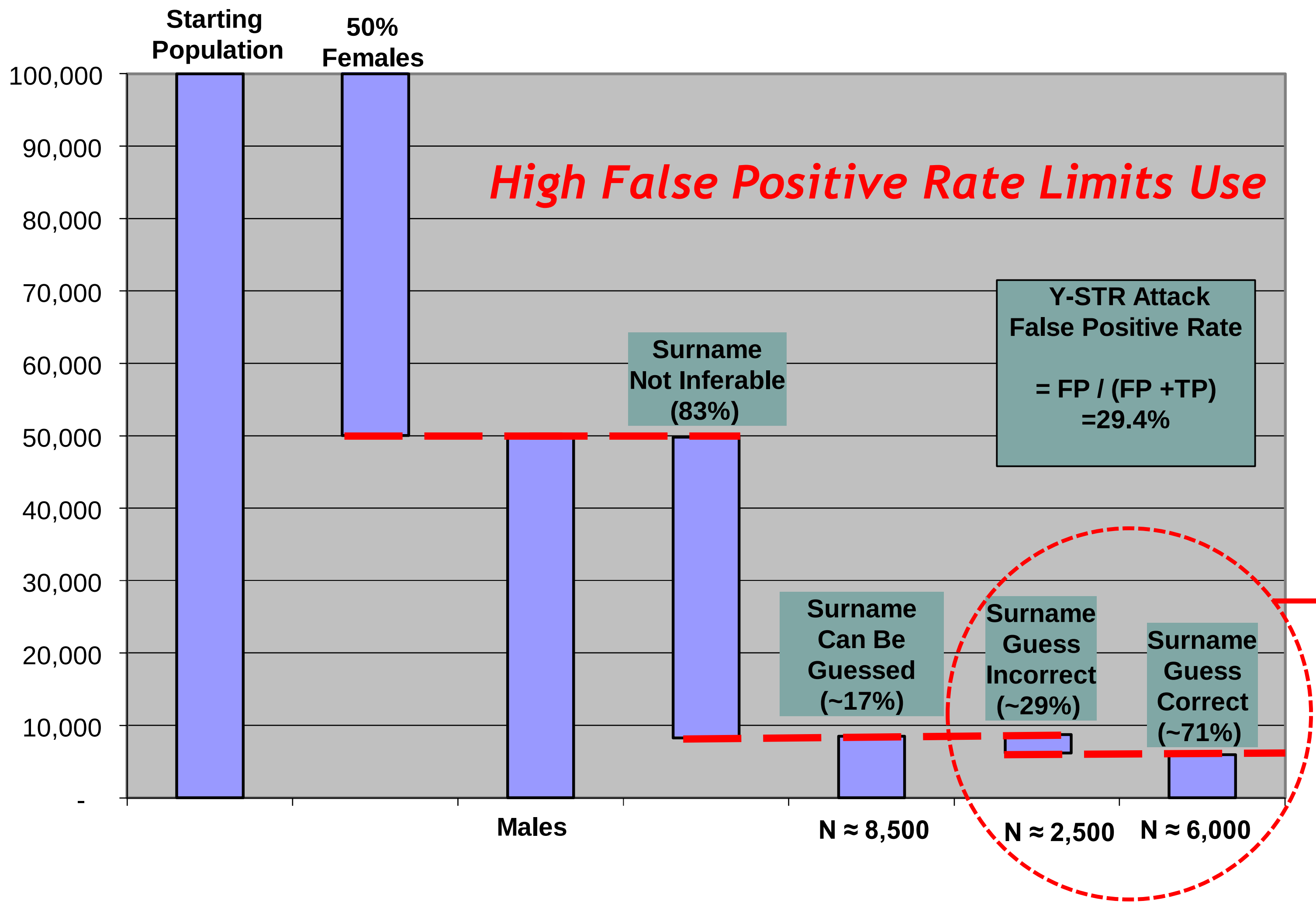
It may now be possible for anyone, even if they follow rigorous privacy and anonymity practices, to be identified by DNA data from people they do not even know.

Question 1: Is Y-STR Attack Economically Viable?

Probably not -- unclear whether it eventually could be.

Question 2: Is "De-identification" pointless?

No, removing State, Grouping YoB would help importantly.



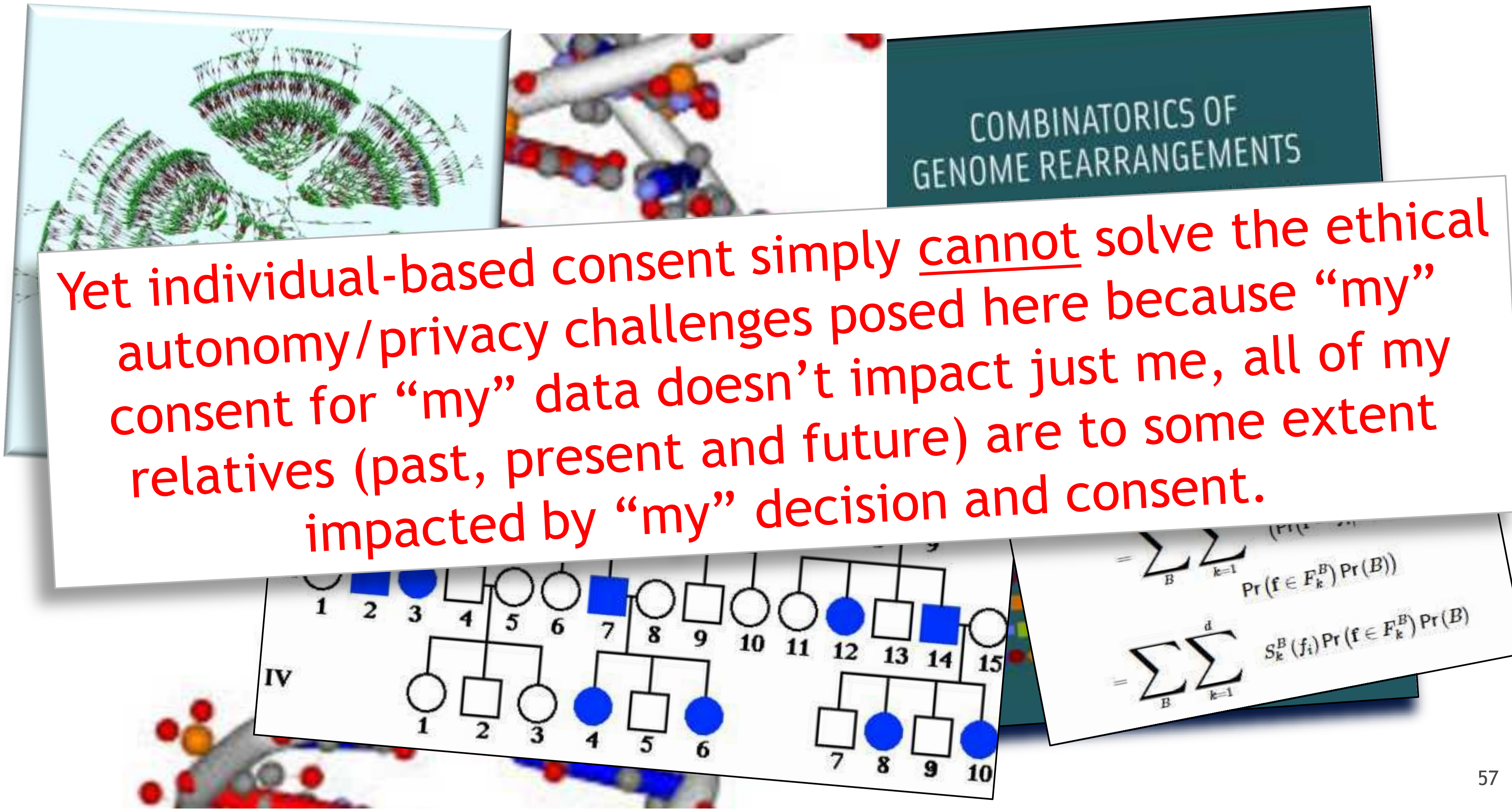
Re-ID isn't achieved by Surname Guess.

So what's the Threat Model?

Surname Guess Could Serve as a (Faulty) Quasi-identifier (e.g., w/ YoB & State)

But Will Produce Substantive Re-identification Errors

Given the inherent extremely large combinatorics of genomic data nested within inheritance networks which determine how genomic traits (and surnames) are shared with our ancestors/descendants, the degree to which such information could be meaningfully <u>"de-identified"</u> are non-trivial.



Yet individual-based consent simply <u>cannot</u> solve the ethical autonomy/privacy challenges posed here because "my" consent for "my" data doesn't impact just me, all of my relatives (past, present and future) are to some extent impacted by "my" decision and consent.

WA State Hospital Discharge Attack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Frustrated Republicans Pressure Boehner to End Shutdown

Shutdown Jokes, Day 3: Letterman, Colbert, Stewart

BREAKING NEWS Telecom Italia Ceo Bernabe Is Said to Resign

States' Hospital Data for Sale Puts Privacy in Jeopardy

By Jordan Robertson - Jun 5, 2013 12:01 AM ET

113 COMMENTS QUEUE

Your Health Data for Sale: Who's Selling, Buying?

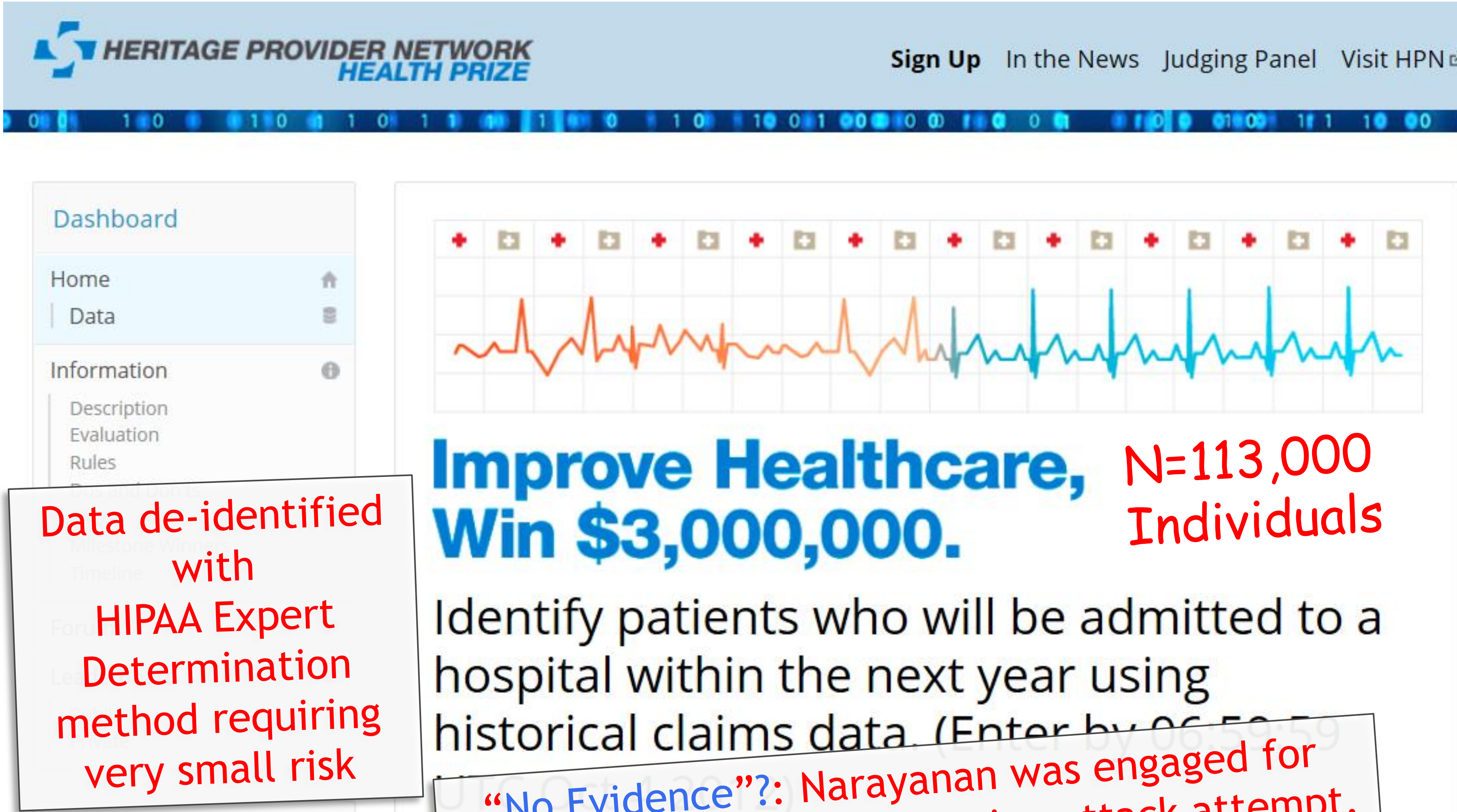
Consider Ray Boylston, who went into diabetic shock while riding his motorcycle in rural Washington in 2011. He careened off the road and was thrown into the woods, an accident that was covered only briefly, in the local newspaper. Boylston disclosed his medical condition and history to a handful of loved ones and the hospital that treated him.

After Boylston's discharge, Washington collected the paperwork of his week-long stay from Providence Sacred Heart Medical Center in Spokane and added it to a database of 650,000 hospitalizations for 2011 available for sale to researchers, companies and other members of the public. The data was supposed to remain anonymous. Yet because of state exemption from federal regulations governing discharge information, Boylston could be identified and his medical background exposed using only publicly available information.

"I don't really feel that the public has a right to read up on my medical history," said Boylston, who is 62 and a veteran. "I feel I've been violated."

40/648,384
= 1/16,200

How Someone Can Re-identify Your Medical Records



N=113,000 Individuals

Data de-identified with HIPAA Expert Determination method requiring very small risk

"No Evidence"?: Narayanan was engaged for Heritage Prize re-identification attack attempt. He was unable to re-identify anyone.

n = 0 were Re-identified

Forbes · New Posts +30 posts this hour · Most Popular Hip-Hop's Top Earners · Lists The Forbes 400

Adam Tanner, Contributor
I write about the business of personal data.
+ Follow (120)

Used Zip5, Sex, DoB & embedded Names

TECH | 4/25/2013 @ 3:47PM | 13,065 views

Harvard Professor Re-Identifies Anonymous Volunteers In DNA Study

"Personal Genome Project" Attack

5 comments, 5 called-out + Comment Now + Follow Comments

103 (18%) of the persons in study had their names embedded within their data files.

These "anonyomous" names were used to help re-identify.

Without names only 28% could be re-identified by Zip5, Sex & DoB.

A Harvard professor has re-identified the names of more than 40% of a sample of anonymous participants in a high-profile DNA study, highlighting the dangers that ever greater amounts of personal data available in the Internet era could unravel personal secrets.

From the onset, the Personal Genome Project, set up by Harvard Medical School

Preventing Identification with Geographic Censoring and Masking

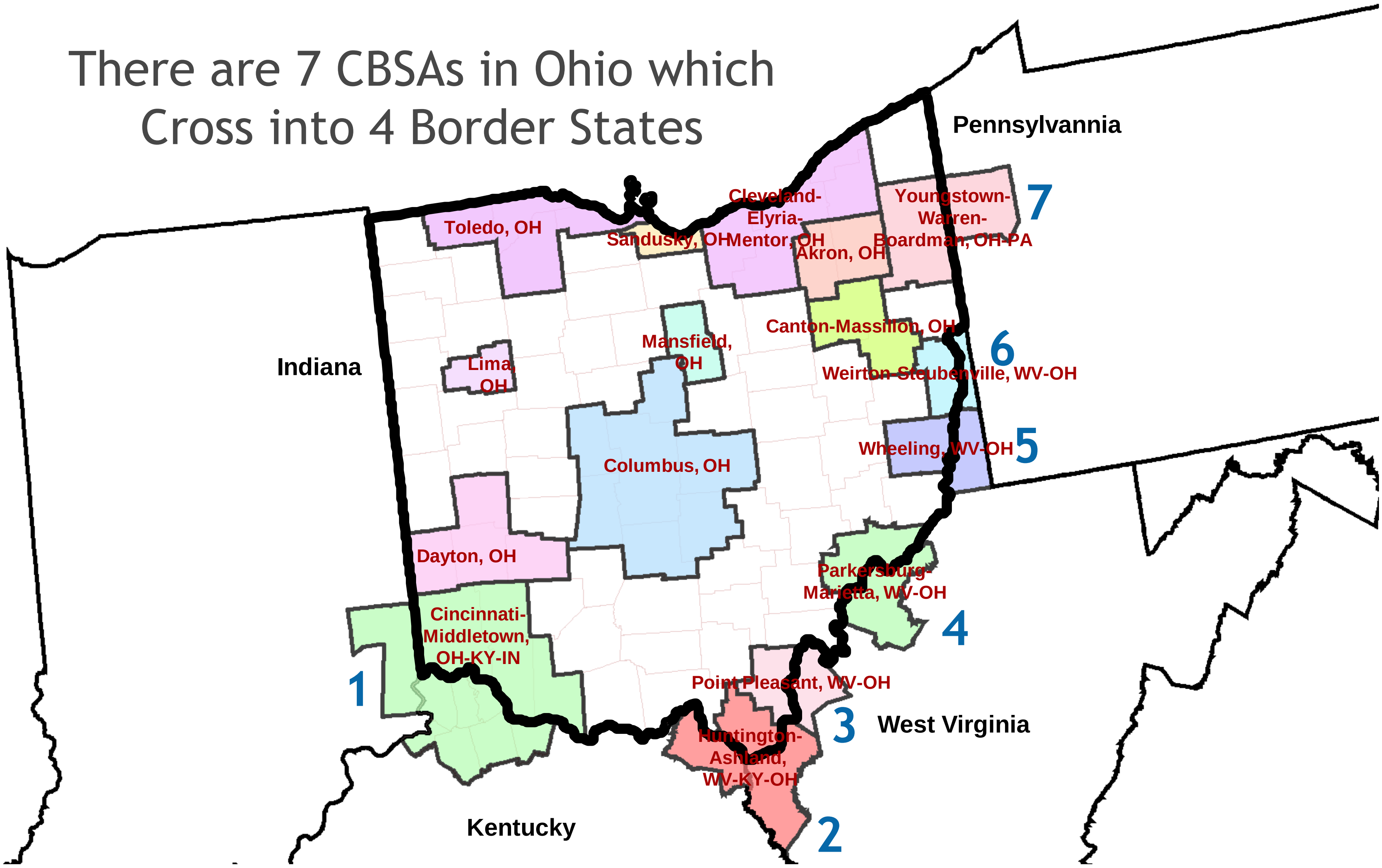
- ***Geographic Censoring*** refers to preventing identification by not reporting data from individuals within those areas with high disclosure risks
  - Obviously, geographic censoring is preferable only when the populations requiring censoring are very small.
- ***Geographic Masking*** refers to preventing identification by modifying the original geographic reporting areas.
  - The simplest method of geographic masking is to combine or aggregate geographic units with high re-identification risks into larger population units.

Challenge: Subtraction Geography (i.e., Geographical Differencing)

- Challenge: Data recipients often request reporting on more than one geography (e.g., both State and 3 digit Zip code).
- ***Subtraction Geography*** creates disclosure risk problems when more than one geography is reported for the same area and the geographies overlap.
- Also called ***geographical differencing***, this problem occurs when the multiple overlapping geographies are used to reveal smaller areas for re-identification searches.

Example: OHIO Core-based Statistical Areas

There are 7 CBSAs in Ohio which
Cross into 4 Border States



Re-identification Science Policy Short-comings:

6 ways in which "Re-identification Science" has (thus far) typically failed to best support sound public policies:

1. Attacking only trivially "straw man" de-identified data, where modern statistical disclosure control methods (like HIPAA) weren't used.
2. Targeting only especially vulnerable subpopulations and failing to use statistical random samples to provide policy-makers with representative re-identification risks for the entire population.
3. Making bad (often worst-case) assumptions and then failing to provide evidence to justify assumptions.

   Corollary: Not designing experiments to show the boundaries where de-identification finally succeeds.

Re-identification Science Policy Short-comings:

6 ways in which "Re-identification Science" has (thus far) typically failed to support sound public policies (Cont'd):

4. Failing to distinguish between sample uniqueness, population uniqueness and re-identifiability (i.e., the ability to correctly link population unique observations to identities).
5. Failing to fully specify relevant threat models (using data intrusion scenarios that account for all of the motivations, process steps, and information required to successfully complete the re-identification attack for the members of the population).
6. Unrealistic emphasis on absolute "Privacy Guarantees" and *failure to recognize unavoidable trade-offs between data privacy and statistical accuracy/utility*.

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