

Privacy-Preserving Medical Data Sharing

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* Part of the reported research was conducted while the authors were employed by Vanderbilt University







Allow <u>medical data</u> to be <u>shared</u> in a way that preserves patients' <u>privacy</u> and <u>data utility</u>

privacy legislation, attacks, disclosures, privacy models

support medical research, decision making, personalized medicine





Part 1: Motivation: medical data sharing and use

Part 2: Research challenges and state-of-the-art solutions

Part 3: Open problems and research directions



Part 1 - Content

- Part 1: Medical data sharing and the need for privacy
 - Patient data: EMRs, sharing, and use in applications
 - Introduction to privacy-preserving data sharing
- Part 2: Research challenges and solutions

Part 3: Open problems and research directions

Patient data



Patient data

- Registration data (e.g., contact info, SSN)
- Demographics (e.g., DOB, gender, race)
- Billing information (e.g., diagnosis codes)
- Genomic information (e.g., SNPs)
- Medication and allergies
- Immunization status
- Laboratory test results
- Radiology images





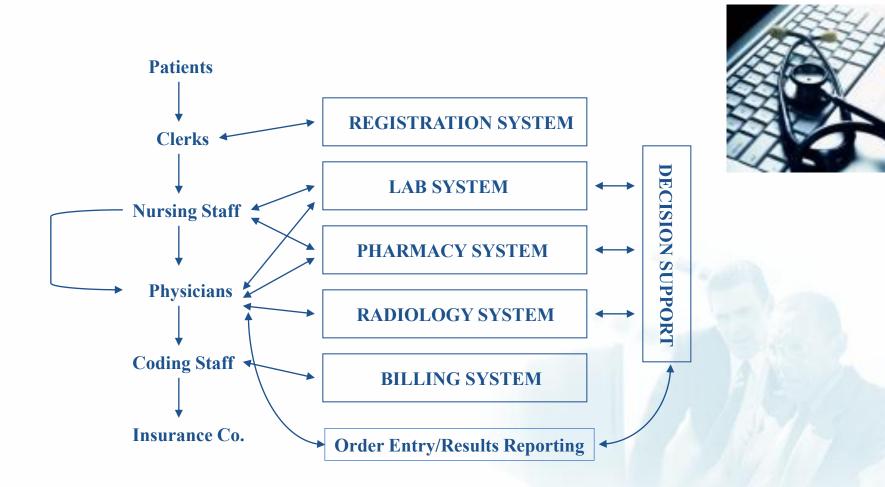
EMR System – a system of systems

- Registration System (identifiers, date & time of visit)
- Billing System (diagnosis codes)
- Lab System (lab results)
- Radiology System (reports)
- Pharmacy System (medications)
- Order Entry System (orders, prescriptions)
- Decision Support System (clinical knowledge, guidelines)





Interaction with an EMR System





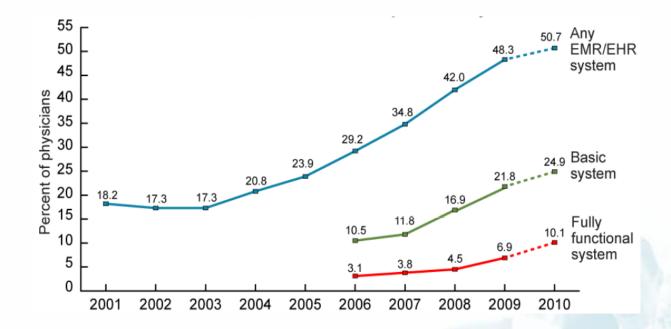
A view from VUMC's EMR

User simmsvg (Scott Simms) Messages: 4 4 24 (Test-Physician)	Devictration		
Go to: Pt.Chart StarVisit StarNotes Forms Rx Panels PatientLists MsgBaskets	Registration		
	MR#		
Vanderbilt University Medical Center Void#ztest, Bethany History and Physical examination MR# 019457829	Demographics		
Case#			
Date of Services Monday, 05/16/2005 16:42 Warning: date does not match	39 year old		
	Female		
IDENTIFYING INFORMATION: This is a 39 year old female .	<u>Clinical</u>		
HISTORY OF PRESENT ILLNESS: Include issues of symptom location, quality, duration, timing, context, modifying factors and associated symptoms	History of Present illness		
PAST MEDICAL HISTORY:	Medication		
REPRODUCTIVE HISTORY: menarche at age; last menstrual period: 01/01/05 ()	Allergies		
G.P.; .			
MEDICATIONS:			
 Lasix Oral Tablet 40 mg 1 tablet by mouth three times a day Tablet mou times a as this is a test 	ROS Constitutional		
 Imipramine HCl Oral Tablet 50 mg 1 tablet by mouth twice a day Coumadin Oral Tablet 10 mg 1 tablet by mouth every day 	ROS Neck		
- Imipramine HCl Oral Tablet 25 mg 1 tablet by mouth three times a day	ROS Musculoskeletal		
 Digoxin Oral Capsule 100 mcg 1 capsule by mouth every day for seven day Amoxicillin Oral Tablet 500 mg 1 tablet by mouth one time only 			
- Amoxicilith oral lablet soo mg I tablet by mouth one time only - Prevacid Oral Capsule, Delayed Release(E.C.) 15 mg 1 capsule by mouth e	wery 8 ROS Endocrine ROS Hematologic		
hours	ROS Allergic/Immunologic		
- Imipramine HCl Oral Tablet 25 mg 1 tablet by mouth three times a day	ROS Vascular		
	ROS Head		
ALLERGIES:	ROS Eyes		
- Celecoxib -hives - aaaaaaaLasix Rash	ROS ENT ROS Cardiovascular		
- Celecoxib Rash	ROS Cardiovascular ROS Respiratory		
- Furosemide rash	ROS GI		
- Acetaminophen -hives - Celecoxib hives	ROS GU		





EMRs are increasingly adopted*



- Incentives by US stimulus bill (\$50B) for adoption and meaningful use of EMR systems
- Goal is to utilize an EMR for each person in the US by 2014



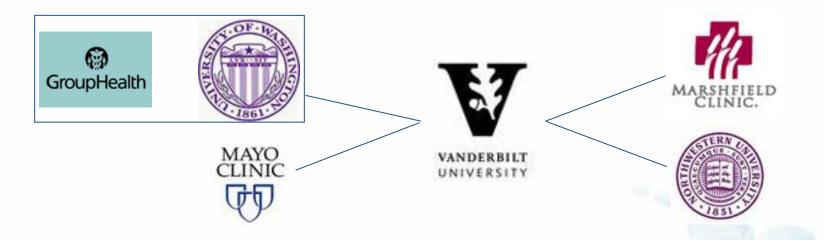
Usefulness of EMRs

- EMRs help improve healthcare
 - physicians to better diagnose and treat diseases
 - patients to be mobile and receive better services
- achieved by Health Information exchange
 - improve accessibility of health information by physicians
 - create a standardized interoperable model that is
 - patient centric, trusted, longitudinal, scalable, sustainable, and reliable
 - e.g., Wisconsin Health Information Exchange, MidSouth E-health Alliance
 - HL7 standard for information exchange between various healthcare systems



Usefulness of EMRs

- EMRs help support "local" research
 - electronic Medical Records & Genomics (eMERGE) Consortium



- Sharing diagnosis codes and DNA from EMRs to enable largescale, low-cost GWAS for many disorders
 - GWAS on asthma* all patients with an ICD code of 493.xx, as well as all patients on asthma medications
- * Pacheco et al. A Highly Specific Algorithm for Identifying Asthma Cases and Controls for Genome-Wide Association Studies. AMIA, 2009.
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Patient data management and sharing

- Support "broad" research
- Database of Genotypes and Phenotypes (dbGaP)
 - archive and distribute data collected for GWAS
 - established in 2006 and funded by the National Center for Biotechnology Information (NCBI), NIH

Tiered data access

- Aggregated data (e.g., questionnaires) open to the public
- Person-specific data (e.g., genotypes) PIs need to apply for access

Data protection

- Security (off-line servers, secure FTP, encryption)
- Privacy (more on this later)



EMR data representation

Relational data

- Registration and demographic data
- Transaction (set-valued) data
 - Billing information
 - ICD codes are represented as numbers (up to 5 digits) and denote signs, findings, and causes of injury or disease*

	Electronic Medical Records					
	Name	YOB	ICD	DNA		
	Jim	1955	493.00, 185	СТ		
Z	Mary	1943	185, 157.3	AG		
	Mary	1943	493.01	CG		
	Carol	1965	493.02	CG		
	Anne	1973	157.9, 493.03	GC		
-	Anne	1973	157.3	AT		

- Sequential data
 - DNA
- Text data
 - Clinical notes

CLINICAL HISTORY: <u>77</u> year old female with a history of B-cell lymphoma (Marginal zone, <u>SH-02-22222</u>, 6/22/01). Flow cytometry and molecular diagnostics drawn.

* Centers for Medicare & Medicaid Services - https://www.cms.gov/icd9providerdiagnosticcodes/ 13



EMR data in analytics

- Statistical analysis
 - Correlation between YOB and ICD code 185 (Malignant neoplasm of prostate)
- Querying
- Clustering
 - Control epidemics*
- Classification
 - Predict domestic violence**
- Association rule mining
 - Formulate a S. Korea government policy on hypertension management***
 IF age in [43,48] AND smoke = yes AND exercise=no AND drink=yes;
 THEN hypertension=yes (sup=2.9%; conf=26%).
- * Tildesley et al. Impact of spatial clustering on disease transmission and optimal control, PNAS, 2010.
- ** Reis et al. Longitudinal Histories as Predictors of Future Diagnoses of Domestic Abuse: Modelling Study, BMJ: British Medical Journal, 2011
- *** Chae et al. Data mining approach to policy analysis in a health insurance domain. Int. J. of Med. Inf., 2001

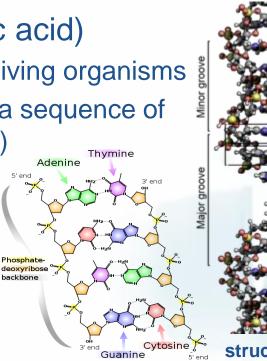
	Records

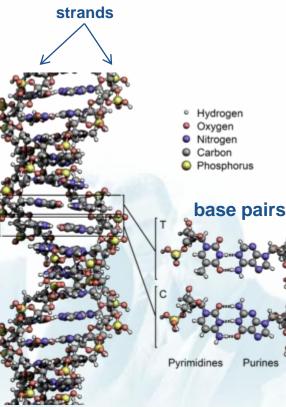
Name	YOB	ICD	DNA
Jim	1955	493.00, 493.01	CT
Mary	1943	185	AG
Mary	1943	493.01, 493.02	CG
Carol	1965	493.02, 157.9	CG
Anne	1973	157.9, 157.3	GC
Anne	1973	157.3	AT



Genome-Wide Association Studies (GWAS)

- aim to discover associations between diseases and genes
- can help improve disease diagnosis and treatment
- "the holy grail for personalized medicine"
- DNA (Deoxyribonucleic acid)
 - Genetic instructions for living organisms
 - Each strand consists of a sequence of nucleobases (A, T, G, C)
 - strands are correlated
 - DNA has 3B base pairs

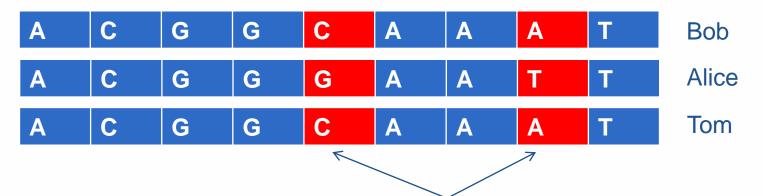




structure of the DNA double helix



Human genetic variation



Single Nucleotide Polymorphism (SNP)

- out of the 3B base pairs, less than 1% differ between any two persons worldwide!
- Scientists have identified about 11M SNPs
 - They have specific (known) positions in the DNA
 - Are indicators of disease susceptibility, drug metabolism, ethnic heritage
 - Each SNP can have each of two possible bases ("values")

- Why SNPs are interesting?
 - SNPs might be associated with diseases
- What is a Genome-Wide Association Study ?

- SNPCGDiseaseIHealthyI
- Each GWAS studies a disease or trait and considers about 1M SNPs
- People are split into two groups: case (diseased) vs. control (non-diseased)
- Statistical tests (e.g., chi-square) are used to identify genetic markers (SNPs) that are associated to the disease/trait susceptibility
- If the variation of some SNPs is found to be higher in the case group than in the control group, these SNPs are reported as a potential marker of the disease/trait (biomarker)
- Why are GWAS important for personalized medicine ?
 - Combinations of SNPs can reflect biomarkers of diseases (e.g., cancer)
 - People who have DNA compatible with a biomarker have predisposition for developing the corresponding disease
 - Medicine can be supplied at an early stage to these people to prevent the development of the disease



Genome-Wide Association Studies (GWAS)

 1,200 human GWASs have examined over 200 diseases and traits and found almost 4,000 SNP associations*

GWAS-related diseases**			
Asthma	Lung cancer		
ADHD	Pancreatic cancer		
Bipolar I disorder	Platelet phenotypes		
Bladder cancer	Pre-term birth		
Breast cancer	Prostate cancer		
Coronary disease	Psoriasis		
Dental caries	Renal cancer		
Diabetes mellitus type 1	Schizophrenia		
Diabetes mellitus type 2	Sickle-cell disease		

* Johnson et al. An open access database of genome-wide association results. BMC medical genetics, 2009.
** Manolio et al. A HapMap harvest of insights into the genetics of common disease. J Clinic. Inv., 2008.
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Part 1 - Content

Part 1: Medical data sharing and the need for privacy

- Patient data: EMRs, sharing, and use in applications
- Introduction to privacy-preserving data sharing
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Part 3: Open problems and research directions



Introduction to privacy-preserving data sharing

- Need for privacy
- Privacy scenarios
- Threats in data sharing
- Privacy policies





Need for privacy

- Why we need privacy in medical data sharing?
- If privacy is breached, there are consequences to patients
 <u>Consequences to patients</u>
 - Emotional and economical embarrassment
 - 62% of individuals worry their EMRs will not remain confidential*
 - 35% expressed privacy concerns regarding the publishing of their data to dbGaP**
 - Opt-out or provide fake data → difficulty to conduct statistically powered studies

- * Health Confidence Survey 2008, Employee Benefit Research Institute
- ** Ludman et al. Glad You Asked: Participants' Opinions of Re-Consent for dbGap Data Submission. Journal of Empirical Research on Human Research Ethics, 2010.



- If privacy is breached, there are consequences to organizations
 - Legal \rightarrow HIPAA, EU legislation (95/46/EC, 2002/58/EC, 2009/136/EC etc.)
 - Financial → It can cost an organization \$7.2M on average*



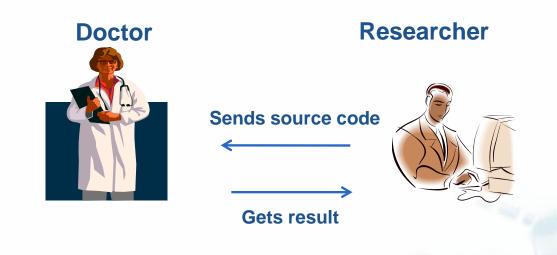
and up to \$35.3M

* Ponema Institute/Symantec corporation, 2010 Annual Study: US cost of a data breach.



Privacy-aware data sharing scenarios

"Send me your source code" scenario



Pros:

- Attacker sees no data
- No infrastructure costs

Cons:

- Only for hypothesis testing
- Result may breach privacy
- Code may be malicious
- Technical issues

Collaboration between researchers in CS & Medical Schools



Privacy-aware data sharing scenarios

Interactive scenario (akin to statistical databases)

Protected data repository







Researchers

Privacy-aware result

Privacy aware query answering

Pros:

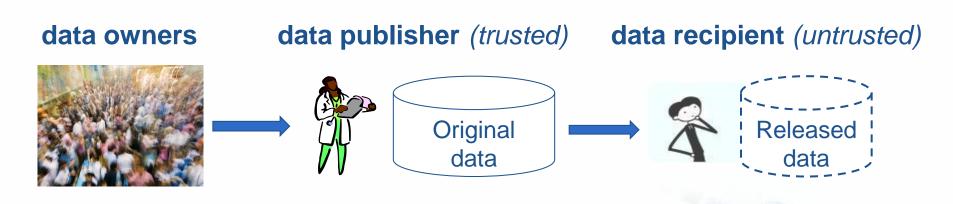
- Data kept in-house
- No need to specify utility requirements
- Strong privacy
- Attack identification and recovery from privacy breaches based on auditing

Cons:

- Difficulty to answer complex queries
- Data availability reduces with time
- Infrastructure costs
- Bad for hypothesis generation



Non-interactive scenario (a.k.a. data publishing)



Pros:

- Constant data availability
- No infrastructure costs
- Good for hypothesis generation and testing
- Seems to model most releases

Cons:

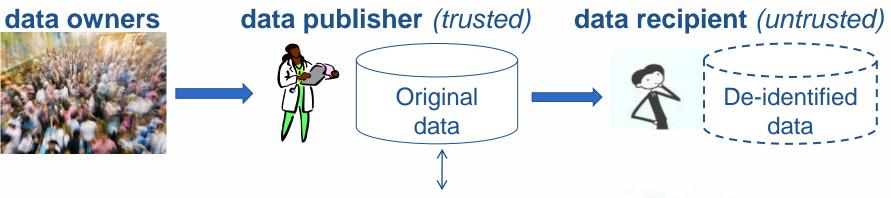
- Privacy and utility requirements need to be specified
- Publisher has no control of the data
- No auditing

Hospitals release discharge summaries



Data publishing needs to preserve privacy

De-identification



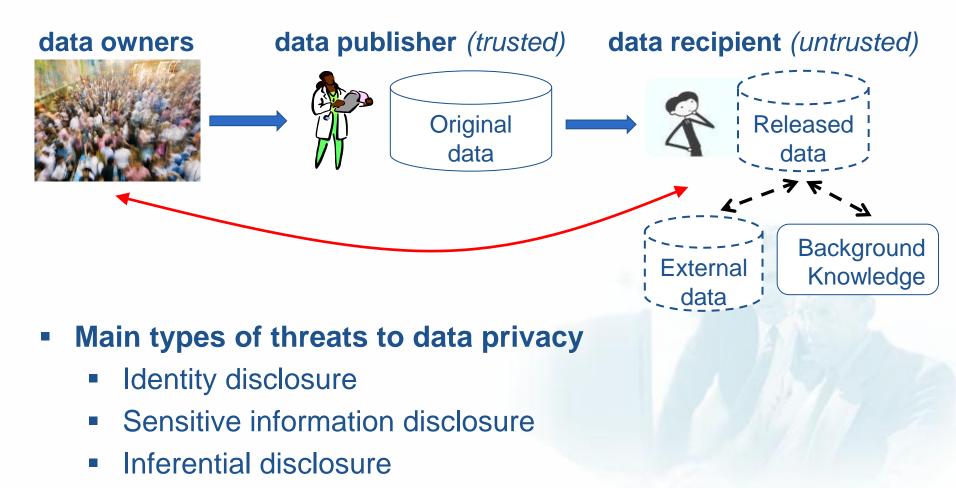
- Find out <u>identifiers</u> (attributes that uniquely identify an individual)
 - SSN, Patient ID, Phone number etc.
- Remove them from the data prior to data publishing

Name	Search Query Terms
John Doe	Harry potter, King's speech
Thelma Arnold	Hand tremors, bipolar,dry mouth, effect of nicotine on the body



Data publishing needs to preserve privacy

De-identification is not enough!





Privacy Threats: Identity Disclosure

- Identity disclosure
 - Individuals are linked to their published records based on <u>quasi-identifiers</u> (attributes that in combination can identify an individual)

Age	Postcode	Sex
20	NW10	М
45	NW15	М
22	NW30	М
50	NW25	F



Name	Age	Postcode	Sex
Greg	20	NW10	М
Jim	45	NW15	М
Jack	22	NW30	М
Anne	50	NW25	F

External data



Real-world identity disclosure cases – medical data



William Weld, Former Governor of MA

 Chicago Homicide database
 Social security death index 35% of murder victims

Public obituaries 26-year old girl who died from drug



Identity Disclosure in EMR data sharing

*De-identifying EMRs is not enough!

Identified EMR data			Released EMR Data	
ID	ICD		ICD	DNA
Jim	333.4		333.4	<i>CTA</i>
Mary	401.0 401.1	\longleftrightarrow	401.0 401.1	ACT
Anne	401.0 401.2 401.3		401.0 401.2 401.3	<i>GCC</i>

Mary is diagnosed with benign essential hypertension (ICD code 401.1) ... the second record belongs to her → all her diagnosis codes

Disclosure based on diagnosis codes*

 \rightarrow general problem for other medical terminologies (e.g., ICD-10 used in EU)

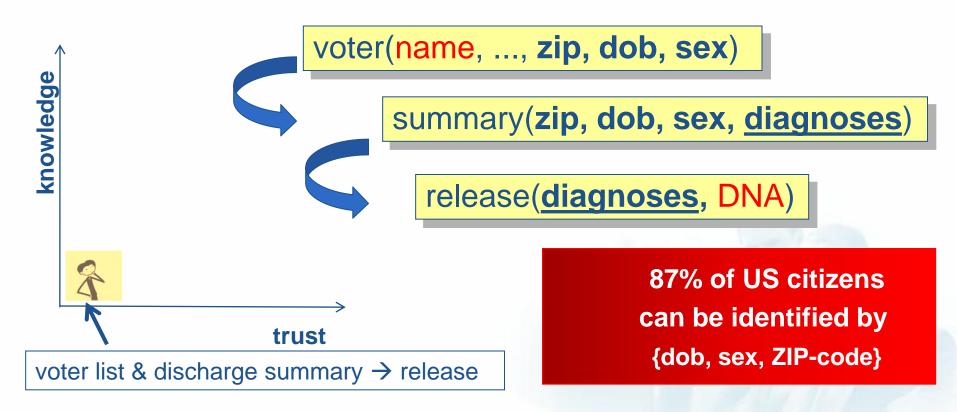
 \rightarrow sharing data susceptible to the attack against legislation

* Loukides et al. The Disclosure of Diagnosis Codes Can Breach Research Participants' Privacy. JAMIA, 2010.



Identity Disclosure in EMR data sharing

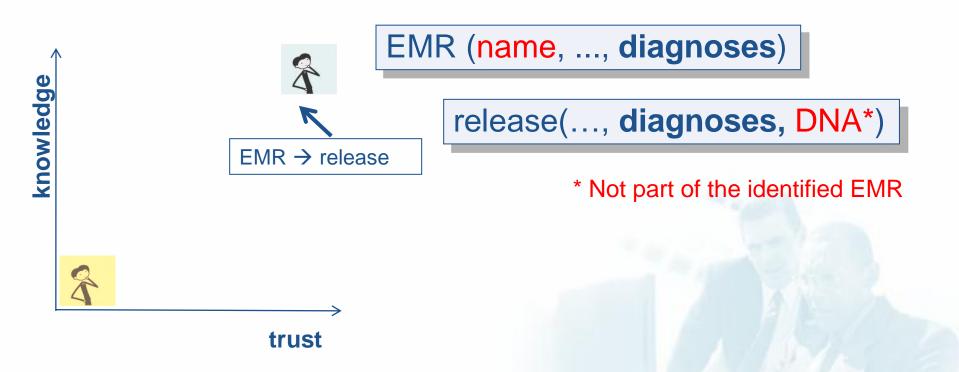
 Two-step attack using publicly available voter lists and hospital discharge summaries





Identity Disclosure in EMR data sharing

One-step attack using EMRs



* Loukides et al. The Disclosure of Diagnosis Codes Can Breach Research Participants' Privacy. JAMIA, 2010.



- De-identified EMR population
 - 1.2M records from Vanderbilt
 - a unique random number for ID

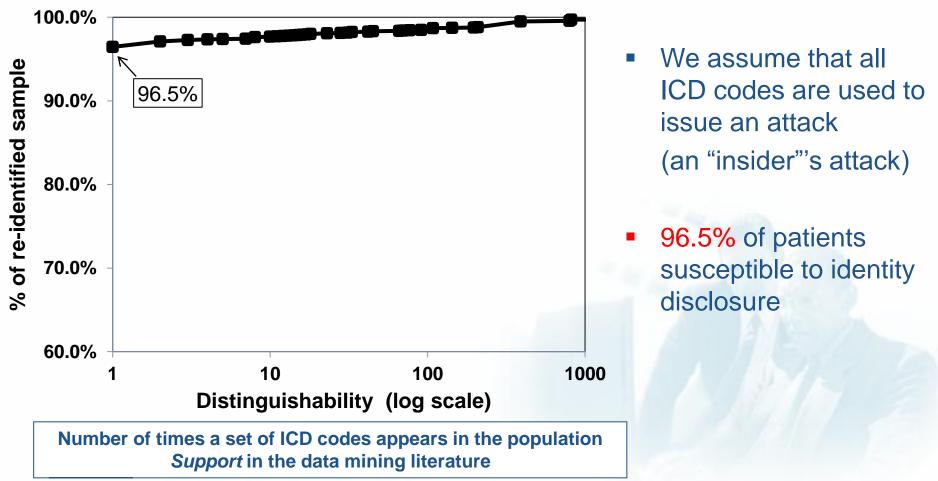
de-identified EMR (ID, ..., diagnoses)

VNEC(..., diagnoses, DNA)

- VNEC de-identified EMR sample
 - 2762 records derived from the population
 - involved in a GWAS for the Native Electrical Conduction of the heart
 - will be deposited into dbGaP
 - useful for other GWAS

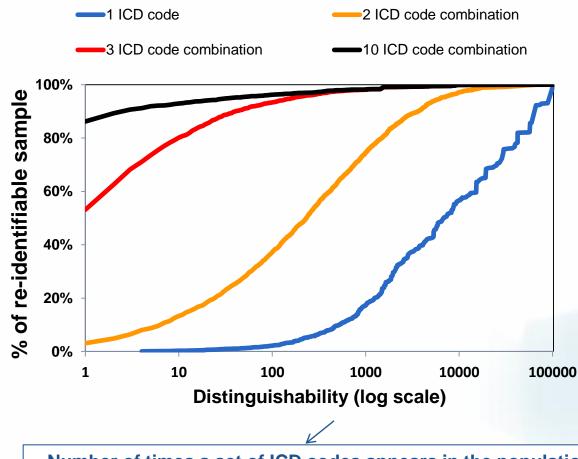


Vanderbilt's EMR - VNEC dataset linkage on ICD codes





Vanderbilt's EMR - VNEC dataset linkage on ICD codes

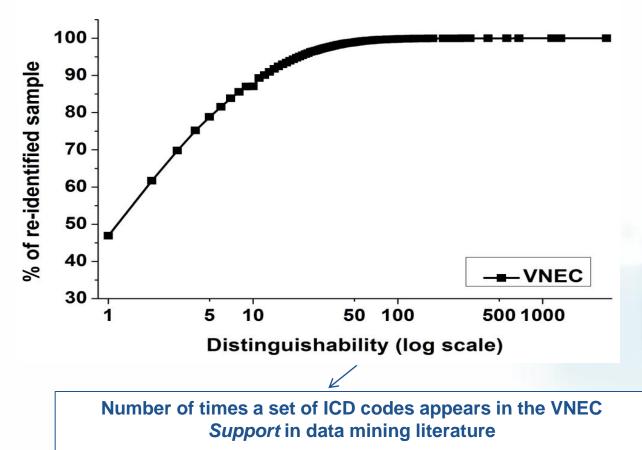


- A random subset of ICD codes that can be used in attack
- Knowing a random
 combination of 2 ICD
 codes can lead to
 unique re-identification

Number of times a set of ICD codes appears in the population Support in data mining literature



VNEC dataset linkage on ICD codes – Hospital discharge records



- All ICD codes for a single visit
- Difficult to know ICD codes that span visits when public discharge summaries are used

46% uniquely re-identifiable patients in VNEC

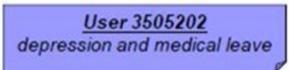


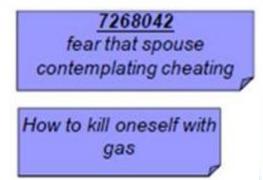
Privacy Threats: Sensitive information disclosure

- Sensitive information disclosure
 - Individuals are associated with sensitive information

Sensitive terms in AOL search logs







* Narayanan et al. Robust De-anonymization of Large Sparse Datasets. IEEE Symposium on Security and Privacy '08.



Sensitive information disclosure – demographic data sharing

			· · ·
			~
Age	Postcode	Sex	Disease
20	NW10	Μ	HIV
45	NW15	Μ	Cold
22	NW30	Μ	Cancer
50	NW25	F	Cancer

Sensitive Attribute (SA)

De-identified data

Age	Postcode	Sex	Disease
20	NW10	М	HIV
20	NW10	М	HIV
20	NW10	М	HIV
20	NW10	М	HIV

De-identified data

Name	Age	Postcode	Sex	
Greg	20	NW10	М	
			-	-

External data

 Can occur without identity disclosure



Sensitive information disclosure – movie rate sharing

NETFLIX

- 100M dated ratings from 480K users to 18K movies
- data mining contest (\$1M prize) to improve movie recommendation based on personal preferences
- movies reveal political, religious, and sexual beliefs and need protection according to Video Protection Act
- "Anonymized"
 De-identification

A lawsuit was filed, Netflix settled the lawsuit

"We will find new ways to collaborate with researchers"

- Researchers inferred movie rates of subscribers*
 - Data are linked with IMDB w.r.t. ratings and/or dates

* Narayanan et al. Robust De-anonymization of Large Sparse Datasets. IEEE Symposium on Security and Privacy '08.



Sensitive information disclosure – EMR data sharing



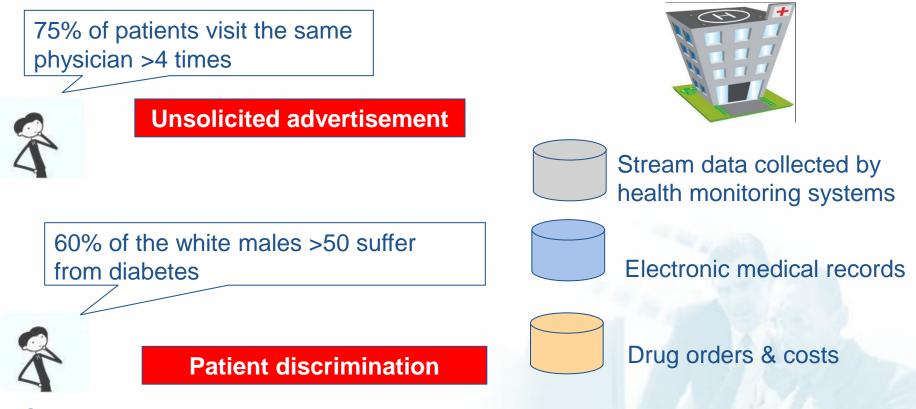
Mary is diagnosed with 401.0 and 401.1... she has Schizophrenia

* Loukides et al. The Disclosure of Diagnosis Codes Can Breach Research Participants' Privacy. JAMIA, 2010.



Privacy-threats: Inferential disclosure

Sensitive knowledge patterns are inferred by data mining^{*,**}



- Competitors can harm data publishers <u>and</u> insurance, pharmaceutical and marketing companies can harm data owners*
- * Das et al. Privacy risks in health databases from aggregate disclosure. PETRA, 2009.
- ** Gkoulalas-Divanis et al. Revisiting sequential pattern hiding to enhance utility. KDD, 2011.



Privacy policies

- Policies related to Protected Health Information (i.e., health information that may identify individuals) in the US
 - Health Insurance Portability and Accountability Act (HIPAA), 1996
 - Health Information Technology for Economic and Clinical Health Act (HITECH), 2009
 - NIH GWAS policy, 2007

Similar policies world-wide

• EU Data Protection Directive 95/46/EC, UK Data Protection Act, etc.



HIPAA & HITECH

- HIPAA specifies three routes for sharing data
 - Expert determination data are statistically verified to be de-identified by a person with appropriate knowledge
 - Safe Harbor

• Limited Dataset

- 17 identifiers (names, SSN etc.) are removed or modified
- no knowledge that the remaining information can lead to identity disclosure
- data are shared for research activities,
- 16 identifiers removed or modified
- a non disclosure agreement is signed

HITECH introduces changes to HIPAA

- Notification in case of privacy breach
- Selling PHI requires patient's approval



NIH GWAS policy

- Applies to GWAS-related grants, contracts, intramural research projects submitted to the NIH on or after Jan. 25, 2008
- NIH-funded investigators are expected to share de-identified GWAS data to dbGaP*
 - <u>descriptive data</u> (questionnaires, genotype phenotype analysis)
 - <u>patient-specific data</u> (coded phenotypes, exposures, genotypes)

- Not sharing is an exception
 - should be justified
 - will be considered for funding on a case-by-case basis

 * National Institutes of Health, Policy for Sharing of Data Obtained in NIH Supported or Conducted Genome-Wide Association Studies. 2007.





Part 1: Medical data sharing and the need for privacy

Part 2: Research challenges and solutions

Part 3: Open problems and research directions





Part 1: Medical data sharing and the need for privacy

Part 2: Research challenges and solutions

- Identifying and modeling adversarial knowledge
- Transforming data to guarantee privacy
- Quantifying data utility
- o Privacy-preserving data publishing:

models, methods, case studies

Part 3: Open problems and research directions



Identifying and modeling adversarial knowledge

- Data adversary's knowledge and data sources are unknown
 - Assumptions based on general properties of data, availability of external datasets, or policies

{YOB, Gender, 3-digit Zip code} unique for 0.04% of US citizens

VS

{DOB, Gender, 5-digit Zip code} unique for 87% of US citizens*

* Sweeney. Achieving k-anonymity privacy protection using generalization and suppression. IJUFKS. 2002.



Identifying and modeling adversarial knowledge

- Data adversary's knowledge and data sources are unknown
 - What if data publishers cannot make such assumptions?

 <u>Automatic specification based on the dataset to be published</u>
 Mine the original data to find negative association rules*
 males do not have "ovarian cancer"
 female Japanese have low chance of heart attack
 Privacy is protected when these rules cannot be used to perform

Privacy is protected when these rules cannot be used to perform sensitive information disclosure

No assumptions on adversarial background knowledge

The line of work of differential privacy^{*,**} we will examine later.

[1] Li et al. Injector: Mining Background Knowledge for Data Anonymization. ICDE, 2008.
[2] Li et al. Modeling and Integrating Background Knowledge in Data Anonymization. ICDE, 2009.
[3] Dwork, Differential Privacy, ICALP, 2006.

[4] Dwork, The Promise of Differential Privacy. A Tutorial on Algorithmic Techniques, FOCS, 2011



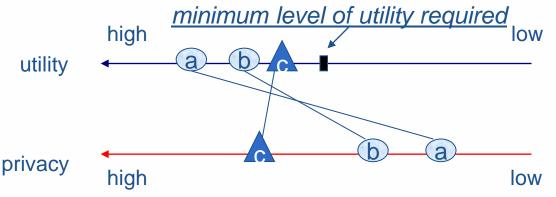
Identifying and modeling adversarial knowledge

- We must preserve privacy and achieve data utility
 ... but utility and privacy can only be traded-off
 - Max utility \rightarrow Min privacy
 - Max privacy \rightarrow Min utility
 - Models to capture privacy
 - Measures to capture utility
 - We will now focus on interesting solutions to trade-off privacy and utility



Identifying and modeling adversarial knowledge

Utility-bound approach



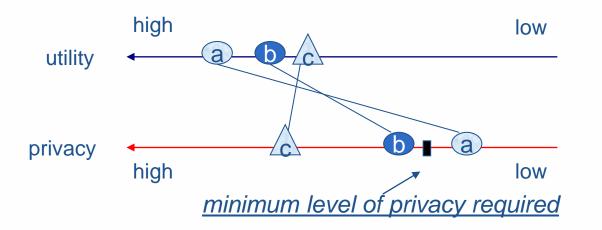
Best privacy the lowest tolerable level of utility

- Works well for some applications
 - classification accuracy in biomedical studies, LBS
- However, the minimum level of utility required may be difficult to be specified



Identifying and modeling adversarial knowledge

Privacy-bound approach



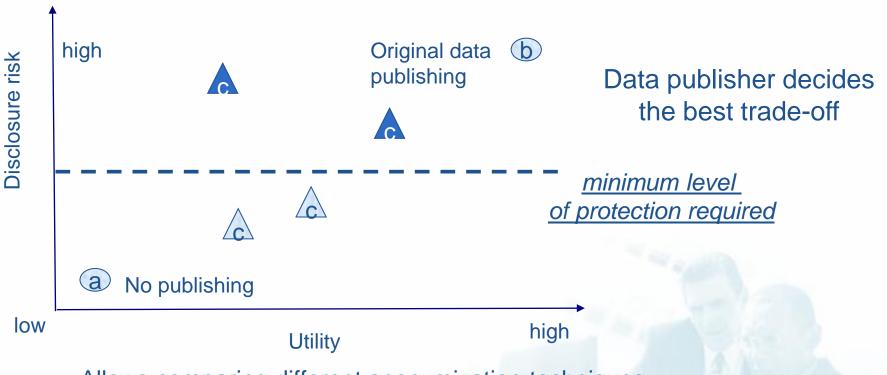
Best utility for a lower bound of privacy

- Adopted by the majority of works (e.g., k-anonymity, I-diversity)
- Utility quantification
 - with an optimization measure (e.g., level of information loss)
 - based on how well anonymized data supports a task compared to original data (e.g., workload of COUNT queries)*
- However, data publishers may still want to consider different solutions



Identifying and modeling adversarial knowledge

R-U Confidentiality map to track the trade-off*



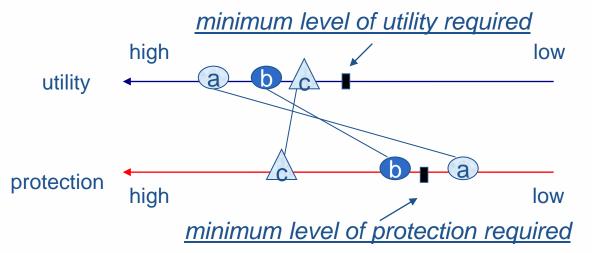
- Allows comparing different anonymization techniques
- Intuitive
- Not easy to use it for comparing methods based on different privacy principles or more complex utility models

* Duncan et al. Disclosure Risk vs. Data Utility: The R-U Confidentiality map. Tech. Rep LA-UR-01-6428, Los Alamos National Library, 2001



Identifying and modeling adversarial knowledge

Utility-and-privacy constrained approach



Lower bound for privacy Minimum tolerable utility

- Constraints for utility and privacy
 - bound on information loss and privacy risk (on specific attributes or values)
- Guarantees privacy and utility
- Not always feasible (e.g., max privacy and max utility)
- Requires domain knowledge reasonable in certain applications



 Synthetic data generation - build a statistical model using a noise infused version of the data, and then synthetic data are generated by randomly sampling from this model

Masking methods

- **Perturbative** aim to preserve privacy and aggregate statistics
 - (e.g., means and correlation coefficients),
 - randomization, data swapping, microaggregation, rounding
 - falsify the data
- Non-perturbative aim to change the granularity of the reported

data

- do not falsify data



Non-perturbative methods – record suppression

- Suppression of demographics
 - Record suppression all values in a record are deleted prior to data publishing
 - Intuition: An individual cannot be associated with a suppressed record or any of its values

Age	Postcode	Sex
20	NW10	Μ
20	NW10	М
45	NW15	М

De-identified data



Non-perturbative methods – record suppression

- Suppression of demographics
 - Record suppression all values in a record are deleted prior to data publishing
 - Intuition: An individual cannot be associated with a suppressed record or any of its values

Name	Age	Postcode	Sex
Greg	20	NW10	Μ
Jim	45	NW15	Μ

External data

Suppressed data

 Protects from both identity and sensitive information disclosure, but results in excessive information loss



Non-perturbative methods – value suppression

Suppression of demographics

 Value suppression – certain values in quasi-identifiers are deleted (replaced by *) prior to data publishing

Intuition: An individual cannot be associated with a record based on a suppressed value

Name	Age	Postcode	Sex		Age	Postcode	Sex	Disease
Greg	20	NW10	М		20	NW10	Μ	HIV
Jim	45	NW15	М		46	NW10	Μ	Flu

External data

De-identified data



Non-perturbative methods – value suppression

Suppression of demographics

 Value suppression – certain values in quasi-identifiers are deleted (replaced by *) prior to data publishing

Intuition: An individual cannot be associated with a record based on a suppressed value

Name	Age	Postcode	Sex		Age	Postcode	Sex	Disease
Greg	20	NW10	Μ	$ \longrightarrow $	*	NW10	Μ	HIV
Jim	45	NW10	Μ		*	NW10	Μ	Flu

External data

Suppressed data

- Incurs less information loss than record suppression
- ... but identifying which values to suppress can be challenging



Non-perturbative methods – code suppression

- Suppression of ICD codes
 - Global removes an ICD code from all records
 - preserves the count of non-suppressed codes, which is beneficial in data mining applications

Identified EMR data		Released EMR Da	ita
ID	ICD	ICD	DNA
Mary	401.0 401.1	401.0 401.1	ACT
Anne	401.0 401.3	401.0 401.3	<i>GCC</i>
		401.0 401.2	ACC



Non-perturbative methods – code suppression

- Suppression of ICD codes
 - Local removes an ICD code from a number of records
 - preserves data utility better than global suppression

Identi	fied EMR data	Released EMR	Data
ID	ICD	ICD	DNA
Mary	401.0 401.1	401.0 401.1	ACT
Anne	401.0 401.3	401.0 401.3	<i>GCC</i>
		401 0 401 3	AC



Non-perturbative methods – code suppression

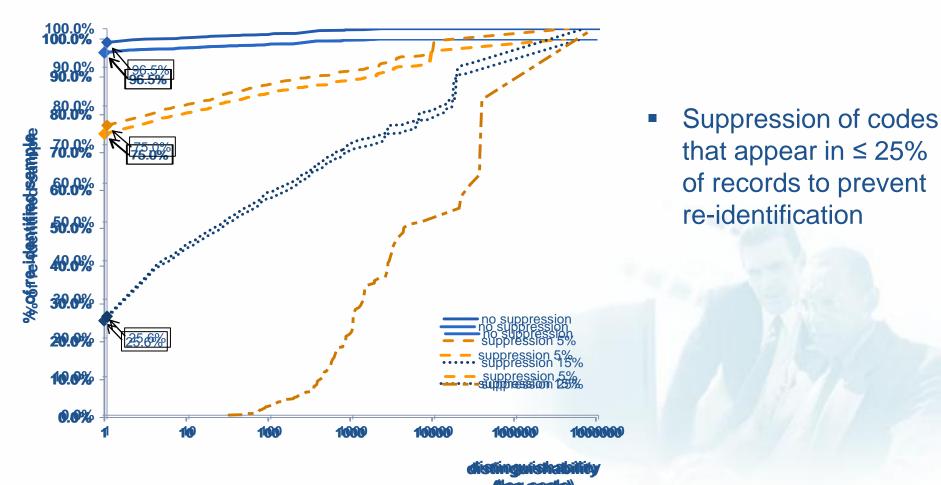
- We applied Vinterbo's method of suppression for ICD codes*
 - **Global** removes an ICD code from all records
 - X% of least frequent ICD codes*
 - Intuition: they distinguish transactions from one another

Identified EMR data			Released EMR Data	
ID	ICD		ICD	DNA
Mary	401.0 401.1	~	401.0 401.1	ACT
Anne	401.0 401.3	\longleftrightarrow	401.0 401.3	GCC



Code suppression – a case study using Vanderbilt's EMR data

Vinterbo's method on VNEC – suppress X% of least frequent codes





Code suppression – a case study using Vanderbilt's EMR data

 What can be safely released when privacy is achieved? – 5 out of ~6K ICD codes are released

5-Digit ICD-9 Codes	3-Digit ICD-9 Codes	ICD-9 Sections
401.1 -Benign \rightarrow	401 -Essential \rightarrow	Hypertensive
essential hypertension	hypertension	disease
780.79 - Other \rightarrow	780- Other \rightarrow	Rheumatism excluding
malaise and fatigue	soft tissue	the back
729.5 - Pain in limb \rightarrow	729 - Other \rightarrow	Rheumatism excluding
	disorders of soft tissues	the back
789.0 - Abdominal \rightarrow	$789 - Other \rightarrow$	Symptoms
pain	abdomen/pelvis	A ALEVAN
	symptoms	1/10/22/2
786.5 - Chest pain \rightarrow	786 -Respiratory \rightarrow	Symptoms
	system	A PART A



Non-perturbative methods – data generalization

- Generalization of demographics
 - Values in quasi-identifiers are replaced by more general ones
 - Intuition: Fewer distinct values → data linkage becomes more difficult

Name	Age	Postcode	Sex	A	ge	Postcode	Sex
Greg	20	NW10	М	2	20	NW10	М
Jim	45	NW15	Μ	— 4	15	NW15	М

External data

De-identified data



Non-perturbative methods – data generalization

- Generalization of demographics
 - Values in quasi-identifiers are replaced by more general ones
 - Intuition: Fewer distinct values → data linkage becomes more difficult

Name	Age	Postcode	Sex		Age	Postcode	Sex
Greg	20	NW10	М	~	[20-45]	NW1 *	М
Jim	45	NW15	М	$ \longrightarrow $	[20-45]	NW1 *	М

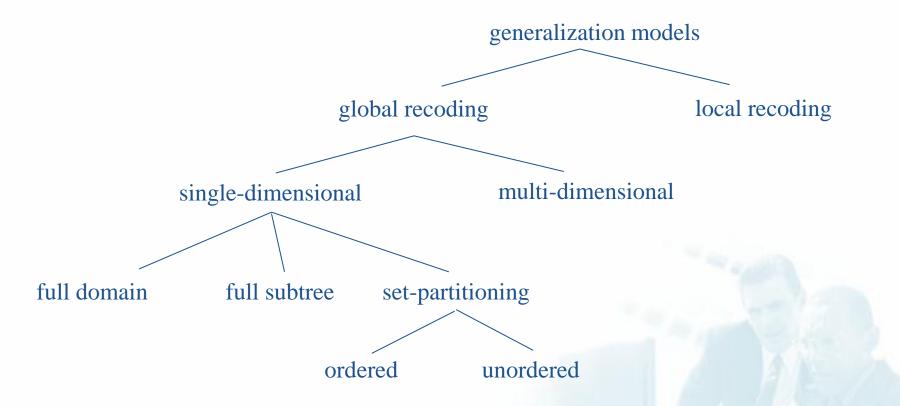
External data

Generalized data

- Typically, it incurs less information loss than suppression
- However, identifying which values to generalize and how can be challenging

Data generalization models for demographics

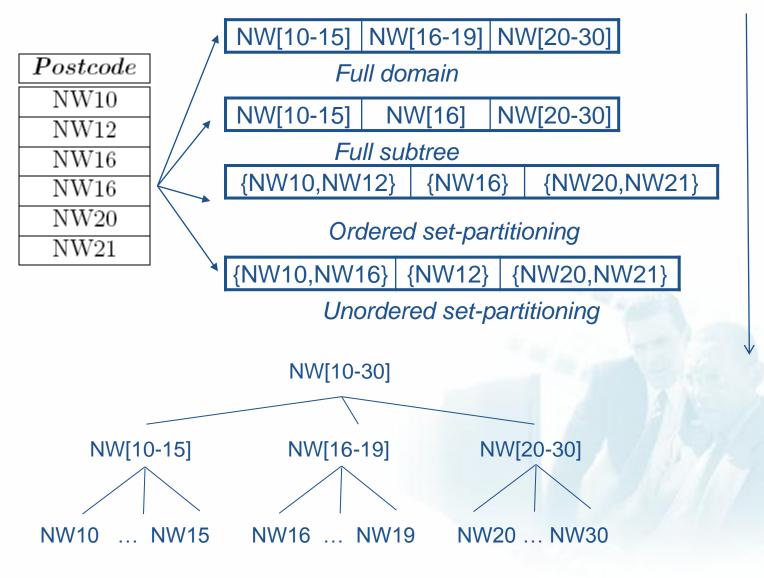




• Global – a value is replaced by the same generalized value in all records



Global data generalization example



Data Utility (+)



Data generalization models – local generalization

Generalization of demographics

 Local recoding – a value can be replaced by multiple generalized values

Age Postcode	
10 NW10	
10 NW12	
10 NW16	
10 NW16	
20 NW16	
20 NW20	
20 NW21	
Postcode Age Pos	stcode
NW[10-16] 10 NW	[10-16]
NW[10-16] 10 NW	[10-16]
NW[10-16] 10 NW	[10-16]
NW[10-16] * N	W16
* 11	W16
* 20 NW	[20-21]
	[20-21]

Multi-dimensional global recoding

Age

10

10

10

10

20 20

20

Local recoding

Pros: Allows exploring a larger number of generalizations than global recoding \rightarrow less information loss

Cons: Anonymized data are difficult to be interpreted and/or mined (e.g., difficult to be used to train a classifier)



Data generalization models for ICD codes

- Generalization of ICD codes
 - Global an ICD code is replaced by a generalized code in all the records

401.1 - benign essential hypertension \rightarrow 401- essential hypertension

Identified EMR data			Released EMR Data	
ID	ICD		ICD	DNA
Mary	401.0 401.1	7	401 .0 401.1	ACT
Anne	401.0 401.3		401.0 401.3	GCC



Data generalization models for ICD codes

- Generalization of ICD codes
 - Local an ICD code can be replaced by more than one generalized codes in different records

401.1 - benign essential hypertension \rightarrow 401- essential hypertension \rightarrow Any

Identified EMR data			Released EMR Data	
ID	ICD		ICD	DNA
Mary	401.0 401.1	7	AG1.0 401.1	ACT
Anne	401.0 401.3	\leftarrow	401.0 401.3	<i>GCC</i>



Data generalization models for ICD codes – hierarchy-based model

- Generalization of ICD codes*
 - Hierarchy-based global generalization model

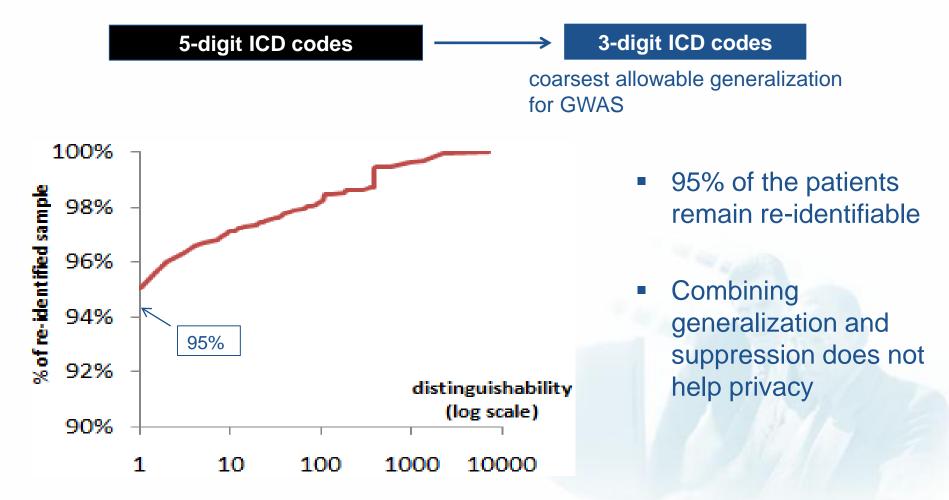


* Sweeney. Achieving k-anonymity privacy protection using generalization and suppression. IJUFKS. 2002. 71



Code generalization – a case study using Vanderbilt's EMR data

Generalizing ICD codes from VNEC*

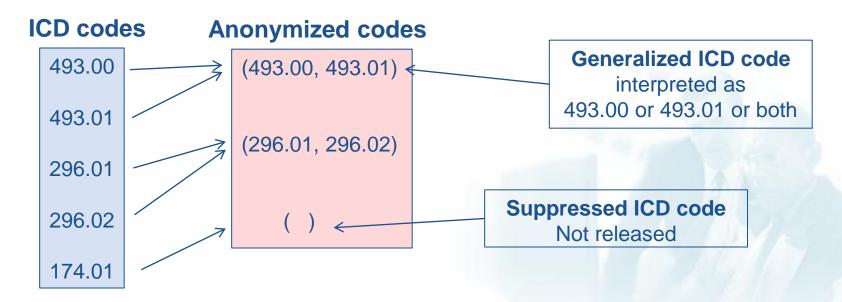


* Loukides et al. The Disclosure of Diagnosis Codes Can Breach Research Participants' Privacy. JAMIA, 2010.



Set-based anonymization model for ICD codes

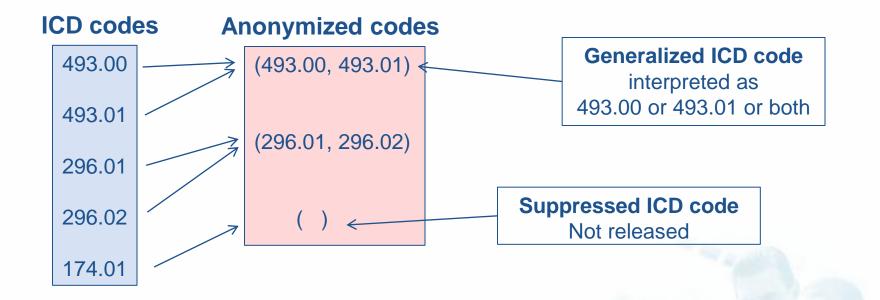
- Set-based anonymization*
 - Global model
 - Models both generalization and suppression
 - Each original ICD code is replaced by a unique set of ICD codes no need for generalization hierarchies



*Loukides et al. Anonymization of Electronic Medical Records for Validating Genome- Wide Association Studies. PNAS, 2010. 73



Set-based anonymization model for ICD codes



EMR Data		
ICD	DNA	
493.00 296.01 296.02	<i>CTA</i>	
493.00 493.01	<i>ACT</i>	
296.01	<i>GCC</i>	

Anonymized EMR Data				
ICD	DNA			
(493.00, 493.01) (296.01, 296.02)	<i>CTA</i>			
(493.00, 493.01)	<i>ACT</i>			
(296.01, 296.02)	<i>GCC</i>			



- Suppression and generalization reduce data utility
- Capture data utility by measuring information loss
 - Assumes that we do not know the applications data will be used for
 - Generalized group all records with the same values in all QIDs

Age Postcode		Disease
[20-30]	CF[0-10]	HIV
[20-30]	CF[0-10]	Cold
[30-40]	CF[26-75]	Cancer
[30-40]	CF[26-75]	Cold

Generalized group g₁

Generalized group g₂

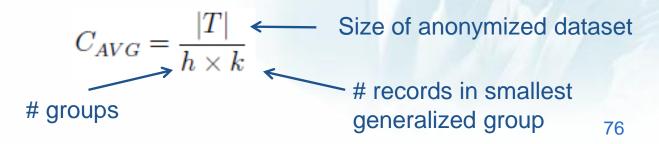
- Capture data utility by measuring the accuracy of performing a specific task using anonymized data
 - Reasonable for data shared between researchers



Quantifying data utility for demographics based on information loss

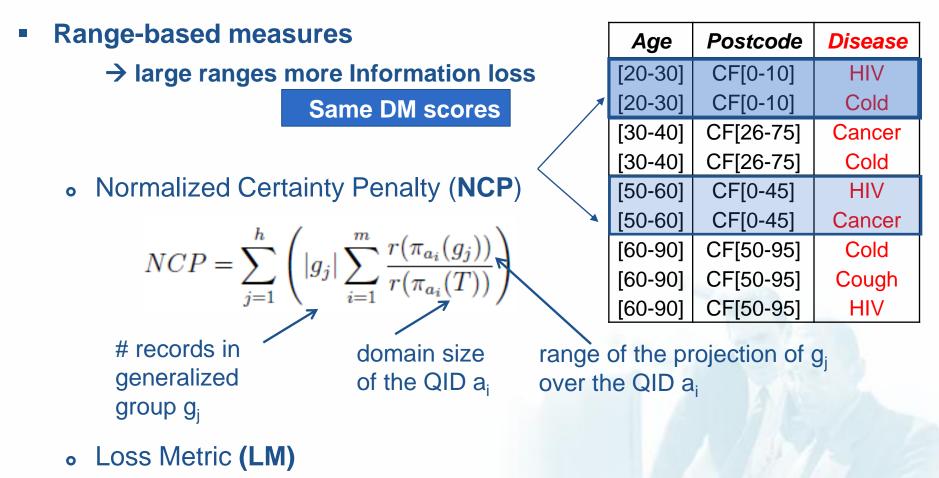
Group size-based measures Age Postcode Disease \rightarrow large groups more Information Loss [20-30] CF[0-10] HIV • Discernability Measure (**DM**) [20-30] CF[0-10] Cold $DM = \sum_{j=1}^{r} (|g_j|^2) + \sum_{j=r+1}^{n} (|T| \times |g_j|)$ [30-40] CF[26-75] Cancer [30-40] CF[26-75] Cold [50-60] CF[0-45] HIV [50-60] CF[0-45] Cancer Penalty for a Penalty for a [60-90] CF[50-95] Cold suppressed group g_i generalized [60-90] CF[50-95] Cough group g_i [60-90] CF[50-95] HIV (removed records)

Normalized Average Equivalence Class Size Metric (C_{AVG})





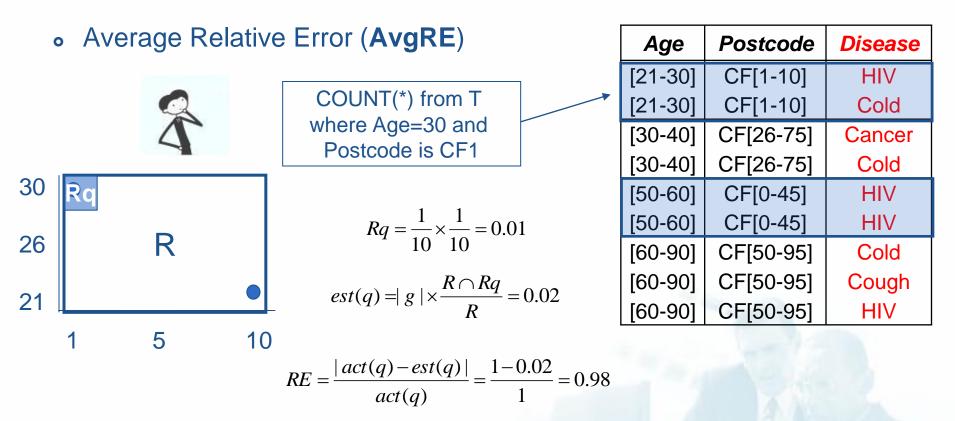
Quantifying data utility for demographics based on information loss



• Utility Measure (UM)



Quantifying data utility for demographics based on analytic tasks

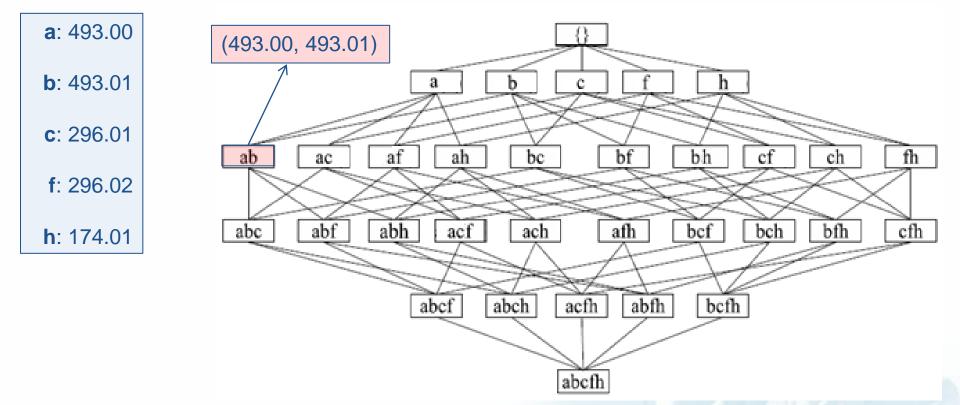


- Classification Metric (CM)
 - Penalizes groups with different classification labels



Quantifying data utility for diagnosis codes based on information loss

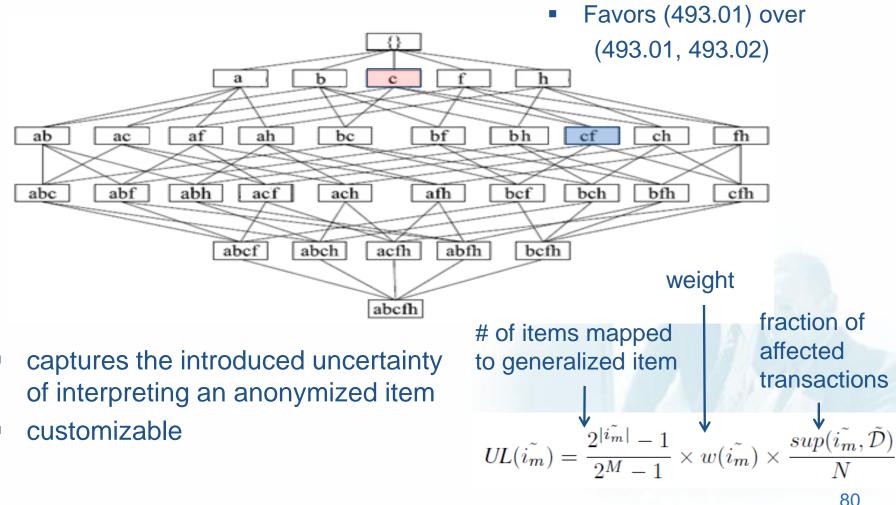
1.01×10¹⁷⁵⁵ possible set-based anonymizations for VNEC





Quantifying data utility for diagnosis codes based on information loss

 Utility Loss (UL): A measure to quantify the level of information loss incurred by anonymization





Quantifying data utility for diagnosis codes based on analytic tasks

• Average Relative Error (AvgRE)

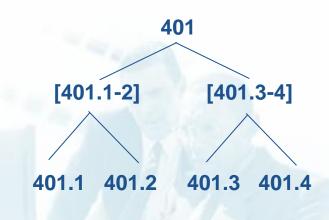
ICD	DNA
401.0 401.1	ACT
401.2 401.3	<i>GCC</i>
401.0 401.1	<i>CCA</i>
401.4 401.3	<i>CAT</i>

ICD	DNA
[401.1-2]	ACT
[401.1-2] 401.3	<i>GCC</i>
[401.1-2]	<i>CCA</i>
401 401.3	<i>CAT</i>



$$est(q) = |g| \times p = 3 \times \frac{2}{3}$$

$$RE = \frac{|act(q) - est(q)|}{act(q)} = \frac{|1 - 2|}{1} = 1$$







Part 1: Medical data sharing and the need for privacy

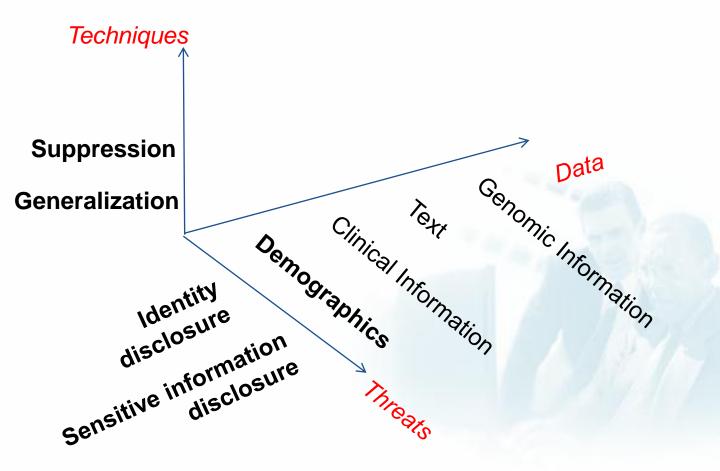
Part 2: Research challenges and solutions

- Identifying and modeling adversarial knowledge
- Transforming data to guarantee privacy
- Quantifying data utility
- **Privacy-preserving data publishing:** principles, methods, case studies
- Part 3: Open problems and research directions



Research challenges and solutions

Privacy-preserving data publishing





Privacy-preserving data sharing: Demographics

Principles

- k-anonymity
- k-map
- I-diversity
- ρ_1 -to- ρ_2 privacy
- differential privacy

Anonymization algorithms

- Partition-based
- Clustering-based
- Case Study: US Census data



k-anonymity*

- Each record in a relational table T needs to have the same value over quasi-identifiers with at least k-1 other records in T
- These records collectively form a k-anonymous group
- Protects from identity disclosure
 - Makes linking to external data more difficult
 - Probability an identified individual is associated with their record is at most 1/k

Name	Age	Postcode	Sex	
Greg	40	NW10	Μ	
Jim	45	NW15	Μ	
Jack	22	NW30	М	
Anne	50	NW25	F	
Extornal data				

External data

	Age	Postcode	Sex
	4*	NW1*	М
\checkmark	4*	NW1*	М
~	*	NW*	*
	*	NW*	*

2-anonymous data

* Sweeney. Achieving k-anonymity privacy protection using generalization and suppression. IJUFKS. 2002. 85



k-anonymity

<u>Pros</u>

- A baseline model
- Intuitive
- Has been implemented in real-world systems

<u>Cons</u>

- Known attacks
- Requires specifying QIDs and k

Name	Age	Postcode	Sex
Greg	40	NW10	М
Jim	45	NW15	М
Jack	22	NW30	М
Anne	50	NW25	F

External data

	Age	Postcode	Sex
	4*	NW1*	М
1	4*	NW1*	М
7	*	NW*	*
	*	NW*	*

2-anonymous data



k-map*

- Each record in a relational table T needs to have the same value over quasi-identifiers with at least k -1 records in a relational table P from which T is derived
- Probability an identified individual in P is associated with their record is at most 1/k

Name	Age	Postcode	Sex
Greg	40	NW10	Μ
Jack	40	NW10	Μ
Jim	45	NW15	Μ
John	45	NW15	Μ

	Age	Postcode	Sex
\times	40	NW10	М
	45	NW15	М

Population table

2-mapped data

* Sweeney, Computational Disclosure Control: Theory and Practice. . Massachusetts Institute of Technology, Laboratory for Computer Science, Tech Report, PhD Thesis. 2001.



k-map

<u>Pros</u>

 May allow more useful data than k-anonymity

<u>Cons</u>

- Weaker than k-anonymity
 - attacker does not know whether a record in P is in T or not
- Assumes knowledge of P
- Variations explore different mappings for better utility
 - (k,k)-anonymization*

Name	Age	Postcode	Sex
Greg	40	NW10	Μ
Jack	40	NW10	Μ
Jim	45	NW15	Μ
John	45	NW15	Μ

Population table

* Gionis et al. k-Anonymization revisited. ICDE, 2008.

	Age	Postcode	Sex
\times	40	NW10	М
	45	NW15	М

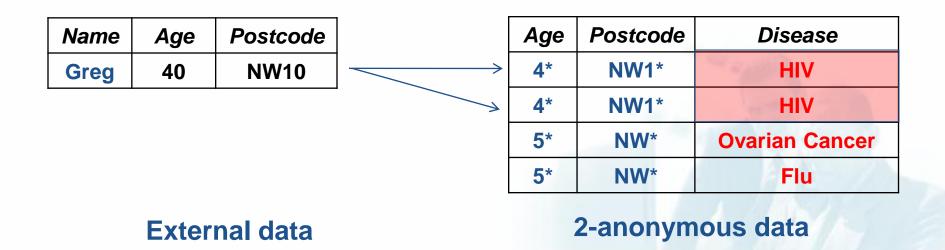
2-mapped data



Attack on k-anonymous data

Homogeneity attack*

All sensitive values in a k-anonymous group are the same
 → sensitive information disclosure





Observation

• Given a k-anonymous group G, the probability of a sensitive value u being disclosed is $\frac{f(u)}{|G|}$

Can we limit this probability to prevent sensitive information disclosure?

Age	Postcode	Disease
4*	NW1 *	HIV
4*	NW1 *	HIV
5*	NW*	Ovarian Cancer
5*	NW*	Flu
		7

The probability of "flu" being disclosed is 0.5



I-diversity principle for demographics

l-diversity*

 A relational table is <u>*l*-diverse</u> if all groups of records with the same values over quasi-identifiers (QID groups) contain no less than *l* "well-represented" values for the SA

Distinct *l*-diversity

l "well-represented" \rightarrow *l* distinct

Age	Postcode	Disease	
4*	NW1 *	HIV	
4*	NW1 *	HIV	1
4*	NW1 *	HIV	
4*	NW1 *	HIV	
4*	NW1 *	Flu	
4*	NW1*	Cancer	

Three distinct values, but the probability of *"HIV"* being disclosed is 0.67



I-diversity principles for demographics

l-diversity*

Entropy *l* –diversity

- each QID group needs to have *l* distinct values that are distributed equally enough: $Entropy(G) \ge \log(l)$
- can be too restrictive if there are some frequent values in the table (e.g., hypertension in a patient dataset)
- Recursive (c,l)-diversity
 - each QID group is (c, *l*)-diverse if and only if $r_1 < c \times (r_l + r_{l+1} + ... + r_n)$ where r_i is the i-th most frequent SA value in the group
 - Intuition: the most frequent value should not appear "too" frequently in the QID group



Addressing the limitations of I-diversity

- Sensitive values may not need the same level of protection
 (a,k)-anonymity^[1]
- *l*-diversity is difficult to achieve when the SA values are skewed
 t-closeness^[2]
- Does not consider semantic similarity of SA values
 - (e,m)-anonymity^[3], range diversity^[4]
- Can patients decide the level of protection for their SA values?
 Personalized privacy^[5]

[1] Wong et al., (alpha, k)-anonymity: an enhanced k-anonymity model for privacy preserving data publishing, KDD 2006.

[2] Li et al., t-Closeness: Privacy Beyond k-Anonymity and I-Diversity, ICDE 2007.

[3] Li et al. Preservation of proximity privacy in publishing numerical sensitive data. SIGMOD 2008.

[4] Loukides et al. Preventing range disclosure in k-anonymised data. Expert Syst. Appl. 2011.

[5] Xiao et al. Personalized privacy preservation. SIGMOD, 2006.



- Probabilistic disclosure prior knowledge of adversaries over SA values
- ρ₁-to-ρ₂ privacy^{*,**} bounds an adversary's posterior belief in a predicate of a sensitive value by ρ₂, given a bound ρ₁ on an adversary's prior belief

Definition

Given constants $\rho_1, \rho_2 \in [0,1]$ s.t. $\rho_1 < \rho_2$, *X* a sensitive value and *Y* its perturbed version, Pr[Q(X)], Pr[Q(X)|Y = y] the adversary's belief in a predicate Q(X) of *X* prior and after observing Y = y, respectively, the ρ_1 -to- ρ_2 privacy states that $Pr[Q(X)] \le \rho_1$ implies that $Pr[Q(X)|Y = y] \le \rho_2$

* Efvimievski et al. Limiting Privacy Breaches in Privacy Preserving Data Mining, PODS, 2003. ** We consider upward ρ1-to-ρ2 privacy breaches.



- Does not limit the difference between adversary's prior and posterior belief
 - 0.1-to-0.5 privacy guards against an adversary with $Pr[Q(x)] \le 0.1$ by limiting Pr[Q(x)|Y = y] to 0.5, but not against adversaries with Pr[Q(x)] > 0.1.
 - Δ -growth* satisfied when $\Pr[Q(x)] \Pr[Q(x)|Y = y] \le \Delta$, for $\Delta \in (0,1]$
- Large amount of noise needs to be added when SA has large domain sensitive values are rarely released intact
 - There are ~15K distinct ICD-9 codes, the probability of releasing a code intact is 3.3×10^4

Small-domain randomization*

- Partition table into disjoint subtables, each table has only some SA values
- Perturb values in each subtable individually to improve utility
 - Higher probability of retaining X
 - Higher probability of replacing *X* with a specific *Y* (chosen among the SA values of a subtable)

* Tao et al. On anti-corruption privacy preserving publication. ICDE, 2008.

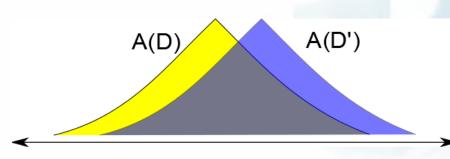
** Chaytor et al. Small domain randomization: same privacy, more utility. PVLDB, 2010.



- Objective Prevent an adversary from inferring <u>any</u> additional information about an individual, regardless of whether the published dataset contains the individual's record or not.
- ϵ -Differential privacy satisfied by a randomized algorithm A if $\Pr[A(D) = \widetilde{D}] \le e^{\epsilon} \times \Pr[A(D') = \widetilde{D}]$

for all datasets D, D' that differ in one record, and for any possible anonymized dataset \tilde{D} , where ϵ is a constant and the probabilities are over the randomness of A^{**}

• Probability of any event increases by at most $e^{\epsilon} \approx 1 + \epsilon$



* Dwork. Differential privacy. ICALP, 2006.

** Definition from Mohammed et al. Differentially private data release for data mining. KDD, 2011.



- Add random noise to f(D) (true output of a function f) to achieve *ε*-differential privacy
- Laplace mechanism^{*} Add noise from Laplace distribution $\Pr[x|\lambda] = \frac{1}{2\lambda} \times e^{-x/\lambda}$

Theorem*

For any function $f: D \to \mathbb{R}^d$, the algorithm A that adds independently generated noise with distribution $\text{Lap}(\Delta_f/\epsilon)$ to each of its *d* outputs satisfies ϵ -differential privacy, where $\Delta_f = max_{D,D'}|f(D) - f(D')|$ for all datasets D, D' that differ in one record.

Age	Sex
20	М
23	F
25	М
40	F

f - returns the number of patients with Age < 40 f(D) = 3 $\Delta_f = 1$ Add noise with distribution $Lap\left(\frac{1}{\epsilon}\right)$ to f(D) $f(\widetilde{D}) = 3 + Lap(\frac{1}{\epsilon})$

* Dwork et al. Calibrating noise to sensitivity in private data analysis. TCC, 2006.



ϵ -Differential privacy

- Exponential mechanism*
 - adding noise makes no sense in some tasks, when the output of a function is not a number (e.g., partition a dataset *D* along an attribute)
 - there is a function $u: (D \times t) \rightarrow R$ that measures the utility of an output $t \in T$ and induces a probability over the output domain
 - the exponential mechanism samples *t* from this distribution, favoring outputs with large utility

Theorem*

For any function u, an algorithm A that output t chosen from T with probability proportional to $exp(e \times \frac{u(D,t)}{2\Delta u})$ satisfies ϵ -differential privacy, where $\Delta_u = max_{\forall t,D,D'}|u(D,t) - u(D',t)|$

Age	Sex
[20-41)	{M,F}
[20-41)	{M,F}
[25-41)	{M,F}
[25-41)	{M,F}

u-scores attribute to specialize according to utility loss

exponential mechanism to select Age or Sex

* McSherry et al. Mechanism design via differential privacy. FOCS, 2007.



ϵ -Differential privacy

(+)

- semantic definition no assumptions on adversarial knowledge
- composability^[1] privacy holds even when multiple differentially-private datasets are obtained by an adversary
- many mechanisms for the interactive^[2] and the non-interactive scenario^[3,4]

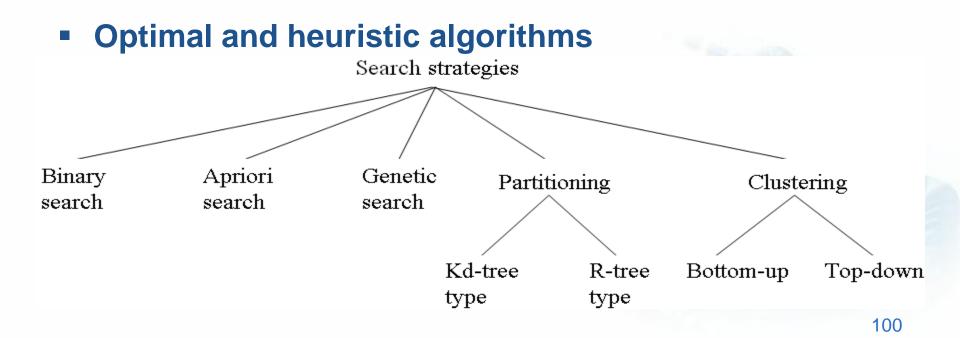
(-)

- data cannot be analyzed at a record-level (important in the medical domain)
- returned answers are noisy and, typically, of low utility
 - several variations^[5], improved mechanisms^[6]
- misconceptions^[7] and susceptibility to attacks^[8]
- [1] Ganta et al. Composition attacks and auxiliary information in data privacy. KDD, 2008.
- [2] Dwork. Differential privacy: a survey of results. TAMC, 2008.
- [3] Mohammed. Differentially private release for data mining. KDD, 2011.
- [4] Xiao et al. Differential privacy via wavelet transforms. ICDE, 2010.
- [5] Machanavajjhala et al. Data Publishing against Realistic Adversaries. PVLDB, 2009.
- [6] Ding et al. Differentially private data cubes: optimizing noise sources and consistency. SIGMOD, 2011.
- [7] Kifer et al. No free lunch in data privacy. SIGMOD, 2011.
- [8] Cormode. Personal privacy vs population privacy: learning to attack anonymization. KDD, 2011.



Anonymization algorithms for demographics

- Goal Transform data in a way that satisfies privacy with minimal utility loss
- Problem many different anonymizations and finding the one with best utility is NP-hard



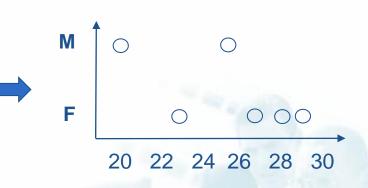


Partition-based algorithms for k-anonymity

Main idea of partition-based algorithms

- A record projected over QIDs is treated as a multidimensional point
- A subspace (hyper-rectangle) that contains at least *k* points can form a *k*-anonymous group → multidimensional global recoding

Age	Sex	Disease
20	М	HIV
23	F	HIV
25	М	Obesity
27	F	HIV
28	F	Cancer
29	F	Obesity

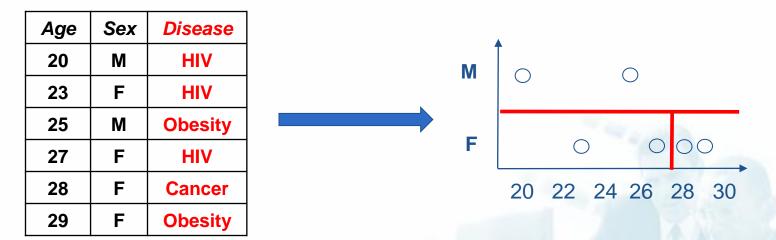




Partition-based algorithms for k-anonymity

Main idea of partition-based algorithms

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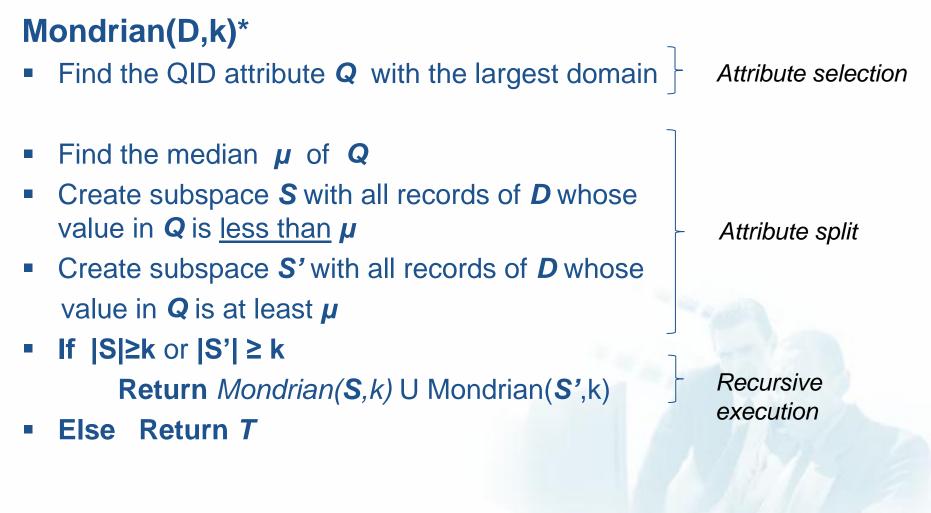


o How to partition the space?

- One attribute at a time which to use?
- How to split the selected attribute?

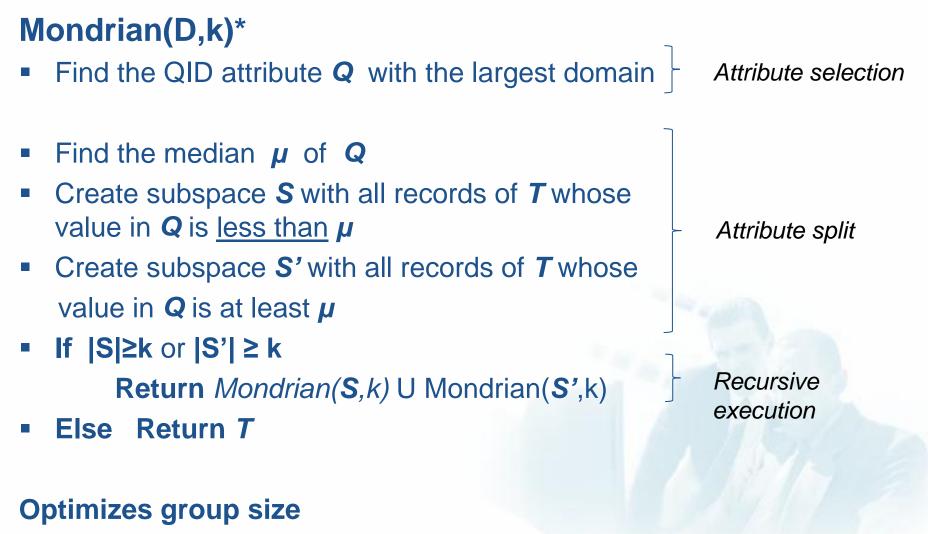


Mondrian algorithm





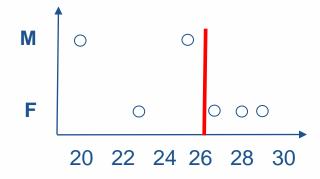
Mondrian algorithm

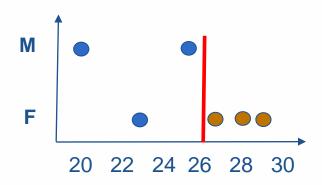


Cost: $O(|T|\log(|T|))$, where T the size of original dataset

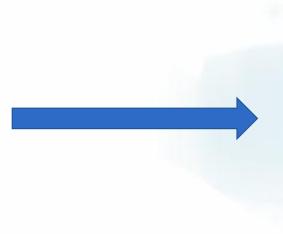


Example of applying Mondrian (k=2)





Age	Sex	Disease
20	Μ	HIV
23	F	HIV
25	Μ	Obesity
27	F	HIV
28	F	Cancer
29	F	Obesity

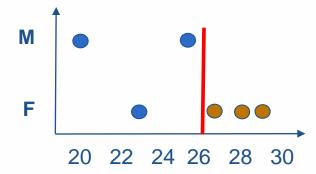


Age	Sex	Disease
[20-26]	{M,F}	HIV
[20-26]	{M,F}	HIV
[20-26]	{M,F}	Obesity
[27-29]	{M,F}	HIV
[27-29]	{M,F}	Cancer
[27-29]	{M,F}	Obesity
		105



Example of applying Mondrian (k=2)

Example of Mondrian algorithm (k=2)



 Heuristic attribute selection for efficiency 	
\rightarrow there may be better splits	



Age	Sex	Disease
[20-25]	Μ	HIV
[20-25]	Μ	Obesity
[23-27]	F	HIV
[23-27]	F	HIV
[28-29]	F	Cancer
[28-29]	F	Obesity

Age	Sex	Disease
[20-26]	{M,F}	HIV
[20-26]	{M,F}	HIV
[20-26]	{M,F}	Obesity
[27-29]	{M,F}	HIV
[27-29]	{M,F}	Cancer
[27-29]	{M,F}	Obesity



Other works on partition-based algorithms

- R-tree based algorithm^[1]
- Optimized partitioning for intended tasks ^[2]
 - Classification
 - Regression
 - Query answering

• Algorithms for disk-resident data ^[3]

• Algorithms to prevent sensitive information disclosure ^[4]

- [1] Iwuchukwu et al. K-anonymization as spatial indexing: toward scalable and incremental anonymization, VLDB, 2007.
- [2] LeFevre et al. Workload-aware anonymization. KDD, 2006.
- [3] LeFevre et al. Workload-aware anonymization techniques for large-scale datasets. TODS, 2008.
- [4] Loukides et al. Preventing range disclosure in k-anonymised data. Expert Syst. Appl. 2011.



Clustering-based anonymization algorithms

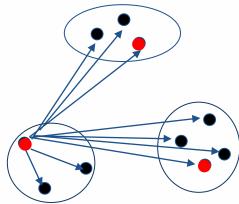
Main idea of clustering-based anonymization

1.Create clusters containing at least **k** records with "similar" values over QIDs

Seed selection

Similarity measurement

Stopping criterion



2. Anonymize records in each cluster separately

Local recoding and/or Suppression

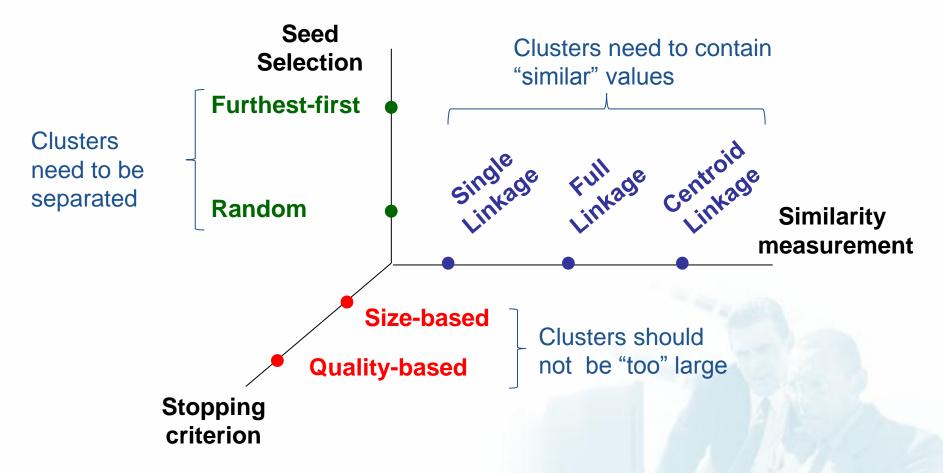
?

2

?



Clustering-based anonymization algorithms



• All these heuristics attempt to improve data utility



Bottom-up clustering algorithm*

- Each record is selected as a seed to start a cluster
- While there exists group G s.t. |G| < k
 - For each group G s.t. |G| < k
 - Find group G' s.t. $NCP(G \cup G')$ is min. and merge G and G'
 - For each group G s.t. $|G| > 2 \times k$
 - Split *G* into $\left\lfloor \frac{|G|}{k} \right\rfloor$ groups s.t. each group has at

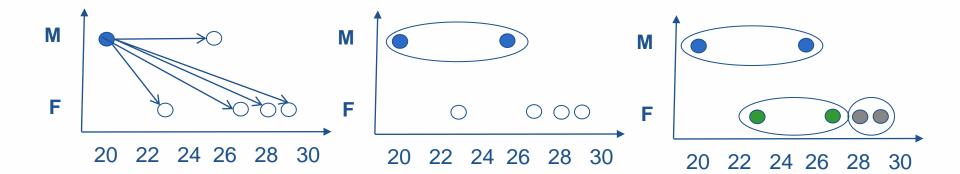
least k records

- Generalize the QID values in each group
- Return all groups

Cost: $O(|T|^2 \times \log(k))$

Example of Bottom-up clustering algorithm (k=2)





Age	Sex	Disease	Age	Sex	Disease
20	М	HIV	[20-25]	М	HIV
23	F	HIV	[20-25]	М	Obesity
25	М	Obesity	[23-27]	F	HIV
27	F	HIV	[23-27]	F	HIV
28	F	Cancer	[28-29]	F	Cancer
29	F	Obesity	[28-29]	F	Obesity



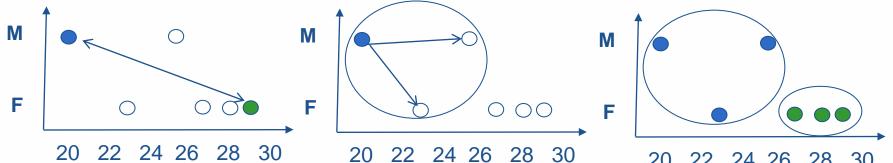
Top-down clustering algorithm*

- If $|T| \leq k$ then Return T
- Else
 - Chose two seeds s and s' from T s.t. $NCP(s \cup s')$ is maximum
 - Form a group *G* that contains *s*
 - Form a group G' that contains s'
 - For each record r in $T \{G \cup G'\}$
 - If $NCP(G \cup r) < NCP(G \cup r)$ then $G \leftarrow G \cup r$
 - Else $G' \leftarrow G' \cup r$
 - If $|G| \ge k$ then recursively partition G
 - If $|G'| \ge k$ then recursively partition G'
- Anonymize each of the final clusters separately

Cost: $O(|T|^2)$ - slightly lower than that of Bottom-up clustering

Example of top-down clustering algorithm (k=2)





20	22	24	26	28	30

Disease

HIV

Cancer

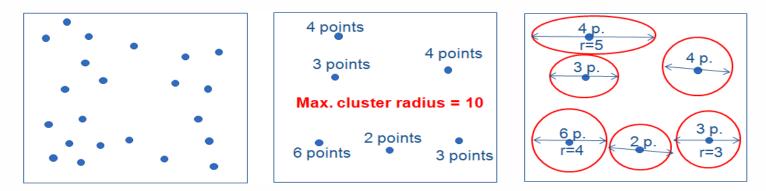
Obesity

Age [20-25	Sex [] {M,F}
[20-25] {M,F}
[20-25	5] {M,F}
[20-25	[] {M,F}
[27-29) F
[27-29) F
[27-29) F
	[20-25 [20-25 [27-29 [27-29 [27-29

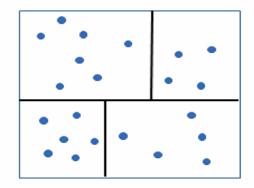


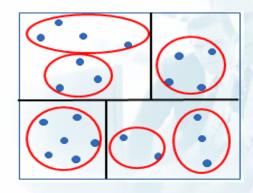
Other works on clustering-based anonymization

- Constant factor approximation algorithms*
 - Publish only the cluster centers along with radius information



Combine partitioning with clustering for efficiency**





* Aggarwal et al. Achieving anonymity via clustering. ACM Trans. on Algorithms, 2010.
 ** Loukides et al. Preventing range disclosure in k-anonymised data. Expert Syst. Appl. 2011.



Case study: US Census Data

- US Census data**
 - Adults dataset 30162 records

Attribute	Domain Size
Age	74
Gender	2
Race	5
Salary	2
Country	41
Work-Class	7
Marital Status	7
Occupation	14
Education	16

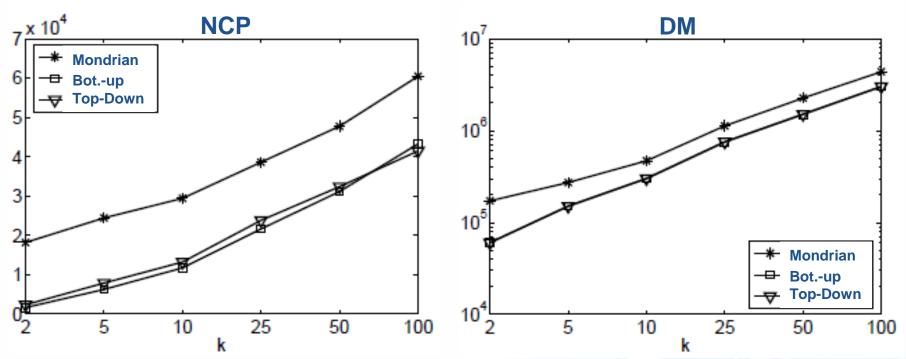
- Clustering Bottom-up, Top-down*
- Partitioning Mondrian
- How much utility is lost by anonymization? *
 - DM
 - NCP
 - RE

* Blake et al. UCI repository of machine learning databases, 1998.

** Some results are based on Xu et al. Utility-based anonymization using local recoding, KDD, 2006. 115



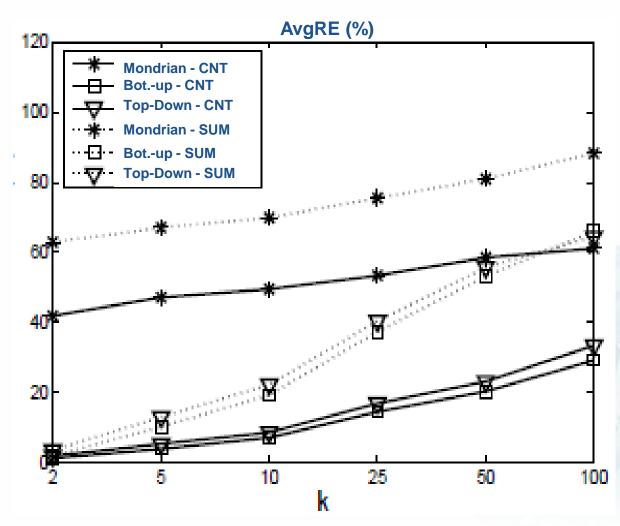
Utility vs. Privacy (varying k) – Information Loss Metrics



- Small k values better for utility
- Clustering outperforms Mondrian
- Bottom-up slightly better



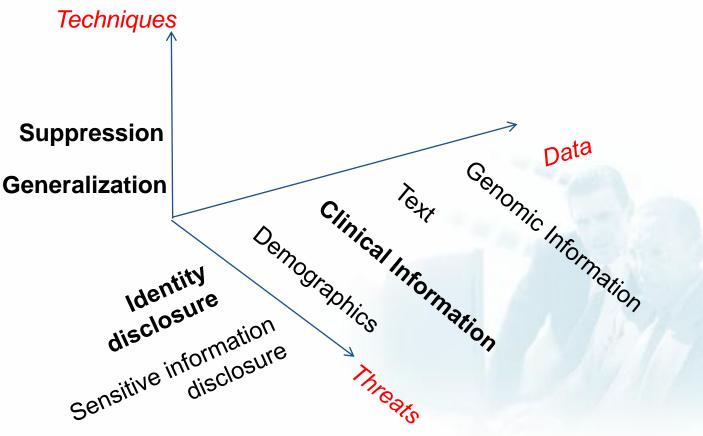
Utility vs. Privacy (varying k) – Query Answering





Research challenges and solutions

Privacy-preserving data publishing





Privacy-preserving data sharing: Clinical information

Focus on diagnosis codes

- High replication (each visit generates a number of diagnosis codes)
- <u>High availability</u> (contained in publicly available discharge summaries)
- High distinguishability (discussed already)

compared to lab results and other clinical information

The problem

- prevent the association between a patient and their record based on diagnosis codes (identity disclosure)
 - Needed to satisfy policies (HIPAA, NIH GWAS policy,...)
 - Records can be associated with DNA sequences that are highly sensitive and can be misused or abused



Complete k-anonymity

 Complete k-anonymity: Knowing that an individual is associated with any itemset, an attacker should not be able to associate this individual to less than k transactions

ICD

401.0 401.1

401.0 401.1

401 401.3

401 401.3

ICD	DNA	
401.0 401.1	ACT	
401.2 401.3	<i>GCC</i>	$ \longrightarrow $
401.0 401.1	CCA	
401.4 401.3	CAT	

Original data

2-complete anonymous data

DNA

AC...T

GC...C

CC...*A*

CA...*T*

Prevents identity disclosure

- Probability of linking an individual to their record is at most 1/k
- Guards against attackers who know any part of the record
 - e.g., physicians with access to identified EMRs



Complete k-anonymity

Complete k-anonymity: Knowing that an individual is associated with any itemset, an attacker should not be able to associate this individual to less than **k** transactions

ICD

ICD	DNA	
401.0 401.1	ACT	
401.2 401.3	<i>GCC</i>	
401.0 401.1	CCA	
401.4 401.3	CAT	

Original data

401.0 401.1 **401** 401.3 $GC \dots C$ *CC*...*A* 401.0401.1 401 401.3 *CA*...*T*

2-complete anonymous data

DNA

AC...T

- Hierarchy-based, local recoding generalization
- Information loss can be high!

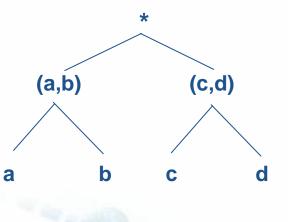




Algorithm to enforce complete k-anonymity

Greedy partitioning (Sketch)

- Start with most general data P (all values are generalized to *)
- If complete k-anonymity is not satisfied
 - Return partition
- Else
 - Find the node \mathcal{U} in the hierarchy that incurs minimum information loss if replaced by its ascendants
 - Replace \mathcal{U} with its ascendants
 - Generate all possible subpartitions of P
 - For each transaction T in P
 - distribute T into a subpartition based on its generalized items
 - Balance subpartitions so that they have at least *k* transactions
 - For each subpartition
 Recursively execute *Greedy partitioning*
- Construct anonymous dataset based on returned partitions



$$P_{(a,b)}$$
 $P_{(c,d)}$ $P_{(a,b)(c,d)}$

ICDDNAa b
$$AC...T$$
c $GC...C$ c d $CC...A$ $\Rightarrow P_{(c,d)}$ a b c d $CA...T$



k^m-anonymity

k^m-anonymity: Knowing that an individual is associated with any *m*-itemset, an attacker should not be able to associate this individual to less than *k* transactions

ICD	DNA
401.0 401.1	ACT
401.2 401.3	<i>GCC</i>
401.0 401.1	<i>CCA</i>
401.4 401.3	<i>CAT</i>

ICD	DNA
401	ACT
401	<i>GCC</i>
401	CCA
401	<i>CAT</i>

Original data

4²- anonymous data

- Prevents from identity disclosure
- Can be used to model different attacks
 - e.g., discharge summaries contain < 10 diagnoses codes → no need for complete k-anonymity to prevent the "two-step" attack

* Terrovitis et al. Privacy-preserving anonymization of set-valued data. PVLDB, 2008.



k^m-anonymity

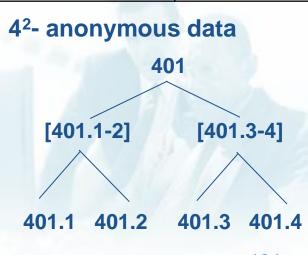
k^m-anonymity: Knowing that an individual is associated with any *m*-itemset, an attacker should not be able to associate this individual to less than *k* transactions

ICD	DNA
401.0 401.1	ACT
401.2 401.3	<i>GCC</i>
401.0 401.1	<i>CCA</i>
401.4 401.3	<i>CAT</i>

Original data

ICD	DNA
401	ACT
401	<i>GCC</i>
401	<i>CCA</i>
401	CAT

Global, full-subtree recoding more information loss than local recoding



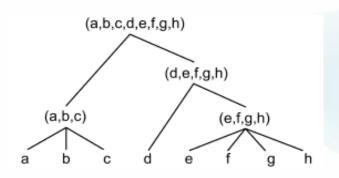
* Terrovitis et al. Privacy-preserving anonymization of set-valued data. PVLDB, 2008.



Algorithm to enforce k^m-anonymity

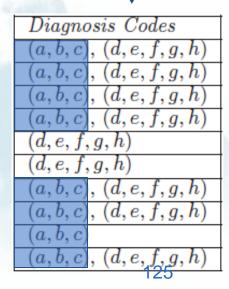
Apriori Anonymization (Sketch)

- Start with original data
- For *j*=1 to *m*
 - For each transaction T
 - Consider all the *j*-itemsets of *T* (generalized or not)
 - Find all those itemsets with support less than k
 - For each of these itemsets
 - Generate all possible generalizations
 - Find the generalization that satisfies
 k^m-anonymity and has minimum information loss



Diagnosis Codes
a, b, c, d, e, f, g, h
a, c, e, f, g
c, d, e, f, h
a, c, e, f
e, f, g, h
d, e, f, g
a, b, d, e
a, c, f
a, c
b, h

5³-anonymity

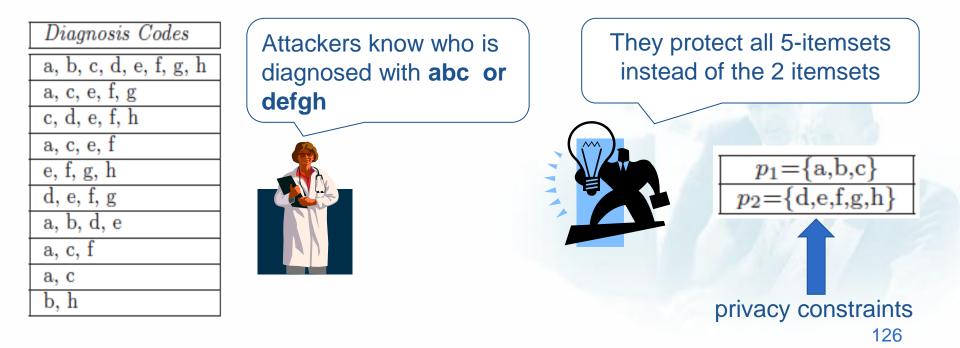




Applicability of complete k-anonymity and k^m-anonymity to medical data

Limited in the specification of privacy requirements

- Assume powerful attackers
 - all *m*-itemsets (combinations of *m* diagnosis codes) need protection
- but... medical data publishers have <u>detailed</u> privacy requirements

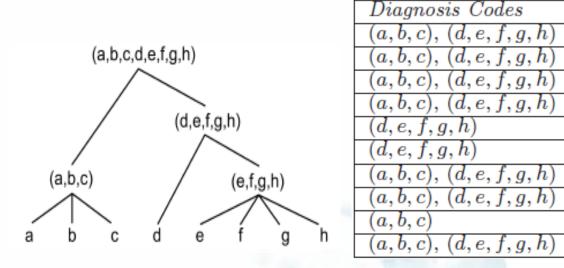




Applicability of complete k-anonymity and k^m-anonymity to medical data

Explore a small number of possible generalizations

Full sub-tree generalization a,b cannot be replaced by (a,b) c,e cannot be replaced by (c,e)



Do not take into account utility requirements

• Can we perform GWAS as accurately as if we had original data?



Policy-based Anonymization: privacy model

- Data publishers specify diagnosis codes that need protection
- Privacy Model: Knowing that an individual is associated with one or more specific itemsets (privacy constraints), an attacker should not be able to associate this individual to less than k transactions

ICD	DNA		ICD	DNA
401.0 401.1	ACT		401.0 401.1	ACT
401.2 401.3	<i>GCC</i>	\longrightarrow	(401.2, 401.4) 401.3	<i>GCC</i>
401.0 401.1	<i>CCA</i>		401.0 401.1	<i>CCA</i>
401.4 401.3	<i>CAT</i>		(401.2, 401.4) 401.3	<i>CAT</i>

Original data

Anonymized data

Privacy Policy: The set of all specified privacy constraints



Policy-based Anonymization: privacy model

 Privacy achieved when all privacy constraints are supported by at least k transactions in the published data or are not supported

ICD	DNA
401.0 401.1	ACT
401.2 401.3	<i>GCC</i>
401.0 401.1	<i>CCA</i>
401.4 401.3	<i>CAT</i>

	ICD	DNA
	401.0 401.1	ACT
\rightarrow	(401.2, 401.4) 401.3	<i>GCC</i>
	401.0 401.1	<i>CCA</i>
Ŕ	(401.2, 401.4) 401.3	<i>CAT</i>

Original data

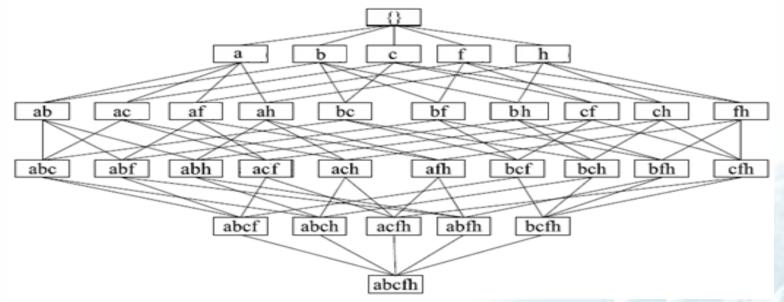
Anonymized data

- Protection against identity disclosure
 - Probability of re-identification given the data and the specified sets of ICD codes ≤ 1/k
- Automatic construction of privacy policies from hospital discharge summaries – PPE algorithm



Policy-based Anonymization: data utility considerations

- Published data must remain as useful as the original data for conducting a GWAS on a disease
- Set-based anonymization to search a large part of the solution space

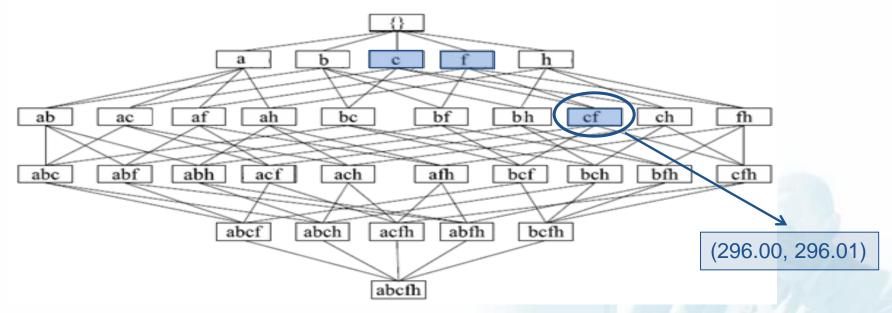


Minimize the Utility Loss (UL) measure



Policy-based Anonymization: data utility considerations

- Utility Constraints to specify the maximum level of anonymization
- Enforcing utility constraints guarantees data utility for GWAS
 - the number of cases and controls are preserved



 Utility constraints can be specified manually or extracted from electronic medical records (UPE algorithm)



UGACLIP (sketch)

- While the Privacy Policy is not satisfied
 - Select the privacy constraint **p** that corresponds to most patients
 - While p is not satisfied
 - Select the ICD code *i* in *p* that corresponds to fewest patients
 - If *i* can be anonymized according to the Utility Policy
 - generalize i to (i,i')
 - Else

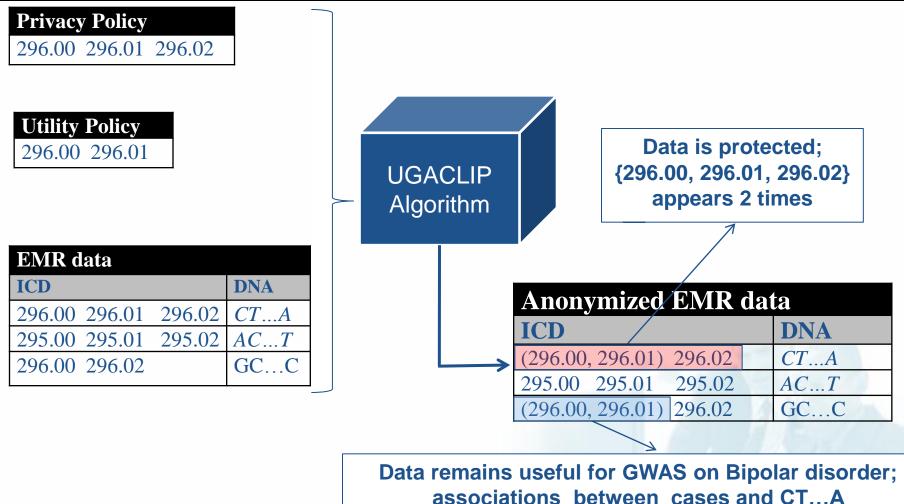
suppress each unprotected ICD code in *p* Considers one privacy constraint at a time

Protects a privacy constraint by set-based anonymization

- Generalization when Utility Policy is satisfied
- otherwise suppression



Example of UGACLIP algorithm (k=2)



and controls and CT...A are preserved

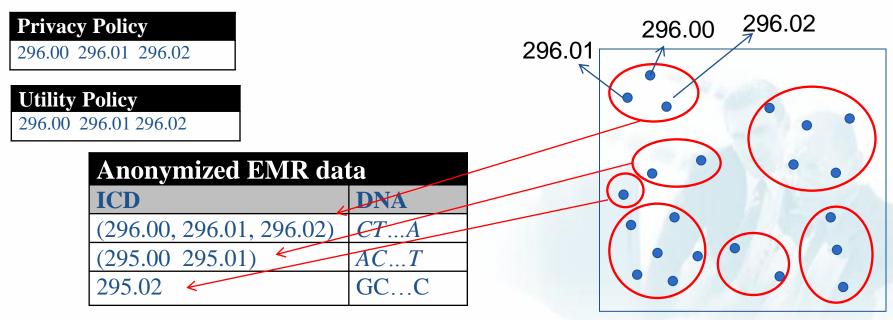


Clustering-Based Anonymization (CBA) algorithm

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CBA (Sketch)

- Retrieve the ICD codes that need less protection from the Privacy Policy
 - Gradually build a cluster of codes that can be anonymized according to the utility policy and with minimal UL
- If the ICD codes are not protected
 - Suppress no more ICD codes than required to protect privacy



*Loukides et al. Privacy-Preserving publication of diagnosis codes for effective biomedical analysis. IEEE ITAB, 2010.



Case Study: EMRs from Vanderbilt University Medical Center

Datasets

- VNEC 2762 de-identified EMRs from Vanderbilt involved in a GWAS
- VNECkc subset of VNEC, we know which diseases are controls for others
- We have seen that sharing VNEC and VNECkc intact risks identity disclosure and that simple solutions are insufficient

Methods

- UGACLIP and CBA
- ACLIP (state-of-the-art method it does not take utility policy into account)



Case Study: EMRs from Vanderbilt University Medical Center

		VNEC			
	Disease	CBA	UGACLIP	ACLIP	
Diseases related to all GWAS ever conducted*	Asthma	\checkmark	\checkmark		
	Attention deficit with				
	hyperactivity	\checkmark			
	Bipolar I disorder		\checkmark		Result of ACLIP is
	Bladder cancer	\checkmark			useless for
	Breast cancer	\checkmark	\checkmark		
	Coronary disease		 ✓ 		validating GWAS
	Dental caries	\checkmark	V		
	Diabetes mellitus type-1		V		UGACLIP preserves
	Diabetes mellitus type-2	,	V		
	Lung cancer	V	v		11 out of 18 GWAS
	Pancreatic cancer	V	\checkmark		
	Platelet phenotypes	V	/		
	Pre-term birth	~	v		CBA 14 out of 18
	Prostate cancer	V	✓		GWAS simultaneously
	Psoriasis	V			
	Renal cancer	V			
	Schizophrenia	V			
	Sickle-cell disease	\checkmark			

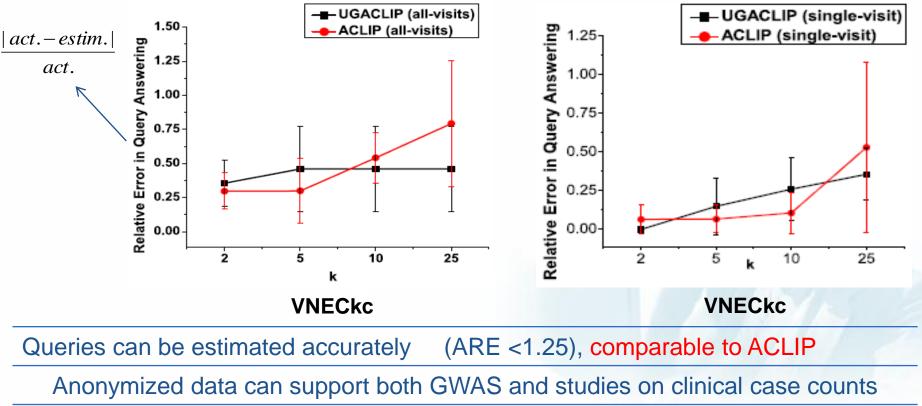
* Manolio et al. A HapMap harvest of insights into the genetics of common disease. J Clinic. Inv. '08. 136



Case Study: EMRs from Vanderbilt University Medical Center

Supporting clinical case counts in addition to GWAS

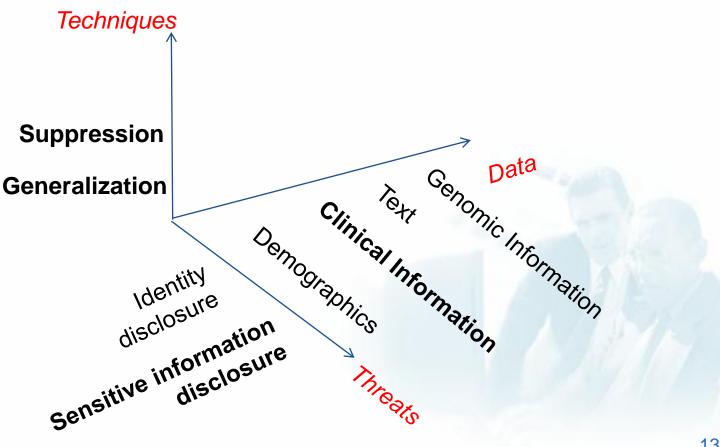
- learn number of patients with sets of codes in ≥10% of the records
- useful for epidemiology and data mining applications





Research challenges and solutions

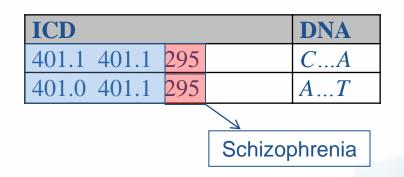
Privacy-preserving data publishing





Sensitive information disclosure for clinical information sharing

- Certain diagnosis codes are sensitive
 - HIV, Alcohol abuse, etc.
- Preventing identity disclosure may not be sufficient → homogeneity attacks on diagnosis codes





(h,k,p)-coherence

- (h,k,p)-coherence: Knowing that an individual is associated with any potentially identifying p-itemset, an attacker should not be able to:
 - associate this individual to < k and >0 transactions, and
 - infer a sensitive item with a probability larger than 1/h

ICD	DNA		ICD	DNA
401.0 401.1	ACT		401.0 401.1	<i>ACT</i>
401.2 401.3 295	<i>GCC</i>	\sim	(401.2, 401.4) 295	<i>GCC</i>
401.0 401.1	CCA		401.0 401.1	<i>CCA</i>
401.4	CAT		(401.2, 401.4)	<i>CAT</i>

Original data

(2,2,2)-coherent data

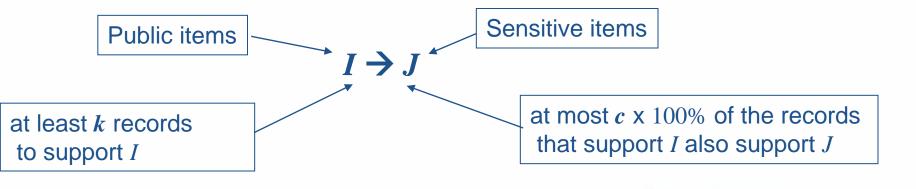
- Protection from both identity and sensitive information disclosure
 - *p* plays the role of m in k^m-anonymity
- Enforced through a global suppression algorithm

* Xu et al. Anonymizing transaction databases for publication. KDD, 2008.



• PS-rules model – more general than (h,k,p)-coherence

supports detailed privacy requirements



(preventing identity disclosure)

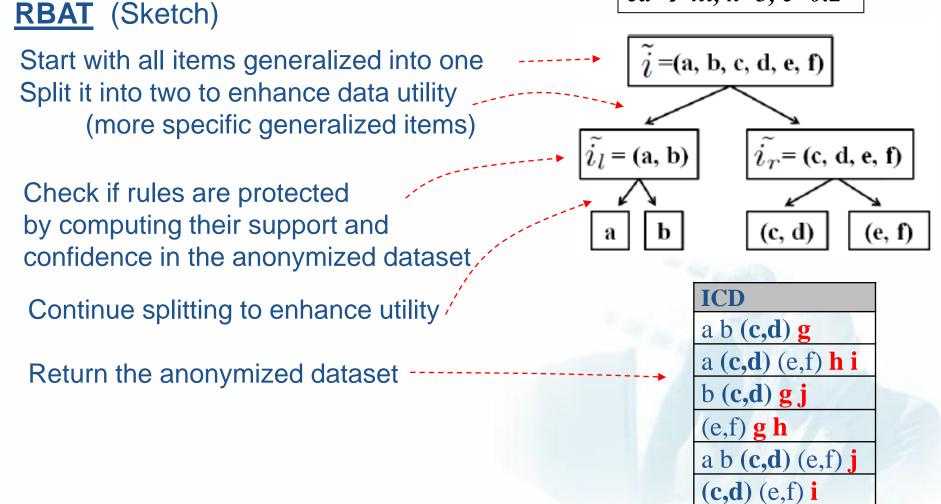
ICD	DNA
401.0	ACT
(401.2, 401.4) 295	<i>GCC</i>
401.3	CCA
(401.2, 401.4)	<i>CAT</i>

(preventing sensitive information disclosure)

401.2 \rightarrow 295 is protected for k=2, c=0.5 because (401.2,401.4) is supported by 2 records and only one of them supports 295

Rule-Based Anonymization of Transactions (RBAT) algorithm

$$cd \rightarrow hi, k=5, c=0.2$$





Other works on anonymizing clinical information

- ρ-uncertainty^[1]
 - Attackers may use both public and sensitive items to infer sensitive information
 - Limit the probability of inferring any sensitive code
 - Enforced through non-sensitive code generalization and/or sensitive code suppression
 - Does not prevent identity disclosure

Other k^m-anonymity algorithms

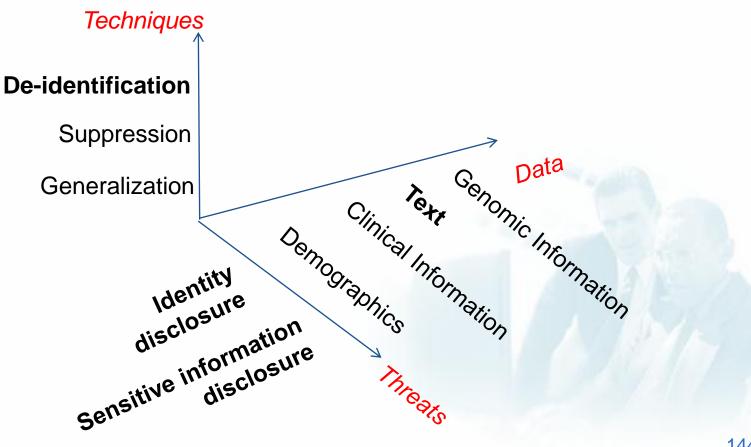
- Local recoding^[2]
- Disassociation^[3]

[1] Cao et al. ρ-uncertainty: Inference-Proof Transaction Anonymization. PVLDB, 2010.
[2] Terrovitis et al. Local and Global Recoding Methods for Anonymizing Set-valued Data. VLDBJ, 2010.
[3] Terrovitis et al. Privacy Preservation by Disassociation. TR-IMIS-2010-1, 2010.



Research challenges and solutions

Privacy-preserving data publishing





- EMRs contain a considerable amount of unstructured data
 - Clinical notes
 - SOAP (Subjective, Objective, Assessment, Patient care plan) notes
 - Radiology and pathology reports
 - Discharge summaries

 CLINICAL HISTORY: 77 year old female with a history of B-cell lymphoma (Marginal zone, SH-02-22222, 6/22/01). Flow cytometry and molecular diagnostics drawn.

 tics drawn.

- Clinical text de-identification is a 2-step process
 - Detect personal identifiers (e.g., name, record#, SSN)
 - Replace or remove the discovered personal identifiers
- Goal: integrity of medical information remains intact while personal identity is effectively concealed



- Named Entity Recognition (NER)
 - Locate atomic elements in text (HIPAA-compliant personal identifiers)
 - Classify elements into pre-defined categories (e.g., name, address, phone)

Grammar-based or Rule-based approaches

- Hand-coded rules and dictionaries (e.g., common names)
- Regular expressions for identifiers that follow a syntactic pattern (e.g., phones, zip codes)

Statistical learning approaches

- Rely on manually annotated training data with pre-labeled identifiers
- Build a classifier to classify the terms of previously unseen (test) data as *identifier* or *non-identifier*
- Feature sets: terms, local/global context, dictionary-related features
- <u>Techniques</u>: Maximum Entropy model, HMMs, SVMs, etc.



Scrub system

Rule-based and dictionary-based system

Detection strategy

- Several detection algorithms
- Aim to recognize specific entities by using rules and lists
- Operate in parallel to label entities as names, addresses, dates, etc.
- Share results and compete based on the certainty of their findings
- The algorithm with highest certainty prevails

Replacement strategy

- Associated with each detection algorithm is a replacement algorithm
- Consistent replacement for names, cities, etc.; lumping for dates

Evaluation

- pediatric medical records: 275 patients; 3198 letters to referring physicians
- 99-100% of personally identifying information was reported to be detected



DE-ID system

- Rule-based and dictionary-based software (DE-ID Data Corp 2004)
- Works with archives of several types of clinical documents
- Supports the 17 HIPAA-specified ids (excl. photo) + more
- Detection strategy
 - Uses rules and dictionaries to identify patient and provider names
 - Uses the UMLS database to identify medical phrases
 - Uses pattern matching to detect phone numbers and zip codes

Replacement strategy

- Identifying terms are replaced by specific tags
- A consistent replacement strategy is used for names, dates, etc.

Evaluation

- Datasets of surgical pathology reports from University of Pittsburgh medical center
- DE-ID reports were evaluated by four pathologists
- No precision or recall were reported

^{*} D. Gupta, et al., Evaluation of a de-identification software engine to share pathology reports and clinical documents for research, *American Journal of Clinical Pathology*, 2004.



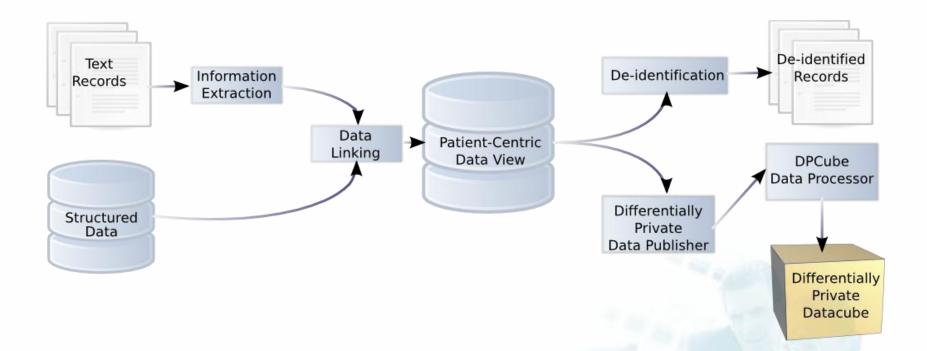
DE-ID system

Example of a clinical report that was de-identified using DE-ID

De-identified VUMC Record	Resynthesized Record
PHYSICIAN: **NAME[WWW VVV], M.D.	PHYSICIAN: Dudley, Jane Carmen, M.D.
PATIENT: **NAME[AAA, BBB M].	PATIENT: Ahmad, Jane Q.
MRN: **ID-NUM	MRN: ID43729
ADMITTED: **DATE[Jan 17 2003]	ADMITTED: Aug 21 2003
DISCHARGED: **DATE[Jan 20 2003]	DISCHARGED: Aug 24 2003
**NAME[BBB AAA] is a **AGE[over 89]-	Jane Ahmad is a 95-year-old woman with a
year-old woman with a history of a left renal	history of a left renal mass who presented for
mass who presented for laparoscopic partial	laparoscopic partial nephrectomy She was
nephrectomy She was instructed to follow up	instructed to follow up with Dr. Williams in one
with Dr. **NAME[UUU] in one week. She was	week. She was given prescription for Percocet
given prescription for Percocet for pain control	for pain control



Health Information DEidentification (HIDE)



*"a configurable, integrated framework for publishing and sharing health data while preserving data privacy"***

* L. Xiong et al. Privacy-Preserving Information Discovery on EHRs. *Information Discovery on Electronic Health Records*, 2008. ** http://www.mathcs.emory.edu/hide/ (open-source software, Emory University)



- Open source system using statistical learning for text de-id
- Detection strategy: iterative process for classifying + retagging
 - A tagging interface allows users to annotate medical data with identifying attributes to build the training set
 - A feature generation component extracts the features from text to build a Conditional Random Field (CRF) classifier
 - The CRF classifier is employed to classify terms into multiple classes
 - Data post-processing strategies are used to feed the classified data back to the tagging software for retagging and corrections

Replacement strategy

• Suppression or term generalization

Evaluation

- Dataset of pathology reports: 100 reports
- Precision and recall are reported to be ~ 97%

t-plausibility

- Generalizes sensitive terms to semantically related terms (e.g., "tuberculosis" → "infectious disease")
- <u>t-plausibility</u>^{*}: Given word ontologies and a threshold t, the sanitized text can be associated with at least t texts; any of them could be the original text

A Sacramento resident purchased marijuana for the lumbar pain caused by liver cancer.

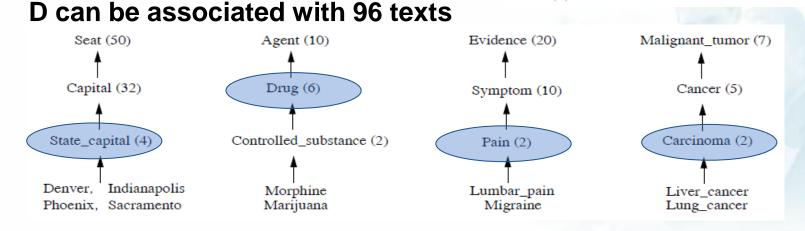
(a) Sample text

A Sacramento resident purchased marijuana for the lumbar pain caused by liver cancer.

(b) Sanitized text

A state capital resident purchased drug for the pain caused by carcinoma.

(c) Semantic preserving sanitized text

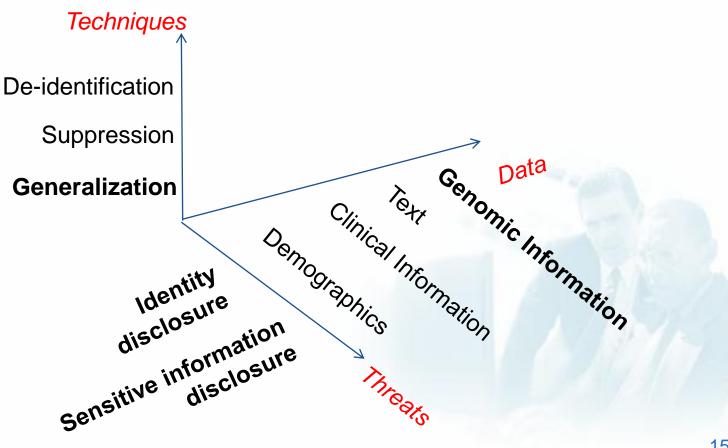


* Jiang et al. t-Plausibility: Semantic Preserving Text Sanitization. CSE, 2009.



Research challenges and solutions

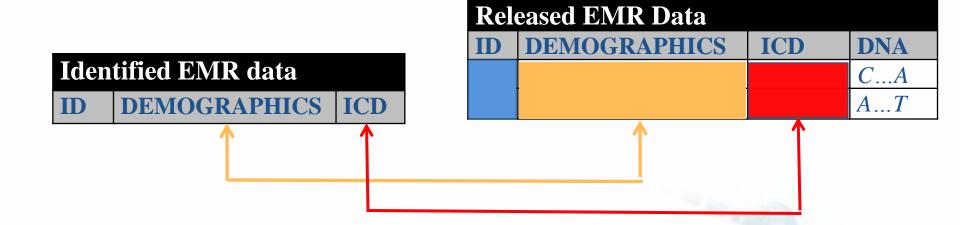
Privacy-preserving data publishing





DNA sequence privacy

So far, we showed how to prevent two linkages



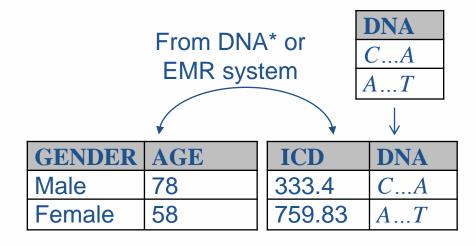


What if DNA sequences themselves reveal sensitive information?



Genotype-Phenotype attack

Disease in Medical Release Data	Known Gene	Illness and Progression	
Huntington's Chorea	HD	Imminent degeneration and death	
Sickle Cell Anemia	Strong	g correlation	
Fragile X	betweer	between age of onset	
Refsum's Disease	and DNA mutation		
Phenylketo- nuria	РАН	Treatment available	
Methemo- globinemia	HBB, HBA1, DIA1	Treatment available	
Galactosemia	GALT	Treatment available	
Amyotrophic Lateral Sclerosis (ALS)	SOD1	Imminent degeneration and death	
Friedrich's Ataxia	Frataxin	Imminent degeneration and death	



 \bowtie

ID	GENDER	AGE
John Doe	Male	78
Mary Ann	Female	58

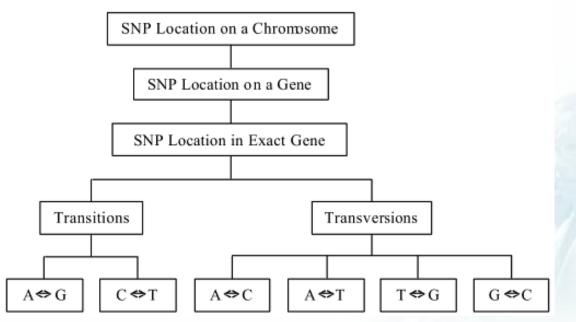
From Voter lists or EMR system

* Malin et al. Determining the Identifiability of DNA Database Entries. AMIA, 2000.



Binning

- Main idea*: Apply a two-step generalization on SNPs using a hierarchybased model so that
 - at least **B** SNPs in a genomic sequence have the same value
 - at least **B'** genomic sequences have the same value for a specific set of SNPs.
- Generalization hierarchy



* Lin et al. Using binning to maintain confidentiality of medical data. AMIA, 2002.

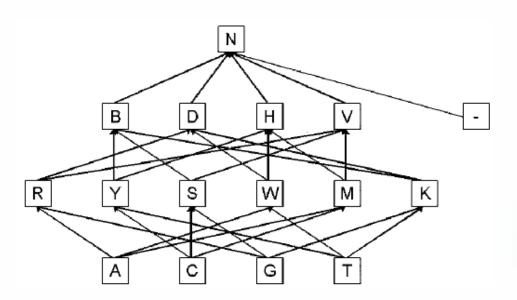


Binning strategies

- To generalize SNPs in a genomic sequence
 - Bottom-up search using the generalization hierarchy
 - nodes are generalized to their closest ancestors one by one until at least *B* SNPs have the same value
- To generalize different SNPs of different genomic sequences
 - Consider all combinations of SNPs one by one
 - starting with the one that is the least represented in the data until at least B' sequences are indistinguishable w.r.t. the SNPs
- B and B' are bin size parameters to control the utility/privacy trade-off
 - similar to **k** in k-anonymity



- The DNA Lattice generalization method* attempts to reduce information loss by
 - Using a lattice (the union of all possible trees for single nucleotide hierarchies) instead of a generalization hierarchy to represent a larger number of generalizations



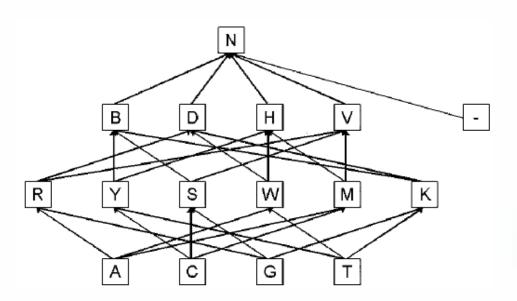
A: Adenine	C: Cytosine
G : Guanine	T : Thymine
R : Purine	Y: Pyrimadine
S: Strong hydrogen	W: Weak hydrogen
M : Amino group	K: Keto group
B: not A	D: not C
H:notG	V: not T
-:gap	N: Indeterminate

* Malin. Protecting DNA Sequence Anonymity with Generalization Lattices. Methods of Information in Medicine, 2005.



- The DNA Lattice generalization method attempts to reduce information loss by
 - Employing a distance measure based on the level of hierarchy to measure distance between two bases *x* and *y* generalized to *z*

$$d(x, y) = 2 \times level(z) - level(x) - level(y)$$

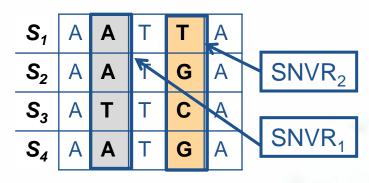


A: Adenine	C: Cytosine
G : Guanine	T : Thymine
R : Purine	Y: Pyrimadine
S: Strong hydrogen	W : Weak hydrogen
M : Amino group	K: Keto group
B:not A	D: not C
H:notG	V: not T
-:gap	N: Indeterminate



DNALA (Sketch)

 Identify Single Nucleotide Variable Regions (positions in which at least one sequence has a different value than another sequence) based on a sequence alignment algorithm



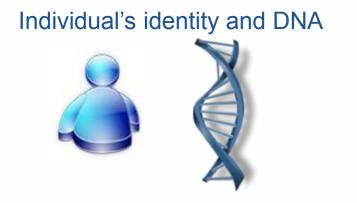
- Pair each sequence with its "closest" according to the sum of generalization distances between the set of SNVRs
- For each pair of sequences
 - Remove the gaps inserted during sequence alignment
 - Generalize according to the lattice



Homer's attack

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 Homer's attack*: Infer whether an individual is in a complex genomic DNA mixture





- Measure the difference between the distance of the individual from the mixture and the distance of the individual from the Population
 - Is individual most likely to be Case for a GWAS-related disease?
 - Is individual most likely to be Control ...?
 - Is individual equally likely to be Case or Control ... ?

* Homer et al. Resolving individuals contributing trace amounts of DNA to highly complex mixtures using high-density SNP genotyping microarrays. PLOS Genetics, 2008.



DNA privacy issues

- Privacy issues are these threats real?
 - Availability of DNA is currently limited
 - GWAS data in dbGaP is accessible only to Pis
 - Attacks
 - complex- not just joins
 - more predictive than Homer's attack*

Utility issues

- DNA has complex semantics
- Unclear how useful generalized DNA sequences are
- Algorithmic issues binning and DNALA are basic heuristics
 - no utility guarantees
 - ad-hoc objective measures
 - inefficient

* Wang et al. Learning Your Identity and Disease from Research Papers: Information Leaks in Genome Wide Association Study, CCS, 2009.





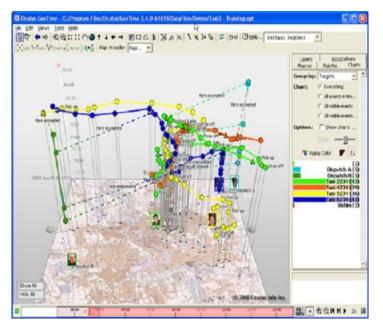
Part 1: Medical data sharing and the need for data privacy

- Part 2: Challenges and state-of-the-art solutions
- Part 3: Open problems and research directions



Complex data sharing

Medical data are inherently complex



- different types of data
 - demographics, clinical notes, lab values, images, spatiotemporal information, etc.
- lack of universal medical classification schemes
 - ICD-9 vs. ICD-10 etc.
- various forms of attacks that must be prevented while maintaining utility
 inferential and membership disclosures, etc.

... but most work focuses on simple data types and prevents a simple attack without offering utility guarantees



Large-scale, distributed data sharing

Medical data are provided by and shared with many parties

Health information exchange

- UK NHS reconsidered plans to build a centralized electronic medical record system because of privacy* and data management concerns**

Collaborative research efforts

- Biobanks, medical data repositories
- Lots of data, stored or processed, also remotely

... but most work focuses on

a static dataset that can be processed in main memory

* Anderson. Undermining data privacy in health information, BMJ, 2001

** Zhang et al. A role-based delegation framework for healthcare information systems, SACMAT, 2002.





- Medical data sharing and the need for data privacy
- Research challenges and solutions for different types of data
- Open problems and research directions



Acknowledgements

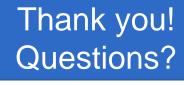
- Joshua Denny VANDERBILT
- Hariklia Eleftherohorinou

Imperial College

Efi Kokiopoulou – Google



- Jianhua Shao –
- CARDIFF UNIVERSITY
- Michail Vlachos





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