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Data Ethics and Privacy for Researchers

Kelley F. Rowan

Florida International University, krowan@fiu.edu

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Data ethics and privacy for researchers

Kelley Rowan, Digital Archives Librarian



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Agenda

Laws, Torts, and Regulations

Definitions, Getting Started, and Workflows

PII v. Personal (Sensitive) Data

Anonymization Techniques & Tools

Encryption Resources

Avoiding Anonymization

Data Anonymization Services

US Federal regulations

- **Privacy Act of 1974**
 - Governs federal records
 - <https://www.justice.gov/opcl/privacy-act-1974>
- **Children's Online Privacy Protection Act of 1988, 15 U.S.C 6501-6505**
 - <https://www.ftc.gov/enforcement/rules/rulemaking-regulatory-reform-proceedings/childrens-online-privacy-protection-rule>

- **Gramm-Leach Bliley Act, 1999 (Financial Modernization Act)**
 - Governs banks and private financial information
 - <https://www.ftc.gov/tips-advice/business-center/privacy-and-security/gramm-leach-bliley-act>
- **Family Educational Rights and Privacy Act (FERPA)**
 - <https://studentprivacy.ed.gov/ferpa>
- **Health Insurance Portability & Accountability Act (HIPAA)**
 - <https://www.hhs.gov/hipaa/for-professionals/privacy/index.html>

4 Privacy Torts: Intrusion into Seclusion;
Public disclosure of private facts and
data

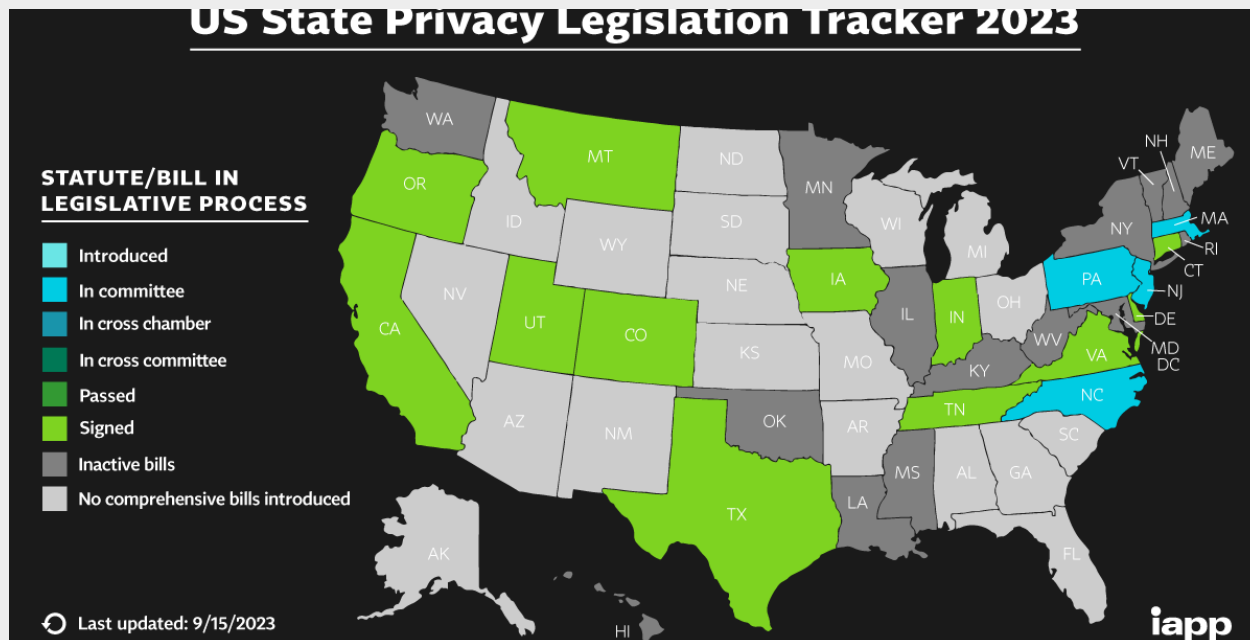
State Privacy Laws

<https://iapp.org/resources/topics/us-state-privacy/>

TITLE 1.81.5. California Consumer Privacy Act of 2018 [1798.100 - 1798.199.100]

CCPA & CPRA

link: <https://oag.ca.gov/privacy/ccpa>



California Privacy Rights Act – 2023

Link to excellent summary:

<https://www.customerlabs.com/blog/ccpa-cpra-unraveling-the-mystery-in-2023/>

Fully enforced beginning July 1, 2023

International Law

GDPR

General Data Protection Regulation (2018)

<https://gdpr.eu/>

*Secure people's data

*Make it easy for people to exercise control over their data

- **Lawfulness, fairness and transparency**— Processing must be lawful, fair, and transparent to the data subject.
- **Purpose limitation**— You must process data for the legitimate purposes specified explicitly to the data subject when you collected it.
- **Data minimization**— You should collect and process only as much data as absolutely necessary for the purposes specified.
- **Accuracy**— You must keep personal data accurate and up to date.
- **Storage limitation**— You may only store personally identifying data for as long as necessary for the specified purpose.
- **Integrity and confidentiality**— Processing must be done in such a way as to ensure appropriate security, integrity, and confidentiality (e.g. by using encryption).
- **Accountability**— The data controller is responsible for being able to demonstrate GDPR compliance with all of these principles.

RTBF

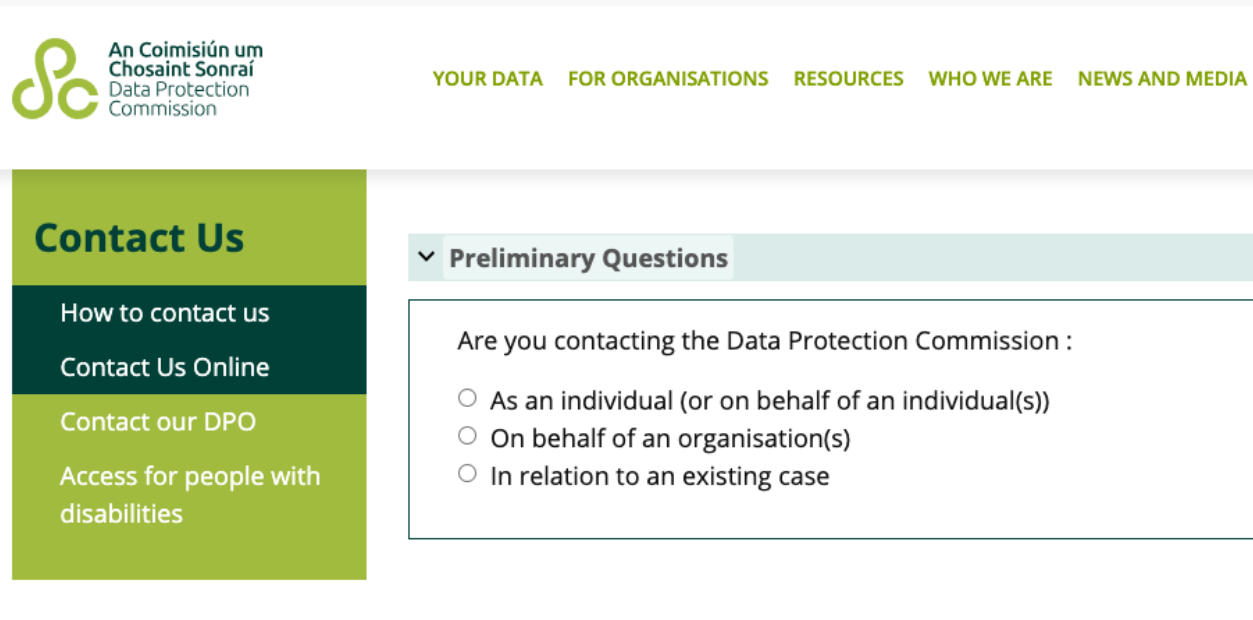
Right to be Forgotten
- erasure obligations

RTBI

Right to be Informed
- must provide a privacy policy



GDPR non-compliance consequences



The screenshot shows the website of the Data Protection Commission. The header includes the logo and name in Irish and English, and a navigation menu with links for 'YOUR DATA', 'FOR ORGANISATIONS', 'RESOURCES', 'WHO WE ARE', and 'NEWS AND MEDIA'. A left sidebar contains 'Contact Us' with sub-links for 'How to contact us', 'Contact Us Online', 'Contact our DPO', and 'Access for people with disabilities'. The main content area is titled 'Preliminary Questions' and contains the question 'Are you contacting the Data Protection Commission :' followed by three radio button options: 'As an individual (or on behalf of an individual(s))', 'On behalf of an organisation(s)', and 'In relation to an existing case'.

\$21,150,500 or 4% of profits, whichever is greater

Enforcement tracker:

<https://www.enforcementtracker.com/>

Chapter 1, Article 4 (GDPR) makes no distinction between companies and individuals

- **PCI DSS**

Payment Card Industry Data Security Standards

<https://www.pcisecuritystandards.org/>

PCI Data Handling Standards

- Do not keep physical copies
- NEVER store the CVV
- Store in a secure locked place
- Limit personnel with access
- Use security cameras in area
- Assess and securely destroy every 3 months
- Provide a privacy plan for clients

Definitions

GDPR Article 4(1)

“personal data” pertains to “any information relating to an identified or identifiable natural person (‘data subject’)”

PII = personally
identifiable
information

**Personal (sensitive)
data** = any
information related
to an individual

Data subject =
person

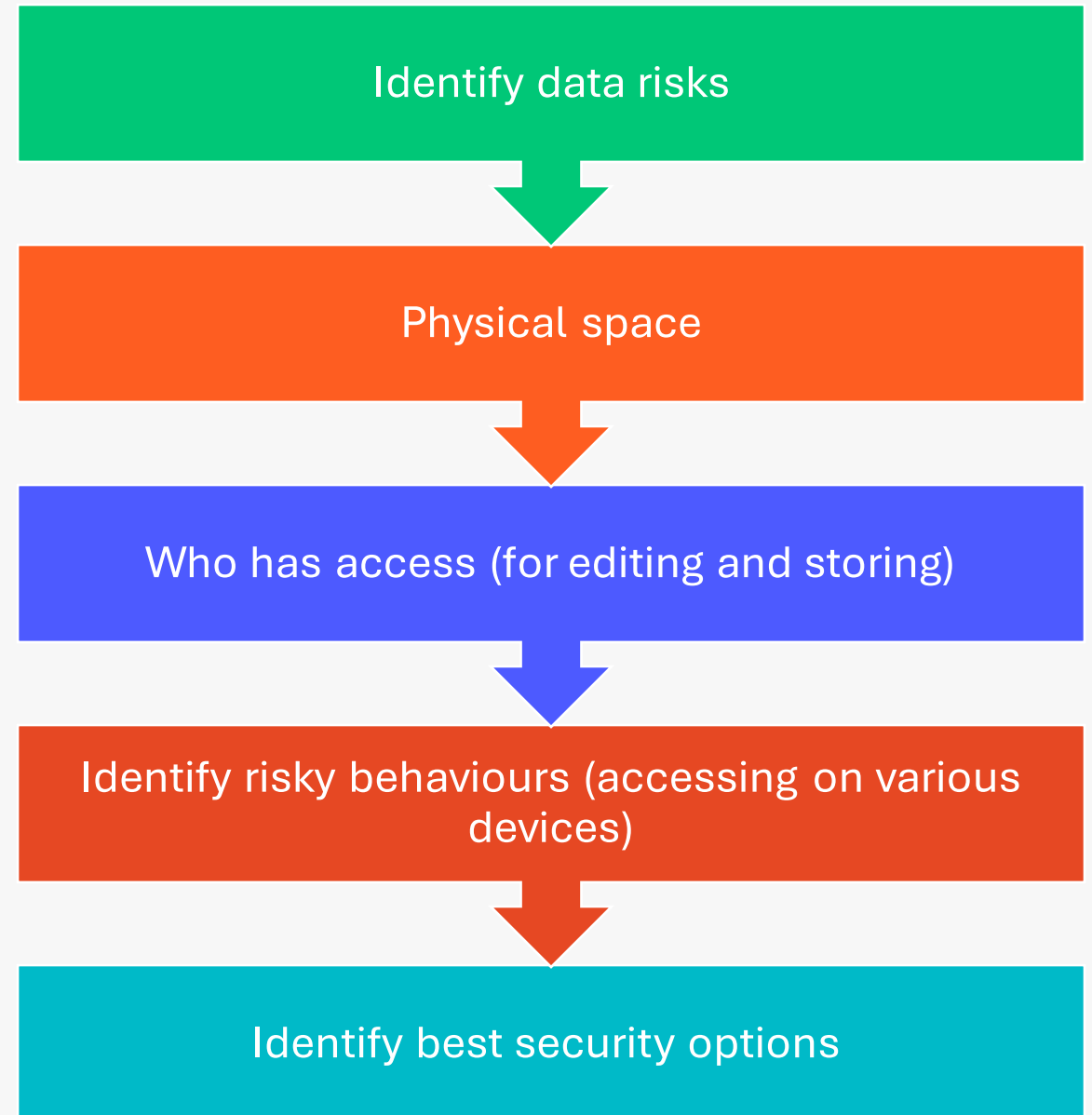
Before collecting data...

Determine your risks (impact assessment)

Develop a security plan (VPN, data anonymization)

Share your privacy policy

Impact assessment



Privacy Policy



-
- ✓ *What data will be collected*
 - ✓ *How it is collected*
 - ✓ *How it will be used and for what purpose*
 - ✓ *Who has access*
 - ✓ *How the data is stored and for how long*
 - ✓ *How the data will be securely destroyed*
 - ✓ *Contact information*

Keeping data safe with anonymization techniques



Identify

Identify your PII and sensitive data



Ascertain

Ascertain whether other individuals will need working access to the data



Determine

Determine whether the data will be published



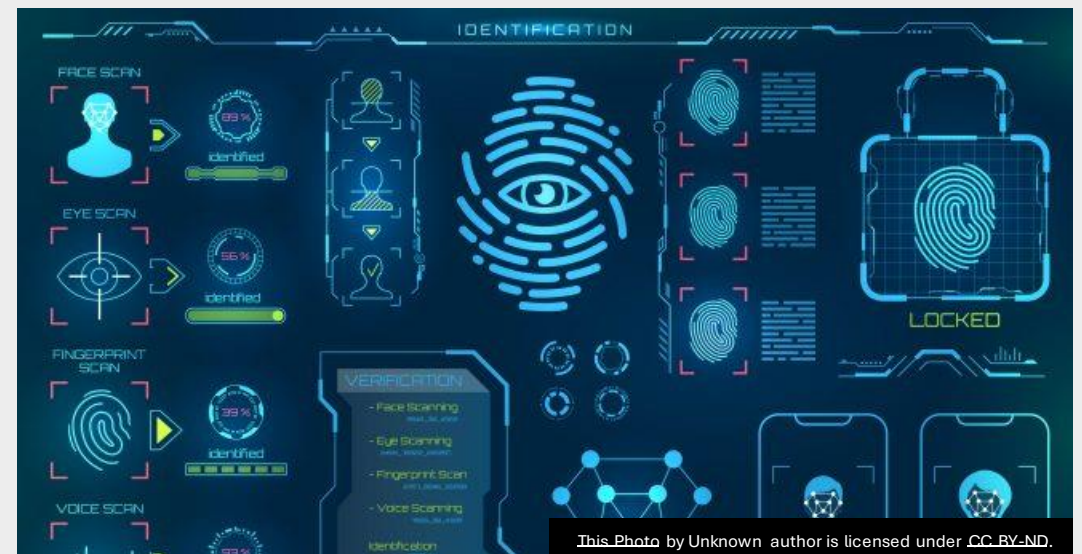
Develop a key

Secure your key

Computer Security

- ✓ *Use passphrases with 2FA*
- ✓ *Use biometrics with 2FA*
- ✓ *Use GDPR compliant tools*

<https://gdpr.eu/compliant-services/>



Workflow for teams with access to personal data

Ideal:

one person has access and anonymizes before granting access to others

Good:

2+ trusted people may work on collecting and anonymizing, including secure storage of a key.

Weak:

Everyone in the workplace has access, anonymization happens at the end before publishing.

Identifying PII and personal data

	A	B	C	D	E	F	G	H	I	J	K
1	Last Name	First Name	FI #	DC# ingest	DC# published	Notes	published	Full text pdf/a	embargo	M/PhD	Major
2	Sale	Tonia	FIDC000332	8431	3670		12.10.1998	12.10.1998		MS	Hospitality
3	Olinger	Patricia	FIDC000333	8432	3671		12.10.1998	12.10.1998	2 yrs.	PhD	Business Admin
4	Bennett	William	FIDC000334	8433	3672		12.10.1998	12.10.1998	2 yrs.	MS	speech pathology
5	Graham	Sharon	FIDC000335	8434	3673		12.10.1998	12.10.1998	1 yr.	PhD	GSS
6	Nelson	Thomas	FIDC000336	8435	3674		12.10.1998	12.10.1998		PhD	biomedical engineering
7	Warren	Carmen	FIDC000337	8436	3675		12.10.1998	12.10.1998		MS	electrical engineering
8	Scalf	Raymond	FIDC000338	8437	3676		12.10.1998	12.10.1998		MS	computer engineering

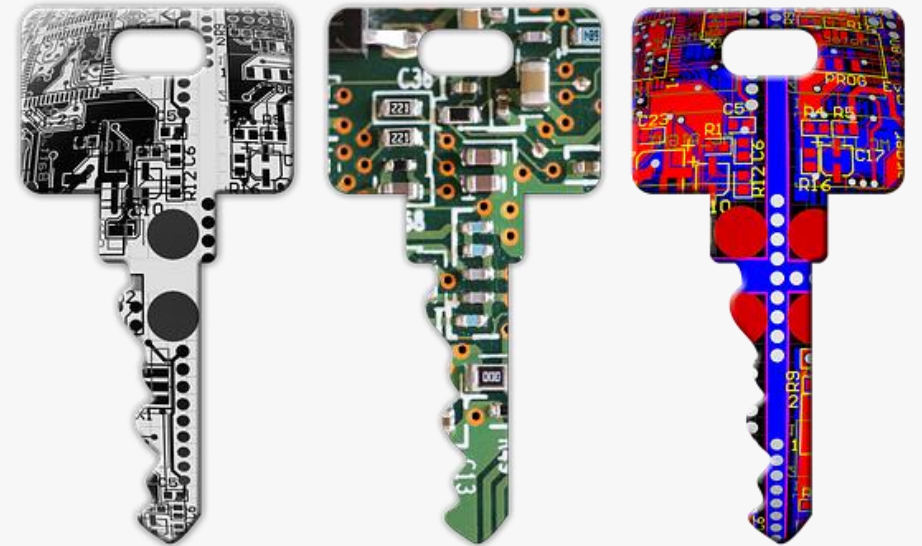
Look for possible points of re-identification!

Pseudonymization (masking)

The processing of personal data in such a way that the data can no longer be attributed to a specific data subject without the use of additional information.

Use multiple pseudonymization techniques to achieve anonymization.

Secure the key.



Anonymized data

Anonymization is the irreversible removal of information that could lead to an individual being identified.

No longer considered PII by the GDPR.

You can achieve anonymization by combining various pseudonymization techniques.



Substitution

	A	B	C
1	Last Name	First Name	FI #
2	Sale	Tonia	FIDC000332
3	Olinger	Patricia	FIDC000333
4	Bennett	William	FIDC000334
5	Graham	Sharon	FIDC000335
6	Nelson	Thomas	FIDC000336
7	Warren	Carmen	FIDC000337
8	Scalf	Raymond	FIDC000338
9	Fossum	Stephen	FIDC000339
10	Stevens	Aubrey	FIDC000340
11	Pierce	Nicole	FIDC000341

Definition:

Replacing one column or row of data with completely different values. These could be names or numbers.

Effectiveness:

Highly effective in masking data and securing privacy. Pseudonymization.

Considerations:

Full substitution of an entire group of data can attain full anonymization status and will no longer be considered sensitive data by the GDPR.

Tools:

fake name generator (free)

<https://www.fakenamegenerator.com/order.php>

	A	B	C
1	GivenName	Surname	
2	Tonia	Sale	
3	Patricia	Olinger	
4	William	Bennett	
5	Sharon	Graham	
6	Thomas	Nelson	
7	Carmen	Warren	
8	Raymond	Scalf	
9	Stephen	Fossum	
10	Aubrey	Stevens	
11	Nicole	Pierce	
12	Lillian	Saenz	

The Fake Name Generator believes in supporting the development community. To achieve this goal, we provide free bulk generated identity files. Please use the form below to place your order.

Step 1 - Read and agree to terms of service

I agree to the terms of service and understand that all generated information is fake.

Step 2 - Choose output format and compression

Output Format: Compression:

Comma separated (.csv) .zip

Step 3 - Choose name sets, countries, gender, and age

Name set

American
Arabic
Australian
Brazil
Chechen (Latin)

Country

Australia
Austria
Belgium
Brazil
Canada

Gender

Male: 50% Female: 50%

Age

19 - 85 years old

Step 4 - Choose fields to include

Fields in the box on the right will be included with your order. Use the Up/Down buttons to choose which order you want the fields in.

Not all fields are available for every country. Please use the homepage to determine what information is available for the countries you have chosen.

Don't include these:

Incrementing number
Gender
Name set
Title
Given name
Middle Initial
Surname
Street address
City
State abbreviation

>>

All >>

<<

All <<

Include these:

Up

Down

Step 5 - Enter quantity & choose delivery options

You are allowed to have three (3) orders in the queue at a time.

Estimated wait: 11 minutes

Quantity: (Maximum: 50,000 100,000)

Tools:

Random number generator

<https://numbergenerator.org/random-6-digit-number-generator#!numbers=25&length=6&addfilters=>

Random 6 Digit Number Generator

Roll

956805 820361 020941

947018 904669 691248


186730 427914 048005

A [] Options Download Copy GoClip

25 random 6 digit numbers

options Go Start

Nulling out

Last Name	First Name	FI #	DC# ingest	DC# published	Notes
XXXX	XXXX	FIDC000350	8449	3688	
XXXX	XXXX	FIDC000351	8450	3689	
XXXX	XXXX	FIDC000352	8451	3690	
XXXX	XXXX	FIDC000353	8452	3691	
XXXX	XXXX	FIDC000354	8453	3692	
					

Definition:

Replacing a data field with a null value.

Effectiveness:

Highly effective. Achieves anonymization.

Considerations:

Often reduces data integrity.

JOHN



HJNO

Scrambling

Definition:

Scrambling the letters or numbers in a data field.

Effectiveness:

Weak form of pseudonymization. The data is susceptible to being "unscrambled" and re-identified. Can be stronger for long number sequences where the same scrambling algorithm is not used in each data field.

Word Scrambler

Our Word Scramble Maker will scramble words & letters for word scramble games.



Kelley Rowan

Go

Scrambled Word

elwko nireya	eonylare kwl	or laelnekwy	ea oeylrkwnl
ae lyernkolw	wrlloeakn ey	enlea lykorw	aneerowkyll
lkwnrylaee o	alkoleweyn r	o lknlwayee	wl rlykaneeo
wla orekylen	eink erloyaw	ylaowr lkeen	llkeraywn eo
yelwolka ner	n lwlrakoeye	llo aenwyekr	oenka yllrew
y elolerwnka	rakelweyoln	waeerllokny	orleynla ekw
wela oyneklr	larny loeekw	aenlelry wok	eelylknorw a
eylnkoalew r	alrkoey ewnl	eoeynklrwal	n lrwlekyaeo

Tools:

word scrambler

<https://www.wordunscrambler.net/word-scrambler.aspx>

First Name	FI #	DC# ingest	DC# published
Tonia	FIDC000332	8431	3670
Patricia	FIDC000333	8432	3671
William	FIDC000334	8433	3672
Sharon	FIDC000335	8434	3673
Thomas	FIDC000336	8435	3674
Carmen	FIDC000337	8436	3675
Raymond	FIDC000338	8437	3676
Stephen	FIDC000339	8438	3677

First Name	FI #	DC# ingest	DC# published
Tonia	FIDC000332	8431	3670
Stephen	FIDC000333	8432	3671
Raymond	FIDC000334	8433	3672
Carmen	FIDC000335	8434	3673
Thomas	FIDC000336	8435	3674
Sharon	FIDC000337	8436	3675
William	FIDC000338	8437	3676
Patricia	FIDC000339	8438	3677

Shuffling

Definition:

Shuffling the values in a data field.

Effectiveness:

Weak form of pseudonymization if used alone. Susceptible to re-identification by determining the shuffling algorithm. Can achieve anonymization when used with other masking techniques.

Date Aging

Definition:

Choosing a random number of days to "age" a date.

Effectiveness:

Intermediate to strong form of pseudonymization. Somewhat susceptible to re-identification by determining the aging value.

published	Full text pdf/a
12.11.1998	3.16.1996
12.11.1998	3.16.1996
12.11.1998	3.16.1996
12.12.1998	3.16.1996
12.12.1998	3.16.1996

Variance



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Definition:

varying the date and number values. Common usage is with financial data.

Example:

for number values $\pm 10\%$;
dates ± 200 days

Masking out

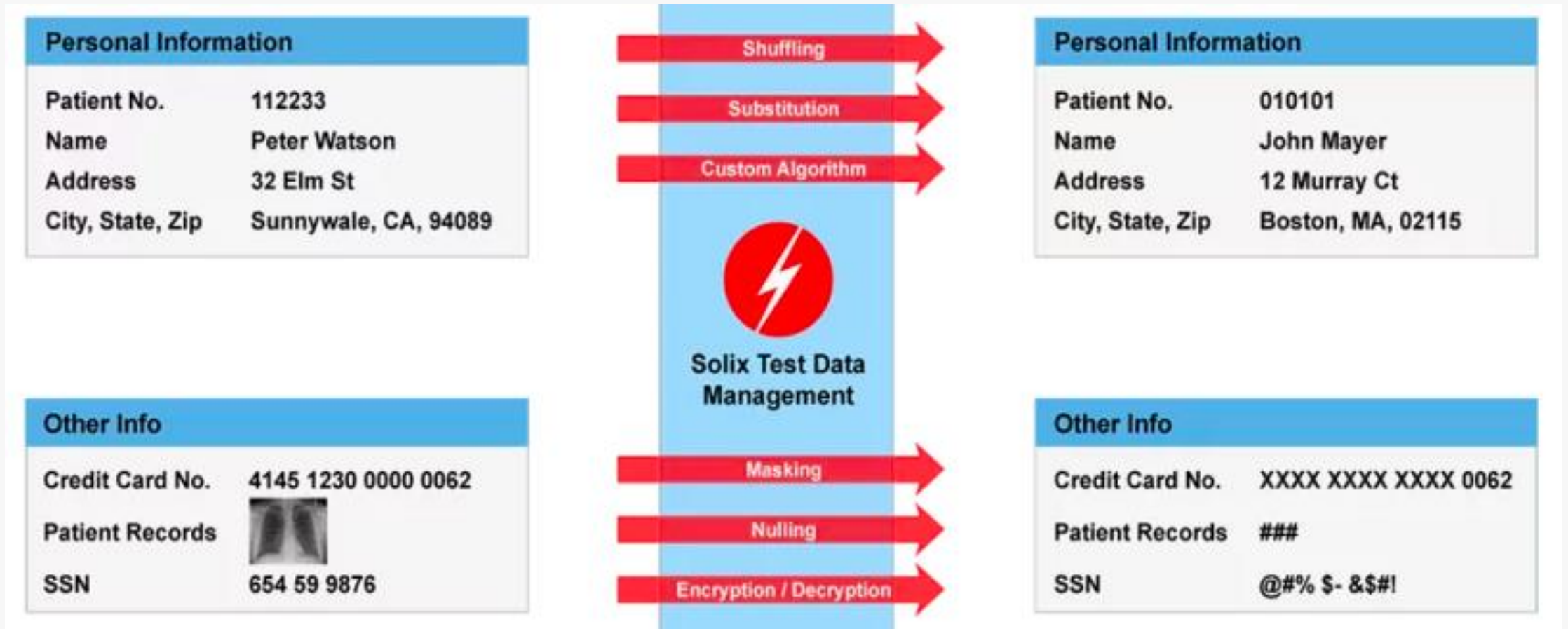
Definition:

Hiding some (not all) of the digits in a field.

e.g. xxxx-xxxx-xxxx-1079



Examples





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Size of the data group

A small group of data subjects undermine most forms of pseudonymization as anyone with knowledge of the subjects can re-identify the data.

Tools:

Fake data

<https://www.coderstool.com/fake-test-data>

Evelyn Feest Marvin Ltd Fitness Trainer 293 Vincenzo Parkway Louisiana 24060-9543 ilittel@gmail.com
Loraine Olson McLaughlin Group Agricultural Science Technician 13473 Brown Route Massachusetts 91737
turcotte.cielo@hotmail.com
Kiara Bashirian Schultz, Leannon and Miller Telemarketer 24494 Raleigh Plaza Apt. 132 West Virginia 14488 xwalker@hotmail.com
Ashley O'Keefe Lebsack-Schinner Drilling and Boring Machine Tool Setter 90882 Lynch Extensions Tennessee 59634
price52@hotmail.com
Chelsie Muller Metz, Rohan and Pacocha Shipping and Receiving Clerk 2338 Reichert Passage Iowa 63199
loraine.corwin@hotmail.com

Fake Test Data Generator Tool

Generate meaningful Fake data for test purposes

Field Type

First Name Female

Last Name

Company

Job Title

Street Address

State

Post Code

Free Email

Country

English (U.S.)

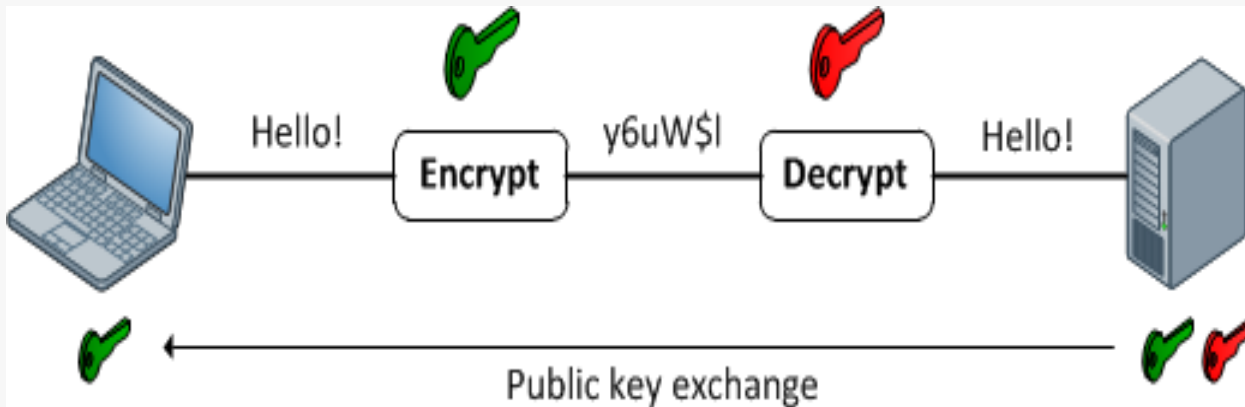
Output Rows

10

Output Delimiter

Tab

Encryption



[This Photo](#) by Unknown author is licensed under [CC BY-SA](#).

Definition:

An algorithm masks the data for you and requires a key to un-encrypt for editing and usage.

Effectiveness:

Highly effective unless the key or password to the encrypted folder is compromised.

Considerations:

Mobile versions can be less safe.

Free encryption options

1. Microsoft OneDrive

(personal vault not available for macOS)

2. Proton Drive, VPN,

Email: <https://proton.me/drive>

3. Folder Lock

<https://www.newsoftwares.net/folderlock/>

4. AxCrypt

<https://www.axcrypt.net/pricing/>

5. VeraCrypt

<https://www.veracrypt.fr/en/Downloads.html>

Other encryption options

<https://www.techradar.com/best/best-encryption-software>

For Windows

1. Secure IT 2000
2. SensiGuard
3. Renee File Protector

For macOS

1. Concealer

How to avoid anonymization

1

Do not collect any personal data

2

Do not store any personal data

3

Do not share any personal data



Survey

Workflows

Distributions

Data & Analysis

Results

Reports



Options



General

Language, title, survey description



Responses

Survey expiration, incomplete responses, back button and more



Security

Passwords, file uploads, bot detection and more

Post-Survey

Thank you emails, completed survey messages, and triggers

Advanced

Scoring

Attach point values to specific answers



Saved at 5:33 PM

Draft

a website or tag the response.

Off

Prevent indexing

Block search engines from including your survey in their search results.

On

Uploaded files access

Indicate who should be able to view files uploaded by respondents

- Only users with permission to view responses
- Anyone with the link to the file

Anonymize responses

Don't record respondents' IP Address, location data, and contact info.

On

Data anonymization services



1. Accelario

<https://accelario.com/>

2. Anonos

<https://www.anonos.com/product-overview?hsLang=en>

3. K2View

<https://www.k2view.com/>

Considerations:

Be sure services used do not receive actual data, but data already encrypted.

Kelley Rowan

Digital Archives Librarian

[*krowan@fiu.edu*](mailto:krowan@fiu.edu)



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