

## NIST Special Publication NIST SP 800-188

# **De-Identifying Government Datasets: Techniques and Governance**

Simson Garfinkel Joseph Near Aref N. Dajani Phyllis Singer Barbara Guttman

This publication is available free of charge from: https://doi.org/10.6028/NIST.SP.800-188



## NIST Special Publication NIST SP 800-188

# **De-Identifying Government Datasets: Techniques and Governance**

Simson Garfinkel Barbara Guttman Software Quality Group Software and Systems Division

Joseph Near Department of Computer Science University of Vermont

Aref N. Dajani Phyllis Singer Center for Enterprise Dissemination US Census Bureau

This publication is available free of charge from: https://doi.org/10.6028/NIST.SP.800-188

September 2023



U.S. Department of Commerce Gina M. Raimondo, Secretary

National Institute of Standards and Technology Laurie E. Locascio, NIST Director and Under Secretary of Commerce for Standards and Technology Certain commercial equipment, instruments, software, or materials, commercial or non-commercial, are identified in this paper in order to specify the experimental procedure adequately. Such identification does not imply recommendation or endorsement of any product or service by NIST, nor does it imply that the materials or equipment identified are necessarily the best available for the purpose.

There may be references in this publication to other publications currently under development by NIST in accordance with its assigned statutory responsibilities. The information in this publication, including concepts and methodologies, may be used by federal agencies even before the completion of such companion publications. Thus, until each publication is completed, current requirements, guidelines, and procedures, where they exist, remain operative. For planning and transition purposes, federal agencies may wish to closely follow the development of these new publications by NIST.

Organizations are encouraged to review all draft publications during public comment periods and provide feedback to NIST. Many NIST cybersecurity publications, other than the ones noted above, are available at https://csrc.nist.gov/publications.

This document is presented with the hope that its content may be of interest to the general privacy community. The views in this document are those of the authors, and do not represent those of the U.S. Census Bureau.

#### Authority

This publication has been developed by NIST in accordance with its statutory responsibilities under the Federal Information Security Modernization Act (FISMA) of 2014, 44 U.S.C. § 3551 et seq., Public Law (P.L.) 113-283. NIST is responsible for developing information security standards and guidelines, including minimum requirements for federal information systems, but such standards and guidelines shall not apply to national security systems without the express approval of appropriate federal officials exercising policy authority over such systems. This guideline is consistent with the requirements of the Office of Management and Budget (OMB) Circular A-130.

Nothing in this publication should be taken to contradict the standards and guidelines made mandatory and binding on federal agencies by the Secretary of Commerce under statutory authority. Nor should these guidelines be interpreted as altering or superseding the existing authorities of the Secretary of Commerce, Director of the OMB, or any other federal official. This publication may be used by nongovernmental organizations on a voluntary basis and is not subject to copyright in the United States. Attribution would, however, be appreciated by NIST.

#### **NIST Technical Series Policies**

Copyright, Use, and Licensing Statements NIST Technical Series Publication Identifier Syntax

#### **Publication History**

Approved by the NIST Editorial Review Board on 2023-09-07.

#### How to cite this NIST Technical Series Publication:

Garfinkel S, Guttman B, Near J, Dajani AN, Singer P (2023) De-Identifying Government Datasets: Techniques and Governance. (National Institute of Standards and Technology, Gaithersburg, MD), NIST Special Publication (SP) NIST SP 800-188. https://doi.org/10.6028/NIST.SP.800-188

#### Author ORCID iDs

Simson Garfinkel: 0000-0003-1294-2831 Joseph Near: 0000-0002-3203-3742 Aref N. Dajani: 0000-0003-0361-5409 Phyllis Singer: 0000-0002-8885-7273

#### **Contact Information**

sp800-188@nist.gov

National Institute of Standards and Technology Attn: Software and Systems Division, Information Technology Laboratory 100 Bureau Drive (Mail Stop 8970) Gaithersburg, MD 20899-8970

All comments are subject to release under the Freedom of Information Act (FOIA).

#### Abstract

De-identification is a general term for any process of removing the association between a set of identifying data and the data subject. This document describes the use of deidentification with the goal of preventing or limiting disclosure risks to individuals and establishments while still allowing for the production of meaningful statistical analysis. Government agencies can use de-identification to reduce the privacy risk associated with collecting, processing, archiving, distributing, or publishing government data. Previously, NIST IR 8053, De-Identification of Personal Information, provided a detailed survey of deidentification and re-identification techniques. This document provides specific guidance to government agencies that wish to use de-identification. Before using de-identification, agencies should evaluate their goals for using de-identification and the potential risks that releasing de-identified data might create. Agencies should decide upon a data-sharing model, such as publishing de-identified data, publishing synthetic data based on identified data, providing a query interface that incorporates de-identification, or sharing data in non-public protected enclaves. Agencies can create a Disclosure Review Board to oversee the process of de-identification. They can also adopt a de-identification standard with measurable performance levels and perform re-identification studies to gauge the risk associated with de-identification. Several specific techniques for de-identification are available, including de-identification by removing identifiers, transforming quasi-identifiers, and generating synthetic data using models. People who perform de-identification generally use special-purpose software tools to perform the data manipulation and calculate the likely risk of re-identification. However, not all tools that merely mask personal information provide sufficient functionality for performing de-identification. This document also includes an extensive list of references, a glossary, and a list of specific de-identification tools, which is only included to convey the range of tools currently available and is not intended to imply a recommendation or endorsement by NIST.

## Keywords

data life cycle; de-identification; differential privacy; direct identifiers; Disclosure Review Board; k-anonymity; privacy; pseudonymization; quasi-identifiers; re-identification; synthetic data; The Five Safes.

#### **Reports on Computer Systems Technology**

The Information Technology Laboratory (ITL) at the National Institute of Standards and Technology (NIST) promotes the U.S. economy and public welfare by providing technical leadership for the Nation's measurement and standards infrastructure. ITL develops tests, test methods, reference data, proof of concept implementations, and technical analyses to advance the development and productive use of information technology. ITL's responsibilities include the development of management, administrative, technical, and physical standards and guidelines for the cost-effective security and privacy of other than national security-related information in federal information systems. The Special Publication 800-series reports on ITL's research, guidelines, and outreach efforts in information system security, and its collaborative activities with industry, government, and academic organizations.

### Patent Disclosure Notice

NOTICE: ITL has requested that holders of patent claims whose use may be required for compliance with the guidance or requirements of this publication disclose such patent claims to ITL. However, holders of patents are not obligated to respond to ITL calls for patents and ITL has not undertaken a patent search in order to identify which, if any, patents may apply to this publication.

As of the date of publication and following call(s) for the identification of patent claims whose use may be required for compliance with the guidance or requirements of this publication, no such patent claims have been identified to ITL.

No representation is made or implied by ITL that licenses are not required to avoid patent infringement in the use of this publication.

## Table of Contents

Ex	ecutiv	ve Sumn	nary	1	
1.	Intro	duction		3	
	1.1.	Docum	ent Purpose and Scope	7	
	1.2.	Intende	ed Audience	7	
	1.3.	Organi	zation	8	
2.	Intro	ducing	De-Identification	9	
	2.1.	Histori	cal Context	9	
	2.2.	Termin	ology	12	
3.	Gove	ernance	and Management of Data De-Identification	18	
	3.1.	Identify	ying the Goals and Intended Uses of De-Identification	18	
	3.2.	Evalua	ting the Risks and Benefits That Arise from De-Identified Data Re-		
		leases		19	
		3.2.1.	Probability of Re-Identification	21	
		3.2.2.	Adverse Impacts of Re-Identification	24	
		3.2.3.	Impacts Other Than Re-Identification	26	
		3.2.4.	Remediation	27	
	3.3.	Data L	ife Cycle	27	
	3.4.	Data-Sharing Models			
	3.5.	The Fi	e Five Safes		
	3.6.	Disclos	closure Review Boards		
	3.7.	De-Ide	ntification and Standards	40	
		3.7.1.	Benefits of Standards	40	
		3.7.2.	Prescriptive De-Identification Standards	40	
		3.7.3.	Risk-Based De-Identification Standards	42	
	3.8.	Educat	ion, Training, and Research	42	
	3.9.	Alterna	ative Approaches for Computing Statistics on Confidential Information	43	
		3.9.1.	Encryption and Access Control	43	
		3.9.2.	Secure Computation	43	
		3.9.3.	Trusted Execution Environments	44	
		3.9.4.	Physical Enclaves	45	

4.	Tech	inical St	eps for Data De-Identification	46
	4.1.	Determ	nine the Privacy, Data Usability, and Access Objectives	46
	4.2.	Conduc	cting a Data Survey	47
	4.3.	De-Ide	ntification by Removing Identifiers and Transforming Quasi-Identifiers	49
		4.3.1.	Removing or Transforming of Direct Identifiers	51
		4.3.2.	Special Security Note Regarding the Encryption or Hashing of Di- rect Identifiers	52
		4.3.3.	De-Identifying Numeric Quasi-Identifiers	53
		4.3.4.	De-Identifying Dates	54
		4.3.5.	De-Identifying Geographical Locations and Geolocation Data	55
		4.3.6.	De-Identifying Genomic Information	56
		4.3.7.	De-Identifying Text Narratives and Qualitative Information	57
		4.3.8.	Challenges Posed by Aggregation Techniques	57
			4.3.8.1. Example	57
		4.3.9.	Challenges Posed by High-Dimensional Data	58
		4.3.10.	Challenges Posed by Linked Data	59
		4.3.11.	Challenges Posed by Composition	59
		4.3.12.	Potential Failures of De-Identification	60
		4.3.13.	Post-Release Monitoring	61
	4.4.	Synthe	tic Data	61
		4.4.1.	Partially Synthetic Data	62
		4.4.2.	Test Data	63
		4.4.3.	Realistic Test Data	63
		4.4.4.	Fully Synthetic Data	63
		4.4.5.	Synthetic Data with Validation	65
		4.4.6.	Synthetic Data and Open Data Policy	65
		4.4.7.	Creating a Synthetic Dataset with Differential Privacy	66
	4.5.	De-Ide	ntifying with an Interactive Query Interface	67
	4.6.	Validat	ing a De-Identified Dataset	68
		4.6.1.	Validating Data Usefulness	68
		4.6.2.	Validating Privacy Protection	68
		4.6.3.	Re-Identification Studies	69

5.	Software Requirements, Evaluation, and Validation			
	5.1.	Evaluate the Privacy-Preserving Techniques	72	
	5.2.	De-Identification Tools	73	
		5.2.1. De-Identification Tool Features	73	
		5.2.2. Data Provenance and File Formats	73	
		5.2.3. Data Masking Tools	73	
	5.3.	Evaluating De-Identification Software	74	
	5.4.	Evaluating Data Accuracy	74	
6.	Cond	clusion	76	
References				
Α.	Stan	dards	93	
	A.1.	NIST Publications	93	
	A.2.	Other U.S. Government Publications	94	
	Seleo	cted Publications by Other Governments	95	
	Repo	orts and Books	96	
	How	-To Articles	97	
Β.	List	of Symbols, Abbreviations, and Acronyms	98	
C.	Glos	sary	101	

## List of Tables

Table 1.	Reading levels at a hypothetical school, as measured by entrance exami- nations and reported at the start of the school year on October 1. (See	
	example, Sec. 4.3.8)	58
	Reading levels at a hypothetical school, as measured by entrance examina- tions and reported one month into the school year on November 1 after a	
	single new student has transferred to the school. (See example, Sec. 4.3.8) Adjectives used for describing data in data releases (Sec. 4.4.4).	

## List of Figures

Fig. 1.	The data life cycle as described by Michener et al. [105]	28
Fig. 2.	Chisholm's view of the data life cycle is a linear process with a branching	
-	point after data usage [30]	28
Fig. 3.	Altman's "modern approach to privacy-aware government data releases" [97]	30

Fig. 4.	Altman's conceptual diagram of the relationship between post-transformation identifiability, the level of expected harm, and the suitability of selected pri-		
	vacy controls for a data release [97]	31	
Fig. 5.	Advice for Practitioners: A Summary	77	

#### Acknowledgments

The authors wish to thank the U.S. Census Bureau for its help in researching and preparing this publication, with specific thanks to John Abowd, Ron Jarmin, Christa Jones, and Laura McKenna. The authors would also like to thank Luk Arbuckle, Andrew Baker, Paul Black, Daniel Barth-Jones, Christi Dant, Khaled El Emam, Robert Gellman, Tom Krenzke, Naomi Lefkovitz, Bradley Malin, Kevin Mangold, John Moehrke, Linda Sanchez, Denise Sturdy, and Chris Traver for providing comments on previous drafts and their valuable insights, all of which were helpful in creating this publication.

The authors also wish to thank several organizations that provided useful comments on previous drafts of this publication: Anonos (with comments from Odia Kagan Partner, Chair of GDPR Compliance and International Privacy, Fox Rothschild LLP); the Association for Computing Machinery's U.S. Technology Policy Committee; the Defense Contract Management Agency (DCMA) Information Assurance Directorate; the Electronic Privacy Information Center; the Interagency Council on Statistical Policy/Federal Committee on Statistical Methodology (FCSM) Disclosure Review Board Community of Practice; the Office of the Chief Privacy Officer within the U.S. Department of Education; the Office of Planning, Research, and Evaluation (OPRE) within the Administration for Children and Families at the U.S. Department of Health and Human Services; the Millennium Challenge Corporation (MCC) Department of Policy and Evaluation; Integrating the Healthcare Enterprise (IHE), an ANSI-accredited standards organization focused on healthcare standards; the Privacy Tools Project at Harvard University (including Micah Altman, Stephen Chong, Kobbi Nissim, David O'Brien, Salil Vadhan, and Alexandra Wood); Tumult Labs (Gerome Miklau and David Pujol); the United Health Group (Peter Dumont and Ying Zhu); and the U.S. Agency for International Development Chief Data Officer (Brandon Pustejovsky).

### **Author Contributions**

**Simson Garfinkel**: Conceptualization, Supervision, Writing (original draft preparation); **Joseph Near**: Writing (original draft preparation); **Aref N. Dajani**: Writing (original draft preparation of the section on re-identification studies); **Phyllis Singer**: Writing (original draft preparation of the section on re-identification studies); **Barbara Guttman**: Conceptualization, Supervision, Writing.

### **Executive Summary**

Every federal agency creates and maintains internal datasets that are vital for fulfilling its mission. The Foundation for Evidence-based Policymaking Act of 2018 [2] and its Phase 1 implementation memorandum M-19-23 [168] mandate that agencies also collect and publish their government data in open, machine-readable formats when it is appropriate to do so. Agencies can use de-identification to make government datasets available while protecting the privacy of the individuals whose data are contained within those datasets.

The U.S. Government defines *personally identifiable information* (PII) as "information that can be used to distinguish or trace an individual's identity, either alone or when combined with other information that is linked or linkable to a specific individual."[4]

For decades, de-identification based on simply removing identifying information was thought to be sufficient to prevent the re-identification of individuals in large datasets. Since the mid 1990s, a growing body of research has demonstrated the reverse, resulting in new privacy attacks that are capable of re-identifying individuals in "de-identified" data releases. For several years, the goals of such attacks appeared to be embarrassing the publishing agency and achieving academic distinction for the privacy researcher [65]. More recently, as high-resolution de-identified geolocation data have become commercially available, reidentification techniques have been used by journalists, activists, and malicious actors [130, 170, 90] to learn information about individuals that was intended to be kept confidential. These attacks highlight the deficiencies in traditional approaches to de-identification.

Formal models of privacy, like k-anonymity [151] and differential privacy [52], use mathematically rigorous approaches that are designed to allow for the controlled use of confidential data while minimizing the privacy loss suffered by the data subjects.<sup>1</sup> Because there is an inherent trade-off between the accuracy of published data and the amount of privacy protection afforded to data subjects, most formal methods have some kind of parameter that can be adjusted to control the "privacy cost" of a particular data release. Informally, a data release with a low privacy cost causes little additional privacy risk to the participants, while a higher privacy cost results in more privacy risk. When they are available and have sufficient functionality for the task at hand, formal privacy methods should be preferred over informal ad hoc methods.

Decisions and practices regarding the de-identification and release of government data can be integral to the mission and proper functioning of a government agency. As such, an agency's leadership should manage these activities in a way that ensures performance and

<sup>&</sup>lt;sup>1</sup>While k-anonymity and differential privacy are both mathematically rigorous formal models, k-anonymity is a privacy framework based on the content of the published data, while differential privacy places bounds on the amount of information that can be learned about the confidential data from the published data.

results in a manner that is consistent with the agency's mission and legal authority. One way that agencies can manage this risk is by creating a formal Disclosure Review Board (DRB) that consists of legal and technical privacy experts, stakeholders within the organization, and representatives of the organization's leadership. The DRB evaluates applications for data release that describe the confidential data, the techniques that will be used to minimize the risk of disclosure, the resulting protected data, and how the effectiveness of those techniques will be evaluated. The DRB's work complements other parts of the organization, such as the Chief Information Security Officer (CISO), who is responsible for technical controls, as well as the parts of the organization responsible for adopting administrative or organizational controls and written data-sharing agreements.

Establishing a DRB may seem like an expensive and complicated administrative undertaking for some agencies. However, a properly constituted DRB and the development of consistent procedures regarding data release should enable agencies to lower the risks associated with each data release, which is likely to save agency resources in the long term. Agencies can create or adopt standards to guide those performing de-identification and regarding the accuracy of de-identified data. If accuracy goals exist, then techniques such as differential privacy can be used to make the data sufficiently accurate for the intended purpose but not unnecessarily more accurate, which can limit the amount of privacy loss. However, agencies must carefully choose and implement accuracy requirements. If data accuracy and privacy goals cannot be well-maintained, then releases of data that are not sufficiently accurate can result in incorrect scientific conclusions and policy decisions.

Agencies should consider performing de-identification with trained individuals using software specifically designed for that purpose. While it is possible to perform de-identification with off-the-shelf software like a commercial spreadsheet or financial planning program, such programs typically lack the key functions required for sophisticated de-identification. As a result, they may encourage the use of simplistic de-identification methods, such as deleting columns that contain sensitive data categories and manually searching and removing individual data cells that appear sensitive.<sup>2</sup> This may result in a dataset that appears de-identified but still contains significant disclosure risks.

Finally, different countries have different standards and policies regarding the definition and use of de-identified data. Information that is regarded as de-identified in one jurisdiction may be regarded as being identifiable in another. This may be especially relevant in the case of international scientific collaborations and illustrates the need for agencies that perform de-identification to create mechanisms for data scientists, attorneys, and policymakers to coordinate on these topics.

 $<sup>^{2}</sup>$ For information on characterizing the sensitivity of information, see NIST SP 800-60 Volume I, Revision 1 [147].

## 1. Introduction

The U.S. Government collects, maintains, and uses many kinds of datasets. Every federal agency creates and maintains internal datasets that are vital for fulfilling its mission, such as delivering services to citizens or ensuring regulatory compliance. There are also 13 principal federal statistical agencies, three recognized statistical units, and over 100 other federal statistical programs that collect, compile, process, analyze, and distribute information for statistical purposes [156, 121].

Government programs collect information from individuals and organizations for taxation, public benefits, public health, licensing, employment, censuses, and the production of official statistics. While privacy is integral, many individuals and organizations that provide information to the Government do not typically have the right to opt out of such requests. For example, people and establishments in the United States must respond to mandatory U.S. Census Bureau surveys.

Agencies make many of their datasets available to the public. The U.S. Government publishes data to promote commerce, scientific research, and public transparency. Many datasets contain some data elements that should not be made public, and it is necessary to remove such information before making the rest of the dataset available. Some datasets are so sensitive that they cannot be made publicly available at all but can be available on a limited basis to qualified, vetted researchers in protected enclaves. In some cases, agencies may also elect to release summary statistics of sensitive data or create synthetic datasets that resemble the original data but that have a lower disclosure risk [9, 99].

There is frequent tension between the goals of privacy protection and the release of useful data to the public. One way that the Government attempts to resolve this tension is with an official promise of confidentiality to individuals and organizations regarding the information that they provide [132]. Other information is created by the Government as a consequence of providing government services. This information – sometimes called *administrative data* – is also increasingly being used and made available for statistical purposes and must be protected.

A bedrock principle of official statistical programs is that data provided to the Government should generally remain confidential and not be used in a way that would pose a privacy or confidentiality risk to the individual or the organization providing the data. One justification for this principle is that it helps to ensure high data accuracy. If data providers believe that the information they provide will remain confidential, they may be willing to provide accurate information. In 2018, the U.S. Congress passed three laws that significantly increased the need for expertise regarding privacy-preserving data analysis and data publishing techniques, such as de-identification:

1. The Foundations for Evidence-Based Policymaking Act of 2018 [2], commonly called the Evidence Act, requires federal agencies to track all of their data in data inventories, report public datasets to https://data.gov, perform systematic evidence-making and evaluation activities, and engage in capacity-building so that the federal workforce can meet the requirements of data-centric, evidence-based operations. The Evidence Act is based on the findings of the U.S. Commission on Evidence-Based Policymaking [34] and is implemented in part by Office of Management and Budget (OMB) Memorandum M-19-23 [168].

The Evidence Act contains specific guidance requiring that agencies publishing data take into account "(A) risks and restrictions related to the disclosure of personally identifiable information, including the risk that an individual data asset in isolation does not pose a privacy or confidentiality risk but when combined with other available information may pose such a risk;" and "(B) security considerations, including the risk that information in an individual data asset in isolation does not pose a security risk but when combined with other available information may pose such a risk;" and "(B) security considerations, including the risk that information in an individual data asset in isolation does not pose a security risk but when combined with other available information may pose such a risk" [2].

The Evidence Act incorporated and reauthorized **The Confidential Information Protection and Statistical Efficiency Act of 2002**, now called the 2018 CIPSEA. Part B, "Confidential Information Protection," provides for the legal protection of "data or information acquired by an agency under a pledge of confidentiality for exclusively statistical purposes shall not be disclosed by an agency in identifiable form for any use other than an exclusively statistical purpose, except with the informed consent of the respondent."

Finally, the 2018 CIPSEA promotes Office of Management and Budget Statistical Policy Directive 1, "Fundamental Responsibilities of Federal Statistical Agencies and Recognized Statistical Units,"[100] to statute as 44 U.S. Code §§ 3561-4."

- 2. The Open, Public, Electronic and Necessary (OPEN) Government Data Act, which was passed as part of the Evidence Act, requires that the U.S. Government publish data in machine-readable, open, non-proprietary formats when possible. This act largely codified presidential Executive Order 13642 of May 9, 2013, "Making Open and Machine Readable the New Default for Government Information" [115] and its implementation in OMB Memorandum M-13-13 [24].
- 3. **The Geospatial Data Act of 2018** requires that government agencies make inventories of their geospatial data and that public geospatial data be registered on the U.S. Government's public geospatial platform at https://www.geoplatform.gov/.

Other laws, regulations, and policies that govern the release of statistics and data to the public enshrine this principle of confidentiality. For example:

- US Code Title 13 §§ 8(b) and 9 governs the confidentiality of information provided to the Census Bureau and prohibits "any publication whereby the data furnished by any particular establishment or individual under this title can be identified" [160].
- US Code Title 26, Section 6103 governs the confidentiality of information provided to the U.S. Government on tax returns and other return information. These rules are now spelled out in IRS Publication 1075, "Tax Information Security Guidelines for Federal, State and Local Agencies," published by the Internal Revenue Service (IRS) Office of Safeguards [122].
- **The Privacy Act of 1974** covers the release of personal information of U.S. citizens and lawful permanent residents by the Government. The Act recognizes that the disclosure of records for statistical purposes is acceptable if the data are not "individually identifiable" [133, at a(b)(5)].

Federal laws and regulations recognize that it is not possible to eliminate all privacy risk when deidentifying data. Guidance from the U.S. Department of Health and Human Services (HHS) on the Health Insurance Portability and Accountability Act (HIPAA) deidentification standards notes that "[b]oth methods [the Safe Harbor and expert determination methods for de-identification], even when properly applied, yield de-identified data that retains some risk of identification. Although the risk is very small, it is not zero, and there is a possibility that de-identified data could be linked back to the identity of the patient to which it corresponds" [166].

U.S. law also balances privacy risk with other factors, such as transparency, accountability, and the opportunity for public good. An example of this balance is the handling of personally identifiable information collected by the Census Bureau as part of the decennial census. This information remains confidential for 72 years and is then transferred to the National Archives and Records Administration, where it is released to the public [161, 5].

*De-identification* is "a general term for any process of removing the association between a set of identifying data and the data subject"[85]. This document describes the use of de-identification with the goal of preventing or limiting disclosure risks to individuals and establishments while still allowing for the production of aggregate statistics.<sup>34</sup> Deidentification is not a single technique but a collection of approaches, algorithms, and tools that can be applied to different kinds of data with differing levels of effectiveness. In general, the potential risk to privacy posed by a dataset's release decreases as increasingly

<sup>&</sup>lt;sup>3</sup>This document uses a different definition for *de-identification* than ISO/TS 25737:2008, which defines de-identification as the "general term for any process of removing the association between a set of identifying data and the data subject" [85, p. 3]. This document intentionally adopts a broader definition for de-identification that allows for noise-introducing techniques, such as differential privacy and the creation of synthetic datasets that are based on privacy-preserving models.

<sup>&</sup>lt;sup>4</sup>In Europe, the term *data anonymization* is frequently used as a synonym for de-identification, but the terms may have subtly different definitions in some contexts. For a more complete discussion of de-identification and data anonymization, see NIST IR 8053, *De-Identification of Personal Data* [66].

manipulative de-identification techniques are employed, but data accuracy and – in some cases – the ultimate utility of the de-identified dataset decreases as well.

*Accuracy* is traditionally defined as the "closeness of computations or estimates to the exact or true values that the statistics were intended to measure" [71].<sup>5</sup> The *data accuracy* of de-identified data, therefore, refers to the degree to which inferences drawn on the de-identified data will be consistent with inferences drawn on the original data. Data accuracy can be measured by the ratio of a value computed with de-identified data to the same value computed using the underlying true confidential value. Because there are many potential computations that may be performed with de-identified data, de-identified data that are accurate for one purpose may not be accurate for another. As accuracy decreases, statistical power may be lost, rendering some inferences no longer possible. Alternatively, new biases and errors may be introduced, resulting in incorrect inferences.

In economics, *utility* is traditionally defined as "the satisfaction derived from consumption of a good or service"[71]. *Data utility*, therefore, refers to the value that data users can derive from data in general. When speaking of de-identified data, utility comes from two public goods: the uses of the data and the privacy protection afforded by the de-identification process.

In general, data accuracy decreases as more aggressive de-identification techniques are employed. Therefore, any effort that involves the release of data that contain personal information typically involves making a trade-off between identifiability and data accuracy. However, increased privacy protections do not necessarily result in decreased data utility for certain specified purposes.

Some users of de-identified data may be able to use the data to make inferences regarding specific individuals or establishments by virtue of their inclusion in the dataset rather than on the basis of a statistical model based on the sampled population. Such users may even be able to re-identify the data subjects. Both of these uses undo the privacy goals of de-identification.

In general:

- Agencies that release data should understand what data they are releasing, what other data may already be publicly or privately available, and the protection methods that they have employed to protect against the risk of re-identification.
- Agencies should be aware that it is difficult if not impossible to recall a data release, so de-identified data that are published will remain in the public domain indefinitely. Thus, it is insufficient to only plan and implement a solution that works today but

<sup>&</sup>lt;sup>5</sup>This report avoids the use of the term *precision*, which the Organization for Economic Cooperation and Development (OECD) glossary defines as "The property of the set of measurements of being very reproducible or of an estimate of having small random error of estimation,"[71] as the term is used to describe an aspect of measurement rather than the result of de-identification.

that does not take into account future data releases of a new related dataset by the agency or others.

- Agencies should clearly explain how they continue to monitor and improve to protect privacy.
- Agencies should aim to make an informed decision about the fidelity of the data that they release by systematically evaluating the risks and benefits and choosing deidentification techniques and data-sharing models that are tailored to their requirements.
- When telling individuals that their de-identified information will be released, agencies should disclose that privacy risks may remain despite de-identification.

Planning is essential for successful de-identification and data release. In a research environment, this planning should include the research design, data collection, protection of identifiers, disclosure analysis, and data-sharing strategy. In an operational environment, this planning includes a comprehensive analysis of the purpose of the data release, the expected use of the released data, the privacy-related risks, and the privacy-protecting controls. Both cases should review the appropriateness of various privacy controls given the risks, intended uses, and the ways that those controls could fail. See Sec. 3.6, "Disclosure Review Boards" for a discussion of how a Disclosure Review Board (DRB) or an Institutional Review Board (IRB) can be used to make this process orderly, predictable, and repeatable.

De-identification can have significant time, labor, and data processing costs. However, when properly executed, this effort can result in data that have high value for a research community and the general public while still adequately protecting individual privacy.

## 1.1. Document Purpose and Scope

This document provides guidance on the selection, use, and evaluation of de-identification techniques for U.S. Government datasets. It also provides a framework that can be adapted by federal agencies to shape the governance of de-identification processes. The ultimate goal of this document is to reduce disclosure risks that might result from an intentional data release. However, this document does not provide step-by-step guidance for de-identifying the vast range of possible datasets held by U.S. Government agencies. For each dataset that is to be de-identified, agencies must rely on experts and have their proposed efforts reviewed by an appropriate governance procedure.

## **1.2.** Intended Audience

This document is intended for use by government system engineers, security officers, data scientists, privacy officers, disclosure review boards, and other officials. It is also designed to be generally informative to researchers and academics involved in the technical aspects

of de-identifying government data. While this document assumes a high-level understanding of information system security technologies, it is intended to be accessible to a wide audience.

## 1.3. Organization

The remainder of this publication is organized as follows:

- Section 2, "Organization," presents a background on the science and terminology of de-identification.
- Section 3, "Terminology," provides guidance to agencies on the establishment of or improvement to a program that makes privacy-sensitive data available to researchers and the public.
- Section 4, "Physical Enclaves," provides specific technical guidance for performing de-identification using a variety of mathematical approaches.
- Section 5, "Re-Identification Studies," provides a recommended set of features that should be in de-identification tools, which may be useful for potential purchasers or developers of such software. This section also provides information for evaluating both de-identification tools and de-identified datasets.
- Section 6, "Evaluating Data Accuracy," presents the conclusion.

Following the conclusion is a list of all publications referenced in this document, as well as an appendix that includes standards, related NIST publications, other selected publications by the U.S. and other governments, reports, books, and articles of interest. A second appendix provides a list of symbols, abbreviations, and acronyms. The third appendix contains a glossary.

### 2. Introducing De-Identification

If the information derived from personal data remains in a de-identified dataset, the dataset may inadvertently reveal attributes related to specific individuals. When this happens, the privacy protection provided by de-identification is compromised. Even if a specific individual cannot be matched to a specific data record, de-identified data can be used to improve the accuracy of inferences regarding individuals whose de-identified data are in the dataset. This so-called *inference risk* cannot be eliminated if there is any information in the de-identified data, but it can be managed or reduced to an acceptable level. Thus, the decision of how or whether to de-identify data should be made in conjunction with decisions over how the de-identified data will be used, shared, or released.

De-identification is especially important for government agencies, businesses, and other organizations that seek to make data available to outsiders. For example, significant medical research is made possible through the sharing of de-identified patient information under the framework established by the HIPAA Privacy Rule, which is the primary U.S. regulation that provides for the privacy of medical, billing, enrollment, payment, and claims records, as well as "other records that are used, in whole or in part, by or for the covered entity to make decisions about individuals" [119]. The HIPAA Privacy Rule de-identification framework applies to both government organizations charged with protecting government datasets and to private-sector organizations, such as health plans and health care providers.

Agencies may also be required to de-identify records when responding to a Freedom of Information Act (FOIA) [164, 163] request in a manner that is consistent with Exemption 6, which protects information about individuals in "personnel and medical files and similar files" when the disclosure of such information "would constitute a clearly unwarranted invasion of personal privacy," and Exemption 7(C), which is limited to information compiled for law enforcement purposes and protects personal information when disclosure "could reasonably be expected to constitute an unwarranted invasion of personal privacy." The meaning of these exemptions has been clarified by multiple cases before the U.S. Supreme Court [134, 145, 146]. However, agencies should consider the cumulative privacy impact of multiple FOIA requests and potential releases, as previous releases may be combined with future releases to learn information about individuals that the agency had previously attempted to protect from public release.

## 2.1. Historical Context

The modern practice of de-identification can be broken down into three distinct phases:

1. For four decades, official statistical agencies have researched and investigated methods broadly termed *statistical disclosure limitation* (SDL) or *statistical disclosure*  *control* (SDC) [61, 38, 47].<sup>6</sup> Statistical agencies created these methods so that they could release statistical tables and *public use files* (PUF) to allow users to learn information and perform original research while protecting the privacy of the individuals in the dataset. SDL is widely used in contemporary statistical reporting.

- 2. In the 1990s, there was a significant increase in the release of *microdata* files for public use in the form of both individual responses from surveys and administrative records. Initially, these releases merely stripped obviously identifiable information, such as names and Social Security numbers (what are now called *direct identifiers*). Following some releases, researchers discovered that it was possible to re-identify individuals' data by triangulating some of the remaining data (now called *quasi-identifiers* or *indirect identifiers* [37]). The research resulted in the creation of the k-anonymity model for protecting privacy [153, 137, 138, 152],<sup>7</sup> which is reflected in the Office of Civil Rights guidance on how to apply de-identification in a manner consistent with the HIPAA Privacy Rule [118]. Today, variants of k-anonymity are commonly used for sharing medical microdata, even though some mechanisms that implement k-anonymity have been demonstrated to be reversible [32].
- 3. In the 2000s, research in theoretical computer science and cryptography developed the theory of *differential privacy* [53], which is based on a mathematical definition of the *privacy loss* to an individual that results from queries on a database containing that individual's personal information compared to the same queries on a database that does not.<sup>8</sup> Differential privacy is termed a *formal model for privacy protection* because its definitions for privacy and privacy loss are based on mathematical proofs.<sup>9</sup>

This does not mean that algorithms that implement differential privacy eliminate all privacy risk. Rather, it means that the amount of privacy risk that results from the use of these algorithms can be mathematically bounded. These mathematical limits on privacy risk have created considerable interest in differential privacy in academia, commerce, and business.

During the first decade of the 21<sup>st</sup> century, there was a growing awareness within the U.S. Government about the risks that could result from the improper handling and inadvertent release of personal identifying and financial information. This realization, combined with

<sup>&</sup>lt;sup>6</sup>A summary of the history of statistical disclosure limitation can be found in *Private Lives and Public Policies: Confidentiality and Accessibility of Government Statistics* [132].

<sup>&</sup>lt;sup>7</sup>k-anonymity is a refinement of the approach described by Dalenius in "Finding a needle in a haystack – or identifying anonymous census records" [36].

<sup>&</sup>lt;sup>8</sup>The term "privacy loss," as defined in the literature of differential privacy, is neither a loss function nor a risk metric but an unbounded measure of information gain between two randomized queries – the ratio of two probabilities.

<sup>&</sup>lt;sup>9</sup>Other formal methods for privacy include cryptographic algorithms and techniques with provably secure properties, privacy-preserving data mining, Shamir's secret sharing, and advanced database techniques. A summary of such techniques appears in [158].

a growing number of inadvertent data disclosures within the U.S. Government, resulted in President George W. Bush signing Executive Order 13402, which established an Identity Theft Task Force on May 10, 2006 [25]. One year later, the Office of Management and Budget (OMB) issued Memorandum M-07-16 [80], which required federal agencies to develop and implement breach notification policies. As part of this effort, NIST issued Special Publication (SP) 800-122, *Guide to Protecting the Confidentiality of Personally Identifiable Information (PII)* [103]. These policies and documents had the specific goal of limiting the accessibility of information that could be directly used for identity theft but did not create a framework for processing government datasets so that they could be released without impacting the privacy of the data subjects.

In 2015, NIST published NIST Interagency or Internal Report (IR) 8053, *De-Identification of Personal Information* [66], which provided an overview of de-identification issues and terminology. It also summarized significant publications involving de-identification and re-identification. However, NIST IR 8053 did not make recommendations regarding the appropriateness of de-identification or specific de-identification algorithms. The following year, NIST convened the Government Data De-Identification Stakeholder's Meeting [67].

In 2016, OMB revised Circular A-130, "Managing Information as a Strategic Resource," reflecting changes in law and advances in technology. The revision was also designed to ensure consistency between executive orders, presidential directives, NIST standards and guidelines, and other OMB policies. A-130 defines *personally identifiable information* (PII) as "information that can be used to distinguish or trace an individual's identity, either alone or when combined with other information that is linked or linkable to a specific individual."[4]

De-identification is one of several models for allowing the controlled sharing of data derived from confidential data about individuals.<sup>10</sup> Other models include the use of data processing enclaves, where computations are performed with confidential data using computers that are physically isolated from the outside world. That isolation might be performed with locked doors and guards, or it might be performed using silicon and encryption, as is the case with enclaves implemented on some modern microprocessors. Another approach is to use mathematical techniques, such as secure multi-party computation, so that computations can be carried out on confidential data held by multiple parties without ever bringing all of the confidential data together in a single location. Researchers have introduced more than 80 different privacy metrics in an attempt to characterize privacy and privacy loss in different settings [169].

Techniques for privacy-preserving data-sharing and analysis can be layered to provide stronger protection than any single technique would provide in isolation. Such complementary models are discussed in Sec. 3.4. For a more complete description of data-sharing

<sup>&</sup>lt;sup>10</sup>For information on characterizing the sensitivity of information, see NIST SP 800-60 Volume I, Revision 1 [147].

models, privacy-preserving data publishing, and privacy-preserving data mining, see NIST IR 8053.

Many of the techniques discussed in this publication (e.g., fully synthetic data and differential privacy) currently have limited use within the Federal Government due to cost, time constraints, and the sophistication required of practitioners. However, these techniques are likely to see increased use as agencies seek to make datasets that include identifying information available.

## 2.2. Terminology

While each of the de-identification traditions has developed its own terminology and mathematical models, they share many underlying goals and concepts. Where terminology differs, this document relies on the terminology developed in previous documents by the U.S. Government and standards organizations. This document uses the terms *privacy risk* and *informational risk* to refer in aggregate to various types of disclosure risk, as defined later in this section.

*De-identification* is a "general term for any process of removing the association between a set of identifying data and the data subject" [85]. This document is specifically concerned with de-identification techniques that have the goal of preventing or limiting disclosure risks to individuals and establishments while still allowing for the production of aggregate statistics. As a result, this document devotes attention to noise-introducing techniques, such as differential privacy and the creation of synthetic datasets that are based on privacy-preserving models. De-identification takes an *original dataset* and produces *de-identified data*. This document uses the term *dataset* to refer to the collected data and assumes that data collection is completed before de-identification begins. However, many of the processes and techniques described are also applicable in other collection models (e.g., streaming data).

*Re-identification* is the "process by which information is attributed to de-identified data in order to identify the individual to whom the de-identified data relate"[117]. This definition is from the Organization for Economic Cooperation and Development (OECD) Legal Instruments Recommendation of the Council on Health Data Governance (2016).

*Re-identification risk* is the likelihood that a third party can re-identify data subjects in a de-identified dataset. Re-identification risk is typically a function of the adverse impacts that would arise if re-identification were to occur and the likelihood of occurrence. Re-identification risk is a specific form of privacy risk that can result from the release or use of de-identified data.

*Redaction* is the removal of information from a document or dataset for legal or security purposes. Also known as *suppression*, redaction is a kind of de-identifying technique that relies on the removal of information. In general, redaction alone is insufficient to provide formal privacy guarantees, such as differential privacy. Redaction may also reduce the

accuracy of the dataset since the use of selective redaction may result in the introduction of non-ignorable bias.

*Anonymization* is a "process that removes the association between the identifying dataset and the data subject" [85]. This term is reserved for de-identification processes that cannot be reversed.

Some authors use the terms *de-identification* and *anonymization* interchangeably. In some contexts, the term *anonymization* is used to describe the destruction of a table that maps pseudonyms to real identifiers.<sup>11</sup> Both of these uses are potentially misleading, as many de-identification procedures can be readily reversed if a dataset is discovered that maps a unique attribute or combination of attributes to identifies. For example, a medical dataset may contain a list of names, medical identifiers, the rooms where a patient was seen, the time that the patient was seen, and the results of a medical test. Such a dataset could be de-identified by removing the name and medical identification numbers. However, the dataset of medical test results should not be considered anonymized because the tests can be re-identified if the dataset is joined with a second dataset of room numbers, times, and names. Since it is not possible to know whether such an auxiliary dataset exists, this publication recommends avoiding the word *anonymization* and using the word *de-identification* instead. Because of the inconsistencies in the use and definitions of the word "anonymization," this document avoids the term except in this section and in the titles of some references.

*Pseudonymization* is a "particular type of [de-identification]<sup>12</sup> that both removes the association with a data subject and adds an association between a particular set of characteristics relating to the data subject and one or more pseudonyms" [85]. The term *coded* is frequently used in healthcare settings to describe data that have been pseudonymized. Pseudonymization is commonly used so that multiple observations of an individual over time can be matched and so that an individual can be re-identified if there is a policy reason to do so. Although pseudonymous data are typically re-identified by consulting a key that may be highly protected, the existence of the pseudonym identifiers frequently increases the risk of re-identification through other means.

*Non-public personal information* is used to describe personal information that is in a dataset that is not publicly available. Non-public personal information is not necessarily identifying.

The definition of identifying information above suggests that it is easy – or at least possible – to distinguish personal information from identifying information. However, many

<sup>&</sup>lt;sup>11</sup>For example, "Anonymization is a step subsequent to de-identification that involves destroying all links between the de-identified datasets and the original datasets. The key code that was used to generate the new identification code number from the original is irreversibly destroyed (i.e., destroying the link between the two code numbers)" [157].

<sup>&</sup>lt;sup>12</sup>Here, the word *anonymization* in the ISO 25237 definition is replaced with the more accurate and descriptive term *de-identification*.

techniques for de-identification require an expert to make this distinction and protect only the identifying information. Indeed, as understanding of privacy risk develops, it is increasingly apparent that *all* information is potentially identifying information, and it is necessary to thoughtfully engage in prioritizing the concerns of balancing privacy threats with scientific data accuracy.

This document envisions a *de-identification process* in which an *original dataset* that contains personal information is algorithmically processed to produce *de-identified data*. The result may be a *de-identified dataset*; *aggregate statistics*, such as summary tables; or a *synthetic dataset* in which the data are created by a model. This kind of de-identification is envisioned as a batch process. Alternatively, the de-identification process may be a system that accepts queries and returns responses that do not leak more identifying information than is allowable by policy. De-identified results may be corrected or updated and re-released on a periodic basis. The accumulated leakage of information from multiple releases may be significant, even if the leakage from a single release is small. Issues that arise from multiple releases are discussed in Sec. 3.4, "Data-Sharing Models."

*Disclosure* is generally the exposure of data beyond the original collection use case. According to the traditional SDL literature,

"Disclosure relates to inappropriate attribution of information to a data subject, whether an individual or an organization. Disclosure occurs when a data subject is identified from a released file (*identity disclosure*), sensitive information about a data subject is revealed through the released file (*attribute disclosure*), or the released data substantially make it possible to determine the value of some characteristic of an individual more accurately than otherwise would have been possible (*inferential disclosure*)." [132, p. 23–24, emphasis in original]

A similar definition appears in the Glossary of Statistical Terms:

### Disclosure

Disclosure relates to the inappropriate attribution of information to a data subject, whether an individual or an organisation. Disclosure has two components: identification and attribution. [71]

This traditional definition for disclosure can be ambiguous and can produce incorrect conclusions. An alternative formulation in plain language is that a confidentiality breach occurs when an inference about the attribute associated with a particular entity is improved through the use of that entity's data in producing the statistical output. Privacy-eroding inference in this manner is distinct from inferences that can be drawn independent of the entity's data and through generalizable inference from the larger population.

The definitions from differential privacy are more nuanced than those from traditional SDL. They put a bound on the relative probability of disclosure by comparing when an individual is in the frame and out of the frame (either by removal or replacement from the frame) [49, 50]. Abowd and Hawes show how these privacy-preserving definitions relate to identity and attribute disclosures [7, p. 12].

According to Kifer et al., the "confidentiality-breaching versions of identity, attribute and inferential disclosure all have the same mathematical formulation" [88, p. 4]. Careful definitions show that identity and attribute disclosure are merely high-confidence cases of inferential disclosure. Additional information about disclosure can be found in Sec. 3.1.

*Disclosure limitation* is a general term for the practice of allowing summary information or queries on data within a dataset to be released without revealing information about specific individuals whose personal information is contained within the dataset. Thus, deidentification is a kind of disclosure limitation technique. Every disclosure limitation process introduces inaccuracy into the results [14, 11].

A primary goal of disclosure limitation is to protect the privacy of individuals while avoiding the introduction of *non-ignorable biases* [8] (e.g., bias that might lead a social scientist to come to the wrong conclusion) into the de-identified dataset. One way to measure the amount of bias that has been introduced by the de-identification process is to compare statistics or models generated by analyzing the original dataset with those that are generated by analyzing the de-identified datasets. Such biases introduced by the de-identification process are typically unrelated to any statistical biases that may also exist in the original data.

Formal models of privacy can quantify the privacy protection offered by a de-identification process. With methods based on differential privacy, this measurement takes the form of a number called privacy loss, which quantifies the additional risk that an adversary might learn something new about an individual as the result of a de-identified data release. When a de-identification process is associated with low privacy loss, releasing the data it produces should result in only a small amount of additional risk for individuals in the input dataset. Some formal models, such as differential privacy, allow for *composing* the privacy losses of multiple data releases to quantify the increased privacy loss to individuals from each release, even if an attacker attempts to combine the releases in unanticipated ways. Other formal models, such as *k*-anonymity, do not have this capability.

An upper bound on the total acceptable privacy loss of many data releases is often called a *privacy loss budget* or simply a *privacy budget*. This number quantifies the *total* privacy loss to an individual who participates in all of the releases.

*Differential privacy* [53] is a rigorous mathematical definition of disclosure that considers the increase in accuracy with which an individual's confidential data may be estimated as a result of a mathematical analysis based on that data being made publicly available. Statisticians, mathematicians, and other kinds of privacy engineers then develop mathematical algorithms called *mechanisms*, which process data in a way that is consistent with the definition. Differential privacy limits properly define inferential disclosure by adding non-deterministic noise (random values) to the results of mathematical operations before

the results are reported. Differential privacy is based on information theory and makes no distinction between which data are considered identifying and which are not. Nor does using differential privacy require classifying data as direct identifiers, quasi-identifiers, or non-identifying values. Instead, the most widely used variants of differential privacy – such as  $\varepsilon$ -DP, ( $\varepsilon$ ,  $\delta$ )-DP, and zero-Concentrated Differential Privacy [23] – assume that *all values* in a confidential record must be protected.

Differential privacy's mathematical definition is based on the intuition that the distinctive attributes that contribute to an individuals' data privacy cannot be violated by the analysis of a dataset that does not contain that individual's data. As a result, the mathematical definition of differential privacy is based on the idea of bounding the ratio of information gain possible from an analysis of a dataset with and without the data of any possible single individual. The definition is usually satisfied by adding random noise to the result of a query, ensuring that the added noise masks that hypothetical individual's contribution. The degree of sameness is defined by the parameter  $\varepsilon$  (epsilon) or  $\rho$  (rho). The smaller the parameter  $\varepsilon$  or  $\rho$ , the more noise is added, and the more difficult it is to distinguish the contribution of a single individual. The result is increased privacy for all individuals – both those in the sample and those in the population from which the sample is drawn who are not present in the dataset. The research literature describes differential privacy being used to solve a variety of tasks, including statistical analysis, machine learning, and data sanitization [51]. However, the theory and practice of differential privacy is still in their infancy, and at present, they are not sufficiently well-developed enough to produce privacy-protecting synthetic microdata that preserve interactions between more than a few independent variables.<sup>13</sup>

Differential privacy can be implemented in an online query system or in a batch mode in which an entire dataset is de-identified at one time. In common usage, the phrase "differential privacy" is used to describe both the formal mathematical framework for evaluating privacy loss and for algorithms that provably provide those formal privacy guarantees. Because of the potential for ambiguity, users of differential privacy should clearly state what they mean by the term and what is actually differentially private in their system and data release.

Algorithms that implement differential privacy do not guarantee that privacy will be preserved. Instead, these algorithms place mathematical bounds on what an attacker can learn about the confidential information that was used to produce a specific data publication. Additionally, the privacy guarantee is limited to the privacy loss that an individual experiences based on an analysis of their own data and not from the what the same individual might experience from a statistical analysis of a dataset drawn from a population that does not include the their personal data (see Sec. 3.2.1, "Probability of Re-Identification").

<sup>&</sup>lt;sup>13</sup>For example, while the U.S. Census Bureau used differential privacy to produce the redistricting and demographic data for the 2020 Census, it announced in December, 2022, that it was delaying the implementation of differential privacy for the American Community Survey [35].

*K-anonymity* [137, 152] is a framework for quantifying the difficulty of singling out individual data records based on attributes termed *quasi-identifiers*<sup>14</sup> that are potentially identifying. The technique is based on the concept of an *equivalence class* – the set of records that have the same values on the quasi-identifiers. A dataset is said to be *k-anonymous* if there are no fewer than *k* matching records for every specific combination of quasi-identifiers. For example, if a dataset that has the quasi-identifiers (birth year) and (state) has k = 4 anonymity, then there must be at least four records for every combination of (birth year, state). Subsequent work has refined *k-anonymity* by adding requirements for the diversity of the sensitive attributes within each equivalence class (known as *l-diversity* [98]) and requiring that the resulting data be statistically close to the original data (known as *t-closeness* [94]).

Dozens of other privacy metrics beyond differential privacy and *k*-anonymity have been proposed. See "Technical Privacy Metrics: A Systematic Survey" for a more comprehensive listing [169].

All privacy techniques require the use of subject-matter experts (SMEs) to design the specific application of the technique and to validate that it has been implemented properly. For example, differential privacy requires experts to validate that all uses of confidential data go through the differential privacy mechanism, while k-anonymity requires the use of experts to determine the set of quasi-identifiers by distinguishing between identifying and non-identifying information.

The k-anonymity technique and its subsequent refinements define formal privacy models but come with an important drawback: k-anonymity and related techniques are not compositional. That is, they do not quantify the cumulative privacy loss of multiple data releases, and multiple releases can interact in unpredictable ways, resulting in a catastrophic loss of privacy.

Finally, confidentiality breaches are not the only kinds of risks that can result from the release of de-identified data. Analysts working with de-identified data often have no way of knowing if the de-identification process resulted in the addition of significant noise or bias in the resulting data. Thus, de-identification operations intended to protect the confidentiality of data could result in inaccurate research findings. For agencies with research missions, this threatens the integrity and reputation of the agency and calls into question the ability of the agency to fulfill its mission objectives. Such research might also cause harm if it is used to support harmful policies. Thus, agencies that release de-identified data should explore options for describing the statistical impact that the de-identification process has on the data.

<sup>&</sup>lt;sup>14</sup>A quasi-identifier, also known as an indirect identifier, is a variable that can be used to identify an individual through association with other information. For other discussions regarding "singling out," see [33].

## 3. Governance and Management of Data De-Identification

The decisions and practices regarding the de-identification and release of government data can be integral to the mission and proper functioning of a government agency. As such, these activities should be managed by an agency's leadership in a way that ensures that performance and results are consistent with the agency's mission and legal authority. As discussed above, the need for attention arises from the conflicting goals of data transparency and privacy protection. Although many agencies once assumed that it was relatively straightforward to remove privacy-sensitive data from a dataset so that the remainder could be released without restriction, history shows that this is not the case [66, §2.4, §3.6].

Given this history, there may be a tendency for government agencies to either over-protect data or to simply avoid their release. Limiting the release of data clearly limits the privacy risk that might result from a data release. However, it also creates costs and risks for other government agencies, external organizations, and society. For example, in the absence of a data release, external organizations may suffer the cost of recollecting the data (if it is even possible to do so) or the risk of making poor decisions with insufficient information.

This section begins with a discussion of why agencies may wish to de-identify data and how they should balance the benefits of data release with risks to the data subjects. It then discusses where de-identification fits within the data life cycle. It concludes by discussing the options that agencies have for adopting de-identification standards.<sup>15</sup>

## 3.1. Identifying the Goals and Intended Uses of De-Identification

Before engaging in de-identification, agencies should clearly articulate their goals regarding transparency and disclosure limitation in making a data release. They should then develop a written plan that explains how de-identification will be used to accomplish those goals.

For example:

• Federal statistical agencies collect, process, and publish data for use by researchers, business planners, and other purposes. These agencies are likely to have established standards and methodologies for de-identification. As these agencies evaluate new approaches for de-identification, they should document their rationale for adopting legacy versus new approaches, evaluate how successful their approaches have been over time, and address inconsistencies between data releases.

<sup>&</sup>lt;sup>15</sup>Interested readers will find additional ideas regarding the governance of de-identified data in ISO/IEC 27559:2022 [82].

- Federal awarding agencies are allowed under OMB Circular A-110 to require that institutions of higher education, hospitals, and other non-profit organizations that receive federal grants provide the U.S. Government with "the right to (1) obtain, reproduce, publish or otherwise use the data first produced under an award; and (2) authorize others to receive, reproduce, publish, or otherwise use such data for Federal Purposes" [120, see §36 (c) (1) and (2)]. To realize this policy, awarding agencies can require that awardees establish data management plans for making research data publicly available. Such data are used for a variety of purposes, including transparency and reproducibility. In general, research data that contain personal information should be de-identification standards to ensure the protection of personal information and may consider audits to ensure that awardees have performed de-identification in an appropriate manner.
- Federal research agencies may wish to make de-identified data available to the public to further the objectives of research transparency and allow others to reproduce and build upon their results. These agencies are generally prohibited from publishing research data that contain personal information, thus requiring the use of deidentification.
- All federal agencies that wish to make administrative or operational data available for transparency, accountability, or program oversight or to enable academic research may wish to employ de-identification to avoid sharing the sensitive personally identifiable information of employees, customers, or others. These agencies may wish to evaluate the effectiveness of simple field suppression, de-identification that involves aggregation, and the creation and release of synthetic data as alternatives for realizing their commitment to open data.

Agencies may wish to seek legal guidance as to whether or not de-identification is permitted and what laws, regulations, and policies – if any – would cover de-identified data.

# **3.2.** Evaluating the Risks and Benefits That Arise from De-Identified Data Releases

Once the purpose of the data release is understood, agencies should identify the risks that might result from the data release and weigh them against the possible benefits.

Risk assessments should be based on objective scientific factors and consider the best interests of the individuals in the dataset, the responsibilities of the agency holding the data, and the anticipated benefits to society. The goal of a risk evaluation is not to eliminate risk but to identify risks that can be reduced while still meeting the objectives of the data release, and then deciding whether the residual risk is justified by the data release goals. An agency decision-making process may choose to accept or reject the risk that might result from a release of de-identified data, but participants in the risk assessment should not be empowered to prevent risk from being documented and discussed. Centralized processes also allow for the standardization of the risk assessment and the amount of "acceptable risk" across different programs' releases.

As part of their risk analysis, agencies should specifically evaluate the anticipated negative actions that might result from re-identification, as well as strategies for remediation. It is difficult to measure re-identification risk in ways that are both general and meaningful. Such calculations may result in different levels of risk for different groups. There may be some individuals in a dataset who would be significantly adversely impacted by re-identification and for whom the likelihood of re-identification might be quite high, but these individuals may represent a tiny fraction of the entire dataset. This represents an important area for research in the field of risk communication.

NIST provides guidance for conducting privacy risk assessments in NIST Internal Report (NISTIR) 8062, "An Introduction to Privacy Engineering and Risk Management in Federal Systems" [22], the NIST Privacy Framework: A Tool for Improving Privacy through Enterprise Risk Management, and the NIST Privacy Risk Assessment Methodology (PRAM) [20], all of which can be downloaded from the NIST privacy engineering resources page located at https://www.nist.gov/itl/applied-cybersecurity/privacy-engineering/resources.

Less has been published regarding quantitative approaches for assessing the benefit of data releases. An Organization for Economic Cooperation and Development (OECD) report on the organization's Open, Useful, and Re-usable data (OURdata) Index states:

Open government data promotes transparency, accountability and value creation by making government data available to all with no restriction for its re-use. Public bodies produce and commission huge quantities of data and information. By making their datasets available, public institutions become more transparent and accountable to citizens. By encouraging the use, reuse and free distribution of datasets, governments promote business creation and innovative, citizen-centric services. [116]

The OURdata index rates more than 30 countries according to their data availability and accessibility and government support for data reuse, but these metrics are relative because the report does not attempt to quantify the benefits of data release. At a 2018 conference, Ben Snaith, Peter Wells, and Anna Scott of the Open Data Institute wrote, "Is it possible to measure the value of data? Many now recognise how important data is [sic], but how it should be governed and regulated is often confused by a lack of consensus on how it can be valued" [142].

When conducting a risk analysis, agencies should consider whether the de-identified data will be made publicly available or only be distributed in a controlled manner with some sort of data-sharing agreement. Controlled distributions combined with data-sharing agreements that prohibit re-identification can significantly lower the risk of re-identification

while still preserving many of the potential benefits, such as increased data-sharing and improved decision-making.

## 3.2.1. Probability of Re-Identification

As discussed in Sec. 2.2, "Terminology," potential impacts on individuals include inferential disclosure. Dwork [49, p. 1] first noted that "In 1977 Dalenius articulated a desideratum for statistical databases: nothing about an individual should be learnable from the database that cannot be learned without access to the database." She proved "a general impossibility showing that a formalization of Dalenius' goal along the lines of semantic security cannot be achieved." Dwork and Naor [50, p. 95] proved that for any useful output algorithm, "there exists auxiliary information that an adversary might possess in the context of which the output ... would be disclosive." Both papers refine the definition of inferential disclosure to distinguish between a confidentiality or privacy breach and a scientific or generalizable inference by "shift[ing] from absolute guarantees about disclosures to relative ones: any given disclosure – indeed, any output at all of the privacy mechanism – should be, within a small multiplicative factor, just as likely independent of whether any individual opts in to, or opts out of, the database" [50, p. 103].

It is necessary to "distinguish between identity and attribute inferences that depend upon the use of the protected entity's data and those that are possible without using the protected entity's information" [7, p. 12]. A confidentiality breach occurs when an inference about the attribute associated with a particular entity depends too much on the use of that entity's data in producing the statistical output. According to Kifer et al. [88, p. 4], "(t)he differential privacy framework for SDL methods is designed precisely for the purpose of distinguishing between confidentiality breaches and valid scientific inferences."

*Re-identification probability*<sup>16</sup> is the probability that an individual's identity will be correctly inferred by an outside party using information contained in a de-identified dataset. This outside party was originally termed a *data intruder*, although the terms *adversary* and *attacker* are also used in the literature, borrowing from the colorful language of information security.

Different kinds of re-identification probabilities for this data intruder can be calculated. Here are several kinds of probabilities, as well as proposals for new, declarative, self-describing names:

**Known inclusion re-identification probability** (**KIRP**) is the probability of finding a record that matches a specific individual known to be in the sample. KIRP can be expressed

<sup>&</sup>lt;sup>16</sup>Previous publications described identification probability as "re-identification risk" and used scenarios such as a journalist seeking to discredit a national statistics agency or a prosecutor seeking to find information about a suspect as the bases for probability calculations. That terminology is not presented in this document because of the possible unwanted connotations of those terms and in the interest of bringing the terminology of de-identification into agreement with the terminology used in contemporary risk analysis processes [55].

as the probability for a specific individual or the probability averaged over the entire dataset (AKIRP).<sup>17</sup>

- **Unknown inclusion re-identification probability (UIRP)** is the probability of finding the record that matches a specific individual without first knowing whether the individual is in the dataset. UIRP can be expressed as a probability for an individual record in the dataset averaged over the entire population (AUIRP).<sup>18</sup>
- **Record-matching probability (RMP)** is the probability of finding the record that matches a specific individual chosen from the population. Other useful metrics include the average record-matching probability (ARMP), which is the probability averaged over the entire dataset, and the maximum RMP for all of the individual records.
- **Inclusion probability (IP)** is the probability that a specific individual's presence in the dataset can be inferred.

Whether it is necessary to quantitatively estimate these probabilities depends on the specifics of each intended data release. For example, many cities publicly disclose whether taxes have been paid on a property. Given that this information is already a matter of public record, it may not be necessary to consider inclusion probability when a dataset of property taxpayers for a specific dataset is released. Likewise, there may be some attributes in a dataset that are already public and may not need to be protected with disclosure limitation techniques. However, the existence of such attributes may pose a re-identification risk for other information in the dataset or in other de-identified datasets. The fact that information is public may not negate the responsibility of an agency to provide protection for that information, as the aggregation and distribution of information may cause privacy risks that were not otherwise present. Agencies may also be legally prohibited from releasing copies of information that are similar to information that is already in the public domain.

Although disclosures are commonly thought to be discrete events involving the release of specific data, such as an individual's name matched to a record, disclosures can result from the release of data that merely changes a data intruder's probabilistic belief. For example, a disclosure might change an intruder's estimate that a specific individual is present in a dataset from a 50 % probability to 90 %. The intruder still does not *know* if the individual is in the dataset or not (and the individual might not, in fact, be in the dataset), but a probabilistic disclosure has still occurred because the intruder's estimate of the individual has been changed by the data release. This is similar to the (p,q) rule (also known as the ambiguity rule) in the SDL literature (see 105).

<sup>&</sup>lt;sup>17</sup>Some texts refer to KIRP as "prosecutor risk." The scenario is that a prosecutor is looking for records that belong to a specific named individual.

<sup>&</sup>lt;sup>18</sup>Some texts refer to UIRP as "journalist risk." The scenario is that a journalist has obtained a de-identified file and is trying to identify one of the data subjects, but the journalist fundamentally does not care *who* is identified.

It may be difficult to estimate specific re-identification probabilities, as the ability to reidentify depends on vulnerabilities such as the original dataset, the de-identification technique, and the availability of additional data (publicly available or privately held) that can be linked with the de-identified data, as well as specific threats, such as the technical skill of the data intruder and the intruder's available resources and motivation. It is likely that the true probability of re-identification increases over time as vulnerabilities are likely to increase, such as improvement in re-identification techniques and the availability of more contextual information.

Some researchers have claimed that computing these probabilities "is a fundamentally meaningless exercise" because the calculations are based on assumptions that cannot be validated (e.g., the lack of a database that could link specific quasi-identifiers or sensitive, non-identifying values to identities) [108]. To avoid such a "meaningless exercise," de-identification practitioners must become experts in the range of relevant data that is in both public and private datasets, especially those that are sold by data brokers. Such knowledge must include the quasi-identifiers that the datasets contain, their accuracy, and the ability to generate nearly complete population registers. It is important to recognize practical limitations that apply to potential data intruders and not assume omniscient or omnipotent capabilities to the detriment of the practical data privacy or accuracy trade-offs. However, it is also important to account for unknown datasets that may become available in the future.

De-identification practitioners have traditionally quantified re-identification probability based in part on the skills and abilities of a potential data intruder. In some cases, datasets that were thought to have little possibility for exploitation were deemed to have a lower reidentification probability than datasets that contained sensitive or otherwise valuable information. It is not appropriate to consider the degree of potential exploitation when attempting to evaluate the re-identification probability of government datasets that will be publicly released.

- Although a specific de-identified dataset may not be recognized as sensitive, reidentifying that dataset may be an important step in re-identifying another dataset that is sensitive. Alternatively, the data intruder may merely wish to embarrass the government agency. Thus, adversaries may have a strong incentive to re-identify datasets that are otherwise innocuous.
- Although the public may not generally be skilled in re-identification, many resources on the internet make it easy to acquire specialized datasets, tools, and experts for specific re-identification challenges. Family members, friends, colleagues, and others may also possess substantial personal knowledge about individuals in the data that can be used for re-identification.

De-identification practitioners should assume that de-identified government datasets could be subjected to sustained, worldwide re-identification attempts, and they should gauge their de-identification requirements accordingly. Of course, it is unrealistic to assume that all of the world's resources will be used to attempt to re-identify every publicly released file. Therefore, de-identification requirements should be gauged using a risk assessment [97]. More information on conducting risk assessments can be found in NIST SP 800-30, *Guide for Conducting Risk Assessments* [149], in NISTIR 8062 [22], and using the NIST PRAM [20] discussed in Sec. 3.2.

Members of at-risk and vulnerable populations<sup>19</sup> may be more susceptible to having their identities disclosed by de-identified data than other populations because the characteristic that makes these individuals vulnerable may also make them stand out in the dataset. Likewise, residents of areas with small populations may be more susceptible to having their identities disclosed than residents of areas with large populations. Individuals with multiple traits will generally be more identifiable if the individual's location is geographically restricted. For example, data belonging to a person who is labeled as a pregnant, unemployed veteran will be more identifiable if restricted to Baltimore County, Maryland, than to all of North America.

If agencies determine that the potential for harm is large in a contemplated data release, one way to manage the risk is by increasing the level of de-identification and accepting a lower data accuracy level. This lower level should be communicated to users of the dataset. Other options include data controls, such as restricting the availability of data to qualified researchers in a data enclave.

#### 3.2.2. Adverse Impacts of Re-Identification

As part of a risk analysis, agencies should attempt to enumerate the specific kinds of adverse impacts that can result from the re-identification of de-identified information. These can include potential impacts on individuals, the agency, and society.

Potential adverse impacts on individuals include:

- Increased availability of personal information that leads to an increased risk of fraud, identity theft, discrimination, or abuse
- Increased availability of an individual's location that puts that person at risk for burglary, property crime, assault, or other kinds of violence

<sup>&</sup>lt;sup>19</sup>The Centers for Disease Control and Prevention describe six categories to consider when identifying atrisk groups that could be disproportionately affected by disasters: socioeconomic status, age, gender, race and ethnicity, English language proficiency, and medical issues and disability [110]. Frohlich and Potvin note, "The notion of vulnerable populations differs from that of populations at risk. A population at risk is defined by a higher measured exposure to a specific risk factor. All individuals in a population at risk show a higher risk exposure. A vulnerable population is a subgroup or subpopulation who, because of shared social characteristics, is at higher risk of risks. The notion of vulnerable populations refers to groups who, because of their position in the social strata, are commonly exposed to contextual conditions that distinguish them from the rest of the population. As a consequence, a vulnerable population's distribution of risk exposure has a higher mean than that of the rest of the population" [64]. The characteristics that distinguish at-risk and vulnerable populations may also place them at higher risk of having their data re-identified.

• Increased availability of an individual's non-public personal information that causes psychological harm by exposing potentially embarrassing information or information that the individual may not otherwise choose to reveal to the public or to family members and that potential affects opportunities in the economic marketplace (e.g., employment, housing, college admission)

Potential adverse impacts on agencies include:

- Mandatory reporting under breach reporting laws, regulations, or policies
- Embarrassment or reputational damage
- Respondents who provide data may lose faith in the data, may hesitate to provide data, or may feel compelled to provide inaccurate information in future data collections
- Harm to agency operations if some aspect of those operations required that the deidentified data remain confidential (e.g., an agency that is forced to discontinue a scientific experiment because the data release may have biased the study participants)
- Financial impacts that result from the harm to individuals (e.g., lawsuits)
- Civil or criminal sanctions against employees or contractors that result from a data release contrary to U.S. law

The cascading impacts of re-identification and other breaches threaten all agencies, not just the agency that owns the re-identified data. Potential adverse impacts include:

- Undermining the reputation of researchers in general and the willingness of the public to support or tolerate research and provide accurate information to government agencies and researchers
- Engendering a lack of trust in government individuals may stop consenting to the use of their data, may stop providing data, or may provide false data
- Damaging the practice of using de-identified information de-identification is an important tool for promoting research and accountability, and poorly executed de-identification efforts may negatively impact the public's view of this technique and limit its use

Please see the NIST PRAM [20]

One way to calculate the upper bound on an impact to an individual or agency is to estimate the impact that would result from the inadvertent release of the original dataset. This approach will not calculate the upper bound on the societal impact, however, since that impact includes reputational damage to the practice of de-identification itself. That is, every time data are compromised because of a poorly executed de-identification effort, it becomes harder to justify the use of de-identification in future data releases. As part of a risk analysis process, organizations should enumerate the specific measures that they will take to minimize the risk of successful re-identification. Organizations may wish to consider both the actual risk and the perceived risk to those in the dataset and in the broader community.

As part of the risk assessment, an organization may determine that there is no way to achieve the de-identification goal in terms of data accuracy and identifiability. In these cases, the organization will need to decide whether it should adopt additional measures to protect privacy (e.g., administrative controls or data use agreements), accept a higher level of risk, or choose not to proceed with the project.

The "Privacy Risk Assessment" section of the NIST Privacy Engineering Program website<sup>20</sup> contains tools and use cases for agencies and others interested in conducting privacy risk assessments.

#### 3.2.3. Impacts Other Than Re-Identification

The use of de-identified data can lead to adverse impacts other than re-identification, though risk assessments that evaluate the risks of re-identification can address these other risks as well. Such risks might include:

- The risk of excessive inferential disclosures
- The risk that the de-identification process may introduce bias or inaccuracies into the dataset that result in incorrect decisions<sup>21</sup>
- The risk that releasing a de-identified dataset may reveal non-public information about an agency's policies or practices
- The risk that data may be overly generic or imprecise and of very little use to the intended recipients

It preferable to use de-identification processes that include assessments of data accuracy, including bias and variability components (e.g., confidence intervals based on root mean squared error). When it does not provide information that may aid data intruders, it is also useful to reveal the de-identification process itself so that analysts can understand any potential inaccuracies that might be introduced by the de-identification. This is consistent with *Kerckhoffs's principle* [86], a widely accepted system design principle that holds that the security of a system should not rely on the secrecy of the methods that it employs.

<sup>&</sup>lt;sup>20</sup>The Privacy Risk Assessment is available at https://www.nist.gov/itl/applied-cybersecurity/privacy-engineering/collaboration-space/focus-areas/risk-assessment.

<sup>&</sup>lt;sup>21</sup>For example, a personalized Warfarin dosing model created with data that had been modified in a manner consistent with the differential privacy de-identification model produced higher mortality rates in simulation than a model created from unaltered data [62]. Educational data de-identified with the k-anonymity model can also result in the introduction of bias that leads to spurious results [14, 155].

#### 3.2.4. Remediation

As part of a risk analysis process, agencies should attempt to enumerate the techniques that could be used to mitigate or remediate harm that would result from a successful reidentification of de-identified information. Remediation could include victim education, the procurement of monitoring or security services, the issuance of new identifiers, or other measures.

# 3.3. Data Life Cycle

The *NIST Big Data Interoperability Framework* defines the data life cycle as "the set of processes in an application that transform raw data into actionable knowledge" [112]. The data life cycle can be used in the de-identification process to help analyze the expected benefits, intended uses, privacy threats, and vulnerabilities of de-identified data. As such, the data life cycle concept can be used to select appropriate privacy controls based on a reasoned analysis of the threats. For example, the NIST Privacy Framework [113] and other privacy-by-design concepts [28] can be employed to decrease the number of identifiers collected, thus minimizing the requirements for de-identification prior to data release. The data life cycle can also be used to design a tiered access mechanism based on this analysis [12].

Several data life cycles have been proposed, but none are widely accepted as a standard.

Michener et al. [105] (Figure 1) describe the data life cycle as a true cycle:

 $\rightarrow Assure \rightarrow Describe \rightarrow Deposit \rightarrow Preserve \rightarrow Discover \rightarrow Integrate \rightarrow Analyze \rightarrow Collect$ 

Stobierski [148] also describes the data life cycle as a cycle with different steps:

 $\begin{array}{l} \text{Generation} \rightarrow \text{Collection} \rightarrow \text{Processing} \rightarrow \text{Storage} \rightarrow \text{Management} \rightarrow \text{Analysis} \rightarrow \\ \text{Visualization} \rightarrow \text{Interpretation} \rightarrow \text{Generation} \end{array}$ 

De-identification does not fit into a circular data life cycle model, as the data owner typically retains access to the identified data. However, if the organization employs deidentification, it could be performed during Collect or between Collect and Assure if identified data were collected but the identifying information was not actually needed. Alternatively, de-identification could be applied after Describe and prior to Deposit to avoid archiving identifying information.

Chisholm and others [30] (Figure 2) describe the data life cycle as a linear process with a fork for data publication:

 $\begin{array}{l} \text{Data Capture} \rightarrow \text{Data Maintenance} \rightarrow \text{Data Synthesis} \rightarrow \text{Data Usage} \rightarrow \\ \left\{ \text{Data Publication and Data Archival} \rightarrow \text{Data Purging} \right\} \end{array}$ 

Using this formulation, de-identification can take place either during Data Capture or following Data Usage. However, agencies should consider data release requirements from

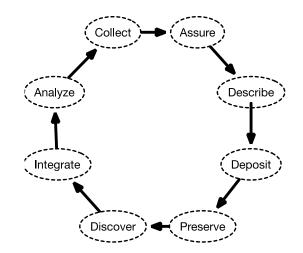
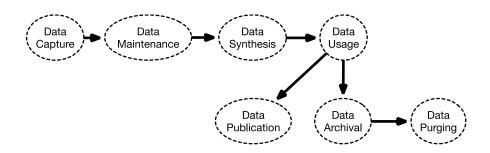


Fig. 1. The data life cycle as described by Michener et al. [105]



**Fig. 2.** Chisholm's view of the data life cycle is a linear process with a branching point after data usage [30]

the very beginning of the planning process for each new data collection. By knowing in advance how they intend to publish the data and for what purposes and by having a plan for how disclosure limitation will be applied, agencies can tailor information collection accordingly.

For example, if specific identifiers are not needed for maintenance, synthesis, and usage, then those identifiers should not be collected. If fully identified data are needed within the organization, the identifying information can be removed prior to the data being published, shared, or archived. Applying de-identification throughout the data life cycle minimizes privacy risk and significantly eases the process of public release. However, agencies should be cognizant of the potential loss of future utility if identifiers are permanently removed. For this reason, agencies may wish to retain an identified dataset or data-linking information, as it may be difficult to predict future needs.

Altman et al. [97] (Figures 3 and 4) propose a "modern approach to privacy-aware government data releases" that incorporates progressive levels of de-identification as well as different kinds of access and administrative controls in line with the sensitivity of the data.

Agencies that perform de-identification should document that:

- The techniques used to perform the de-identification are theoretically sound and generally accepted.<sup>22</sup>
- The software used to perform the de-identification is reliable for the intended task.
- The individuals who performed the de-identification were suitably qualified.
- The tests that were used to evaluate the effectiveness of the de-identification were validated for that purpose.
- Ongoing monitoring is in place to ensure the continued effectiveness of the deidentification strategy.

- (i) Applying such principles and methods, determines that the risk is very small that the information could be used, alone or in combination with other reasonably available information, by an anticipated recipient to identify an individual who is a subject of the information; and
- (ii) Documents the methods and results of the analysis that justify such determination;"

<sup>&</sup>lt;sup>22</sup>To determine that a technique is theoretically sound and generally accepted, agencies should adopt guidance that mirrors the language that the HHS November 26, 2012, *Guidance Regarding Methods for Deidentification of Protected Health Information in Accordance with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule* [166] uses in its discussion of the Privacy Rule's "expert determination method," which states on page 7:

<sup>&</sup>quot;A covered entity may determine that health information is not individually identifiable health information only if:

<sup>(1)</sup> A person with appropriate knowledge of and experience with generally accepted statistical and scientific principles and methods for rendering information not individually identifiable:

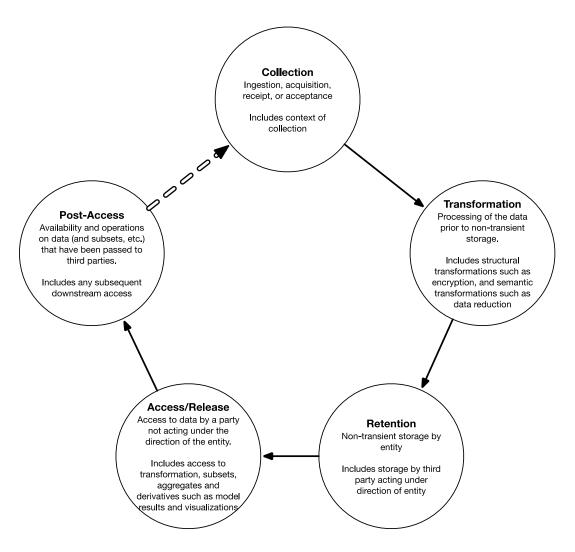
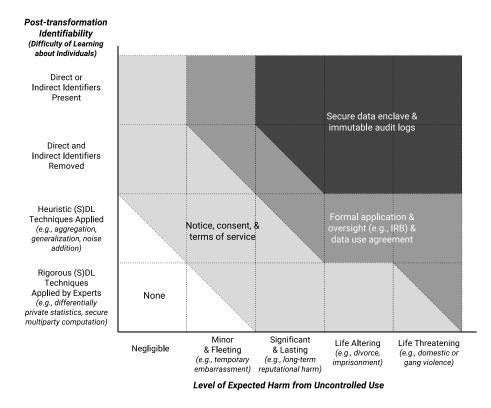


Fig. 3. Altman's "modern approach to privacy-aware government data releases" [97]



**Fig. 4.** Altman's conceptual diagram of the relationship between post-transformation identifiability, the level of expected harm, and the suitability of selected privacy controls for a data release [97]

No matter where de-identification is applied in the data life cycle, agencies should document the answers to the following questions for each de-identified dataset:

- Are direct identifiers collected with the dataset?
- Even if direct identifiers are not collected, is it still possible to identify the data subjects through the presence of quasi-identifiers?
- Where in the data life cycle is de-identification performed? Is it performed in only one place or in multiple places?
- Is the original dataset retained after de-identification?
- Is there a key or map retained so that specific data elements can be re-identified later?
- How are decisions made regarding de-identification and re-identification?
- Are there specific datasets that can be used to re-identify the de-identified data? If so, what controls are in place to prevent intentional or unintentional re-identification?
- Is it a problem if some records in a dataset are re-identified?
- Is there a mechanism that will inform the de-identifying agency if there is an attempt to re-identify the de-identified dataset? Is there a mechanism that will inform the agency if the attempt is successful?

#### 3.4. Data-Sharing Models

Agencies should decide on the data-sharing model that will be used to make the data available outside of the agency after the data have been de-identified [66, p. 14]. Specific models combine *security*, *privacy* and *disassociability* techniques to reduce privacy risks to individuals.

Here we use the term *security* to refer to techniques that limit *who* can view the data, and *privacy* to refer to techniques that limit *what information* the data contains. Disassociability is the degree to which the information in the data can be used while limiting the association to individuals or devices beyond the operational requirements of the system. These concepts can be considered independently. In practice, however, *who* has access to the data and the degree to which the data are associated with individuals or devices makes a significant difference to the expected risk of disclosure and, therefore, influences the extent to which privacy techniques must be used to limit the presence of sensitive personally identifiable information in the data.

The Advanced Encryption Standard (AES) symmetric encryption algorithm, which is one of several traditional encryption algorithms, is an example of a security technique since it allows only the party holding the encryption key to view the data. However, advanced cryptographic techniques that combine secure multiparty cryptography with the application of

differential privacy can provide both security, privacy and even disassociability capabilities (see Sec. 3.9.2).

A number of possible models exist at different points in the spectrum of security and privacy protections. Figure 4 summarizes this spectrum: its x-axis describes various privacy techniques that can limit the informational content of the data; its y-axis describes how much harm would occur if the underlying information were disclosed; and the regions of the graph are labeled with suggested security techniques. Some common combinations of security and privacy techniques include:

- **The release-and-forget model [123].** The de-identified data may be released to the public, typically by being published on the internet. It can be difficult or impossible for an organization to recall the data once released in this fashion and may limit information for future releases.
- The Data Use Agreement (DUA) model. The de-identified data may be made available under a legally binding data use agreement that details what can and cannot be done with the data. Typically, DUAs include security provisions and may prohibit attempted re-identification, linking to other data, and redistribution of the data without a similarly binding DUA. A DUA will typically be negotiated between the data holder and qualified researchers (the "qualified investigator model" [58]) or members of the general public (e.g., citizen scientists or the media), although they may be simply posted on the internet with a click-through license agreement that must be agreed to before the data can be downloaded (the "click-through model" [58]).
- The synthetic data with validation model. Statistical disclosure limitation techniques are applied to the original dataset and used to create a synthetic dataset that contains many of the aspects of the original dataset but does not contain disclosing information. The synthetic dataset is released, either publicly or to vetted researchers. The synthetic dataset can then be used as a proxy for the original dataset, and if constructed well, the results of statistical analyses should be similar. If used in conjunction with the enclave model, researchers may use the synthetic dataset to develop queries and/or analytic software. These queries and/or software can then be taken to the enclave or provided to the agency and applied on the original data. There are a growing number of techniques for using differential privacy to create synthetic data.
- The enclave model [58, 114, 141]. The de-identified data may be kept in a segregated enclave that restricts the export of the original data and instead accepts queries from qualified researchers, runs the queries on the de-identified data, and responds with results. Enclaves can be physical or virtual and can operate under a variety of different models. For example, vetted researchers may travel to the enclave to perform their research, as is done with the Federal Statistical Research Data Centers operated by the U.S. Census Bureau. Enclaves may be used to implement the verification step of the synthetic data with validation model. Queries made in the enclave model may be vetted automatically or manually (e.g., by the DRB). Vetting can try to screen for

queries that might violate privacy or are inconsistent with the stated purpose of the research. However, even vetted queries may lead to unanticipated privacy risks when the results are released and combined with external data.

Sharing models should consider the possibility of multiple or periodic releases. Just as repeated queries to the same dataset may leak personal data from the dataset, repeated deidentified releases (whether from the same dataset or from different datasets that contain some of the same individuals) by an agency may result in compromising the privacy of individuals unless each subsequent release is viewed in light of the previous release. Even if a contemplated release of a de-identified dataset does not directly reveal identifying information, federal agencies should ensure that the release – combined with previous releases – will also not reveal identifying information [167].

Instead of sharing an entire dataset, the data owner may choose to release a sample. If only a sample is released, the probability of re-identification decreases because a data intruder will not know whether a specific individual from the data universe is present in the de-identified dataset [57]. However, releasing only a sample may decrease the statistical power of tests on the data, may cause users to draw incorrect inferences if proper statistical sampling methods are not used, or may not align with agency goals regarding transparency and accountability.

#### 3.5. The Five Safes

Agencies should use a repeatable methodology for evaluating the terms under which data will be made available, such as The Five Safes [42, 16]. The Five Safes was created in the United Kingdom to assist a national statistical agency in evaluating proposed collaborative projects with a larger research community. The framework was developed to assist in "designing, describing and evaluating" data access systems. Here, the term "data access system" is viewed broadly as any mechanism that allows outsiders to gain access to the agency's confidential data. That is, a data access system might include setting up an enclave for academic researchers who undergo extensive background checks, but it also includes publishing data on the internet.

The Five Safes framework derives its name from the use of five categories (called "risk" or "access" dimensions) that are used in the evaluation:

- 1. Safe projects. Is this use of the data appropriate?
- 2. Safe people. Can the researchers be trusted to use it in an appropriate manner?
- 3. Safe data. Is there a disclosure risk in the data itself?
- 4. Safe settings. Does the access facility limit unauthorized use?
- 5. Safe outputs. Are the statistical results non-disclosive?

The legal, moral, and ethical reviews of each of these dimensions are independent of the others. In practice, this might mean that the project is safe (the proposed use of the appropriate), the people are safe (e.g., the researchers are noted academics with respected histories of collaborative work), the data are safe (i.e., there is no disclosure risk in the data), and the output is safe (i.e., it will not disclose personal information). However, because the setting is not safe (perhaps the facility has poor internal security), the project should not go forward. In this example, the Five Safes framework would provide a decision-maker with the tools to separate each of these dimensions and resolve the problems so that the project can proceed.

One of the positive aspects of the Five Safes framework is that it forces data controllers to consider many different aspects of data release when evaluating data access proposals. It is common for data owners to "focus on one, and only one, particular issue (such as the legal framework surrounding access to their data or [Information Technology] (IT) solutions)." With the Five Safes, people who may be specialists in one area are forced to consider (or to explicitly not consider) aspects of privacy protection with which they may not be familiar and might otherwise overlook.

The so-called evidence-based, default-open, risk-managed, user-centered (EDRU) approach [73, 136], which provides tools for putting these decisions into context and weighing potential risks against potential benefits.

Agencies should determine if a framework such as The Five Safes is appropriate for designing access systems, evaluating existing systems, communication, and training.

## 3.6. Disclosure Review Boards

Disclosure Review Boards (DRBs), also known as Data Release Boards, are administrative bodies created within an organization that are charged with ensuring that intended disclosures meet the policy and procedural requirements of that organization. DRBs provide organizations with a structured approach for identifying, managing and documenting risks associated with data publishing in a systematic, consistent and accountable manner. DRBs can act as a center to keep records and release reports. DRBs also allow for the accumulation of disclosure avoidance expertise within an organization and can serve as centers of training and advocacy for proper disclosure handling practices. As such, DRBs can be a powerful tool to allow agencies and their Chief Data Officers to comply with the legal requirements of the Evidence Act and with its implementation memorandum M-19-23. [168]<sup>23</sup>

<sup>&</sup>lt;sup>23</sup>OMB Memorandum M-19-23, "Phase 1 Implementation of the Foundations for Evidence-Based Policymaking Act of 2018: Learning Agendas, Personnel, and Planning Guidance" [168] requires that agencies undertake learning agenda activities that are "in accordance with applicable law governing the collection, use and disclosure of data and information." (p. 19) It also requires that Chief Data Officers have "strong business acumen and familiarity with data science approaches, cloud computing, cyber security, privacy, confidentiality, data analytics, statistical methods, policy analysis, information quality standards set out in

DRBs should be governed by a written *mission statement* and *charter* (or equivalent document) that are ideally approved by the same mechanisms that the organization uses to approve other organization-wide policies.

The DRB should have a mission statement that guides its activities. For example, the U.S. Department of Education's DRB has the mission statement:

The Mission of the Department of Education Disclosure Review Board (ED-DRB) is to review proposed data releases by the Department's principal offices (POs) through a collaborate technical assistance, aiding the Department to release as much useful data as possible, while protecting the privacy of individuals and the confidentiality of their data, as required by law. [54]

Most DRBs are established to weigh the interests of data release against those of individual privacy protection. However, a DRB may also be chartered to consider *group harms* [66, p. 13] that can result from the release of a dataset. Such harms go beyond the harm to the privacy interests of a specific individual.

The DRB charter specifies the mechanics of how the mission is implemented. A formal, written charter promotes transparency in the decision-making process and ensures consistency in the application of its policies. The DRB charter should frame the DRB's responsibilities in reference to existing organizational policies and components, as well as applicable regulations and laws. Some agencies may balance these concerns by employing data use models other than de-identification (e.g., by establishing data enclaves where a limited number of vetted researchers can access sensitive datasets in a way that provides data value while minimizing the possibility for harm or by authorizing the use of secure multi-party computation, homomorphic encryption, or other privacy-preserving data analytics to compute various statistics). In those agencies, a DRB would be empowered to approve the use of such mechanisms.

Certain agencies may engage in data disclosure on a routine basis (e.g., research and evaluation agencies), in which case it may be beneficial for the DRB to establish policies and procedures for de-identification rather than being responsible for every review. The DRB charter should clearly specify how the group will provide oversight and ensure organizational accountability to the agreed-upon policies.

the Information Quality Act (IQA), record disclosure laws and policy, and the Paperwork Reduction Act (PRA)." (p. 23) The memo's further states that an agency's Annual Evaluation Plans will discuss how information will be disseminated and used while taking into account "applicable law and policies governing the collection, use, and disclosure of data and information." (p. 35) Footnote 34 on p. 22 cites section 202(e) of the evidence act noting that the Chief Data Officer "shall be designated on the basis of demonstrated training and experience in data management, governance (including creation, application, and maintenance ofdata standards), collection, analysis, protection, use, and dissemination, including with respect to any statistical and related techniques to protect and de-identify confidential data."

The DRB charter should also specify the DRB's composition. To be effective, the DRB should include representatives from multiple groups and experts in both technology and privacy policy. Specifically, DRBs may wish to have as members:

- Individuals who represent the interests of potential users (such individuals need not come from outside of the organization)
- Representation from among the public, specifically from groups represented in the datasets if they have a limited scope
- Representation from the organization's leadership team, such as the Senior Agency Official for Privacy [4, Appendix II, section 4] (such representation helps to establish the DRB's credibility with the rest of the organization)
- A representative of the organization's senior privacy official
- Subject-matter experts
- Outside experts

The charter should establish rules for ensuring a quorum and specify whether members can designate alternates on a standing or meeting-by-meeting basis. The DRB should specify the mechanism by which members are nominated and approved, their tenure, conditions for removal, and removal procedures.<sup>24</sup>

The charter should set policy expectations for record keeping and reporting, including whether records and reports are considered public or restricted. For example, the charter could direct the DRB to issue an annual report with a list of every dataset that was approved for release. The charter should indicate whether it is possible to exclude sensitive decisions from these reporting requirements and the mechanism for doing so. Ideally, the charter should be a public document to promote transparency.

To meet its requirement of evaluating data releases, the DRB should require that written applications be submitted to the DRB that specify the nature of the dataset, the deidentification methodology, and the result. An application may require that the proposer present the re-identification risk, the risk to individuals if the dataset is re-identified, and a proposed plan for detecting and mitigating successful re-identification. In addition, the DRB should require that when individuals are informed that their information will be deidentified, they also be informed that privacy risks may remain despite de-identification.

The DRB should keep accurate records of its request memos, their associated documentation, the DRB decision, and the actual files released. These records should be appropri-

<sup>&</sup>lt;sup>24</sup>For example, in 2022, the Census Bureau's DRB had 12 voting members: two technical co-chairs, a representative from the Policy Coordination Office, a representative from the Associate Director for Communications, two representatives from the Center for Enterprise Dissemination-Disclosure Avoidance (CED-DA), two representatives from the Economic Programs Directorate, two representatives from the Demographic Programs Directorate, and two representatives from the Decennial Programs Directorate [29].

ately archived and curated so that they can be recovered. In the case of large data releases, the definitive version of the released data should be curated using an externally validated procedure, such as a recorded cryptographic hash value or signature, and a digital object identifier (DOI) [83].

DRBs may wish to institute a two-step process in which the applicant first proposes and receives approval for a specific de-identification process that will be applied to a specific dataset and then submits and receives approval for the release of the dataset that has been de-identified according to the proposal. However, because it is theoretically impossible to predict the results of applying an arbitrary process to an arbitrary dataset [31, 159], the DRB should be empowered to reject a proposed release of a dataset even if it has been de-identified in accordance with an approved procedure because performing the de-identification may demonstrate that the procedure was insufficient to protect privacy. The DRB should be able to delegate the responsibility of reviewing the de-identified dataset, but such responsibility should not be delegated to the individual or group that performed the de-identification.

The DRB charter should specify whether the DRB needs to approve each data release by the organization or if it may grant blanket approval for all data of a specific type that are de-identified according to a specific methodology. The charter should specify the duration of the approval. Given advances in the science and technology of de-identification, a Board should not be empowered to grant release authority for an indefinite or unlimited amount of time.

In most cases, a single privacy protection methodology will be insufficient to protect the varied datasets that an agency may wish to release. That is, different techniques might best optimize the trade-off between re-identification risk and data usability, depending on the specifics of each kind of dataset. Nevertheless, the DRB may wish to develop guidance, recommendations, and training materials regarding specific de-identification techniques that are to be used. Agencies that standardize on a small number of de-identification techniques will gain familiarity with these techniques and are likely to have results with a higher level of consistency and success than those that have no such guidance or standardization.

Although it is envisioned that DRBs will work in a cooperative, collaborative, and congenial manner with those inside an agency seeking to release de-identified data, there will at times be a disagreement of opinion. For this reason, the DRB's charter should state whether the DRB has the final say over disclosure matters or if the DRB's decisions can be overruled, by whom, and by what procedure. For example, an agency might give the DRB final say over disclosure matters but allow the agency's leadership to replace members of the DRB as necessary. Alternatively, the DRB's rulings may merely be advisory, with all data releases being individually approved by agency leadership or its delegates.<sup>25</sup>

<sup>&</sup>lt;sup>25</sup>At the Census Bureau, staff members who are not satisfied with the DRB's decision may appeal to the Data Stewardship Executive Policy Committee (DSEP), which has on several occasions instructed the DRB to revise the way that it handles a particular request.

Agencies should decide whether the DRB charter will include any kind of performance timetables or be bound by a service-level agreement (SLA) that defines a level of service to which the DRB commits.

The key elements of a Disclosure Review Board include:

- A written mission statement and charter
- Members who represent different groups within the organization, including leadership
- The Board receives written applications to release de-identified data
- The Board reviews *both* the proposed methodology *and* the results of applying the methodology
- Applications should identify the risks associated with data release, including reidentification probability, potentially adverse events that would result if individuals are re-identified, and a mitigation strategy if re-identification takes place
- Approvals may be valid for multiple releases but should not be valid indefinitely
- Reliable records management for applications, approvals, and released data
- Mechanisms for dispute resolution
- Timetable or service-level agreement (SLA)
- Legal and technical understanding of privacy

Example outputs of a DRB include specifying access methods for different kinds of data releases, establishing acceptable levels of re-identification risk, and maintaining detailed records of previous data releases that ideally include the dataset that was released and the privacy-preserving methodology that was employed.

There is some similarity between DRBs as envisioned here and the Institutional Review Board (IRBs) system created by the Common Rule<sup>26</sup> for regulating human subject research in the United States. For example, both IRB and DRB members require an understanding of ethical principles, public policy and an understanding of how the collection and release of data can cause harms to individuals. However, there are also important differences:

• While the purpose of IRBs is to protect human subjects involved in human subject research, DRBs are charged with protecting data subjects, institutions, and – potentially – society as a whole.

<sup>&</sup>lt;sup>26</sup>The Federal Policy for the Protection of Human Subjects or the "Common Rule" was published in 1991 and codified in separate regulations by 15 federal departments and agencies. The Revised Common Rule was published in the Federal Register (FR) on January 19, 2017, and was amended to delay the effective and compliance dates on January 22, 2018, and June 19, 2018 [165].

- Whereas IRBs are required to have "at least one member whose primary concerns are in nonscientific areas" and "at least one member who is not otherwise affiliated with the institution and who is not part of the immediate family of a person who is affiliated with the institution," there are no such requirements for members on a DRB.
- Whereas IRBs give approval for research and then typically receive reports only during an annual review or when a research project terminates, DRBs may be involved at multiple points during the process.
- Whereas approval of an IRB is required before research with human subjects can commence, DRBs are typically involved after research has taken place and prior to the release of data or other research findings.
- Whereas service on an IRB requires knowledge of the Common Rule [165], service on a DRB requires knowledge of the Evidence Act [2] and agency-specific privacy rules, as well as a working knowledge of statistics and computation techniques.

## 3.7. De-Identification and Standards

Agencies can rely on de-identification standards to provide standardized terminology, procedures, and performance criteria for de-identification efforts. Agencies can adopt existing de-identification standards or create their own. De-identification standards can be prescriptive or risk-based.

## 3.7.1. Benefits of Standards

De-identification standards assist agencies with the process of de-identifying data prior to public release. Without standards, data owners may be unwilling to share data, as they may be unable to assess whether a procedure for de-identifying is sufficient to minimize privacy risk.

Standards can increase the availability of individuals with appropriate training by identifying a specific body of knowledge and practice that training should address. Absent standards, agencies may forego opportunities to share data. De-identification standards can help practitioners develop a community, as well as certification and accreditation processes.

Standards decrease uncertainty and provide data owners and custodians with best practices to follow. Courts can consider standards as acceptable practices that should generally be followed. In the event of litigation, an agency can point to the standard and say that it followed good data practice.

## 3.7.2. Prescriptive De-Identification Standards

A prescriptive de-identification standard specifies an algorithmic procedure that – if followed – results in data that are de-identified to a previously established benchmark. This approach focuses on the *process* of de-identification rather than on the specific properties of the de-identified data.

The Safe Harbor method of the HIPAA Privacy Rule [3] is an example of a prescriptive deidentification standard. The intent of the Safe Harbor method is to "provide covered entities with a simple method to determine if the information is adequately de-identified" [118]. It does this by specifying that health information is considered to be de-identified through the removal of 18 kinds of identifiers and the explicit assurance that the entity does not have *actual knowledge* that the remaining information can be used to identify an individual who is the subject of the information. Once de-identified, the dataset is no longer subject to HIPAA privacy, security, and breach notification regulations. Nevertheless, "a covered entity may require the recipient of de-identified information to enter into a data use agreement to access files with known disclosure risk" [118].

As noted on page 5, Guidance from the U.S. Department of Health and Human Services (HHS) on the Health Insurance Portability and Accountability Act (HIPAA) deidentification standards states that even when properly applied, both the Safe Harbor and expert determination methods for de-identification "yield de-identified data that retains some risk of identification. Although the risk is very small, it is not zero, and there is a possibility that de-identified data could be linked back to the identity of the patient to which it corresponds" [166]. Specifically, the combination of quasi-identifiers (indirect identifiers) left in the de-identified dataset (e.g., race, gender, income and education level) may raise re-identification issues.

The Privacy Rule states that a covered entity that employs the Safe Harbor method must have no "actual knowledge" that the information – once de-identified – could still be used to re-identify individuals. However, covered entities are not obligated to employ experts or mount re-identification attacks against datasets to verify that the use of the Safe Harbor method has in fact resulted in data that cannot be re-identified.

Prescriptive standards have the advantage of being relatively easy for users to follow, but developing, testing, and validating such standards can be burdensome. Because prescriptive de-identification standards do not depend on the particulars of a specific case, there is a tendency for them to be more conservative than is necessary, resulting in a decrease in data for corresponding levels of risk. Even so, there is typically no mathematically provable assurance that following a procedure specified by the standard actually produces the intended privacy-preserving outcome.

Agencies that create prescriptive de-identification standards should ensure that data deidentified according to the standards have a sufficiently small risk of being re-identified consistent with the intended level of privacy protection. Such assurances frequently cannot be made unless formal privacy techniques (e.g., *differential privacy*) are employed, and the assurances made by differential privacy are unlike the simplistic absolute assurances made in the context of traditional SDL techniques. Agencies may nevertheless determine that public policy goals furthered by having an easy-to-use prescriptive standard outweighs the risk of a standard that does not have provable privacy guarantees.<sup>27</sup> If such determinations are made, they should be clearly documented.

Prescriptive de-identification standards carry the risk that the standard may not sufficiently de-identify to avoid the risk of re-identification, especially as methodology advances and more data sources become available. A second risk is that different agencies (or governments) may adopt inconsistent rules. In such cases, information that is legally de-identified for one purpose or in one jurisdiction may not be legally de-identified in another.

## 3.7.3. Risk-Based De-Identification Standards

Risk-based de-identification standards specify the properties that de-identified data must have rather than the process that was used to create the de-identified data. For example, under the "Expert Determination" method of the HIPAA Privacy Rule, a technique for deidentifying is sufficient if an appropriate expert applying generally accepted statistical and scientific principles and methods "determines that the risk is very small that the information could be used, alone or in combination with other reasonably available information, by an anticipated recipient to identify an individual who is a subject of the information" [118]. The rule requires that experts document their methods and the results of their analyses.

Risk-based standards have the advantage of allowing users many different ways to solve a problem by leaving room for innovation. Another advantage is that they can require the desired outcome rather than specifying an aspirational mechanism.

There are two fundamental challenges with the risk-based approach:

- This approach depends on having experts with knowledge of all prior releases of related data.
- The assurance that the experts provide may not be valid if additional data are released or come to light.

Risk-based standards should be sufficiently detailed to perform in a manner that is reliable and repeatable. For example, standards that call for the use of experts can specify how an expert's expertise should be determined. Standards that call for the reduction of risk to an acceptable level should provide a procedure for determining that level.

#### 3.8. Education, Training, and Research

De-identifying data in a manner that preserves privacy can be a complex mathematical, statistical, administrative, and data-driven process. Frequently, the opportunities for identity disclosure will vary from dataset to dataset. Privacy-protecting mechanisms developed for

<sup>&</sup>lt;sup>27</sup>For example, while the HIPAA Safe Harbor method does not have provable privacy guarantees, it provides guidance that is fairly easy to follow. However, it also adds that "(ii) The covered entity does not have actual knowledge that the information could be used alone or in combination with other information to identify an individual who is a subject of the information" [119].

one dataset may not be appropriate for others. For these reasons, agencies that engage in de-identification should ensure that their workers have adequate education and training in the subject domain. Agencies may wish to establish education or certification requirements for those who work directly with the datasets or to adopt industry standards, such as the HITRUST De-Identification Framework [101]. Because de-identification techniques are modality-dependent, agencies using de-identification may need to institute research efforts to develop and test appropriate data release methodologies.

Although some de-identification standards may call for training data recipients [82], this is typically not an option for government datasets that are made freely available on the public internet.

# **3.9.** Alternative Approaches for Computing Statistics on Confidential Information

In addition to de-identification, there are other technologies and methodologies that can secure sensitive data. Many of these approaches can complement de-identification and further reduce privacy risk to data subjects. Combining techniques is an example of *defense in depth* and should be considered whenever possible. The NIST Privacy Framework [113] provides more information about additional measures for defense in depth.

# 3.9.1. Encryption and Access Control

Encrypting sensitive data *at rest* can prevent attackers from obtaining the data directly (e.g., by compromising the server that stores it). Encryption can also serve as a form of *access control* (i.e., it can control *who* can access the data) because examining the data requires access to the encryption keys. If the original data (with identities) are retained, they should be stored encrypted, and access should be limited. Even after de-identification, more sensitive data not intended for public release can be provided to select individuals by limiting access via encryption.

## 3.9.2. Secure Computation

Two technologies enable computing on encrypted data *without decrypting it*:

- 1. Fully-homomorphic encryption (FHE) [70] allows a server to compute a function f(x) on an encrypted value x without decrypting it. The result is a new encrypted value that can only be decrypted by someone who holds the original encryption key.
- 2. Secure multi-party computation (MPC) [95] allows multiple servers to *jointly* compute a function  $f(x_1, ..., x_k)$ , where each server provides one of the inputs  $x_i$ , and no server learns any of the others' inputs.

Both of these approaches are general-purpose in that they can be used to compute any function, and both are considerably slower than performing the equivalent computation

with unencrypted data on a single computer. In addition, both approaches require all participants to agree in advance on the computation to be performed. Nevertheless, both approaches are now sufficiently performant that they can be used for many practical kinds of privacy-preserving data analysis.<sup>28</sup>

Note that even when secure computing approaches are employed, the outputs of the computations can still compromise privacy if they are not protected with a formal privacy mechanism, such as differential privacy.

For more information on secure computation techniques and the efforts of the U.S. government to advance their use, see the *National Strategy to Advance Privacy-Preserving Data Sharing and Analytics* [41].

# **3.9.3.** Trusted Execution Environments

*Trusted execution environments* (TEEs) (also called *trusted hardware enclaves* or *secure hardware enclaves*) are another approach for computing encrypted data. TEEs are implemented in computer hardware, typically within the silicon of a modern central processing unit (CPU), and protect programs that run on that CPU from the surrounding environment. For example, a TEE can cause data from a computer's CPU to be automatically encrypted when written to main memory and decrypted when read back to the CPU. In this way, data in memory are protected from other devices that can access memory, such as a network interface card. In addition to encryption, TEEs typically support attestation so that a program running on a TEE can attest to a remote system that the result is a true, legitimate, and faithful execution of the program.

Traditional cloud services require trusting the cloud provider, who may have a compromised environment (e.g., an operating system that records encryption keys). A TEE decreases the need for trust because it allows a user to validate that they are communicating with the remote program and offers assurance that no other program running on the cloud provider can access the program's data. Secure enclaves can thus allow untrusted infrastructure to operate on sensitive data in much the same way as technologies like FHE and MPC.

Intel's Software Guard Extensions (SGX) [140], ARM's TrustZone [131], and AMD's Secure Encrypted Virtualization (SEV) [13] are all examples of secure hardware enclaves. All of these products are designed to provide similar security to cryptographic techniques while also providing performance similar to a single CPU operating on unencrypted data. These secure hardware products are necessarily complex, and various implementation errors have been discovered that can allow attackers to defeat their security protections. Secure hardware enclaves certainly offer increased security for data compared to plaintext

<sup>&</sup>lt;sup>28</sup>More information about these and other kinds of secure computation can be found on the NIST Privacy-Enhancing Cryptography (PEC) project website at https://csrc.nist.gov/projects/pec.

computation, but agencies should carefully consider the trade-off between performance and security when choosing between secure hardware and cryptographic techniques.

#### 3.9.4. Physical Enclaves

For extremely sensitive data, a *physical enclave* (Sec. 3.4) may provide additional security. In this model, data are stored on a computer that is not connected to any network and are accessible only via physical access to a particular room. Access to the data are then controlled by limiting access to the room. This approach can be quite cumbersome.

#### 4. Technical Steps for Data De-Identification

The goal of de-identification is to transform data in a way that protects privacy while preserving the validity of inferences drawn on that data within the context of a target use case. This section discusses technical options for performing de-identification and verifying the result of a de-identification procedure.

Agencies should adopt a detailed, written process for de-identifying data prior to commencing work on a de-identification project. The details of the process will depend on the particular de-identification approach that is pursued. In developing technical steps for data de-identification, agencies may wish to consider existing de-identification standards, such as the HIPAA Privacy Rule [166, 3], ISO/IEC 27559:2022 ("Privacy enhancing data de-identification framework") [82], the IHE De-Identification Handbook [79], or the HITRUST De-Identification Framework [101].

#### 4.1. Determine the Privacy, Data Usability, and Access Objectives

Agencies intent on de-identifying data for release should understand the nature of the data that they intend to de-identify and determine the policies and standards that will be used to determine acceptable levels of data accuracy, de-identification, and the risk of re-identification. For example:

- Where did the data come from?
- What promises were made when the data were collected?
- What are the legal and regulatory requirements regarding data privacy and release?
- What is the purpose of the data release?
- What is the intended use of the data?
- What data-sharing model (Sec. 3.4) will be used?
- Which standards for privacy protection or de-identification will be used?
- What is the level of risk that the project is willing to accept?
- What are the goals for limiting re-identification? For example:
  - No one can be re-identified.
  - Only a few people can be re-identified.
  - Only a few people can be re-identified in theory, but no one will actually be re-identified in practice.

- Only outliers can be re-identified.
- Only people who are not outliers can be re-identified.
- There is a small percentage chance of re-identification that is shared by everyone in the dataset.
- There is a small percentage chance of re-identification, but some people in the dataset are significantly more likely to be re-identified, and the re-identification probability is somehow bounded.
- What harm might result from re-identification, and what techniques will be used to mitigate those harms?
- How should compliance with that level of risk be determined?

Some goals and objectives are synergistic, while others are in opposition.

#### 4.2. Conducting a Data Survey

Different kinds of data require different kinds of de-identification techniques. As a result, an important early step in the de-identification of government data is to identify the data modalities that are present in the dataset and formulate a plan for de-identification that takes the goals for data release, data accuracy, privacy protection, and the best available science into account.

For example:

• **Tabular containing numeric and categorical data** is the subject of most de-identification research and practice. Such tabular data are most often de-identified by using techniques based on the designation and removal of direct identifiers and the manipulation of quasi-identifiers. The chief criticism of de-identification based on direct and quasi-identifiers is that administrative determinations of quasi-identifiers may miss variables that can be uniquely identifying when combined and linked with external data, including data that are not available when the de-identification is performed but become available in the future.

The k-anonymity [151] technique is commonly used for performing and evaluating the de-identification of tabular numeric and categorical data. However, *risk determinations based on this kind of de-identification will be incorrect if direct and quasi-identifiers are not properly classified*. For example, if there are quasi-identifiers that are not identified or subjected to *k-anonymity*, then it may be possible to re-identify records in the de-identified dataset. Furthermore, because the mechanisms used to implement k-anonymity are data-dependent, it is possible to reverse-engineer the application of these mechanisms on the data and recover the data that were thought to be detected [32].

Tabular data may also be used to create a synthetic dataset that preserves some inference validity but does not have a one-to-one correspondence to the original dataset.

- Dates and times require special attention when de-identifying because temporal information is inherently linked to an external dataset: the natural progression of time. Some dates and times (e.g., February 22, 1732) are highly identifying, while others are not. Dates that refer to matters of public record (e.g., date of birth, death, or home purchase) should be routinely taken as having high re-identification potential. Dates may also form the basis of linkages between dataset records or even within a record. For example, a record may contain the date of admission, the date of discharge, and the number of days in residence. Thus, care should be taken when de-identifying dates to locate and properly handle potential linkages and relationships. Applying different techniques to different fields may result in information being left in a dataset that can be used for re-identification. Specific issues regarding date de-identification are discussed in Sec. 4.3.4, "De-Identifying Dates"[.]
- Geographic and map data also require special attention when de-identifying, as some locations can be highly identifying, other locations are not identifying at all, and some locations are only identifying at specific times. As with dates and times, de-identifying geographic locations is challenging because locations inherently link to an external reality, and some locations during specific time periods are highly correlated with specific individuals (e.g., 38.8977° N, 77.0365° W). Identifying locations can be de-identified through the use of perturbation or generalization. The effectiveness of such de-identification techniques for protecting privacy in the presence of external information has not been well-characterized [66, p. 37][143]. Specific issues regarding geographical de-identification are discussed in Sec. 4.3.5, "De-Identifying Geographical Locations and Geolocation Data."
- Unstructured text may contain direct identifiers, such as a person's name, or may contain additional information that can serve as a quasi-identifier. Finding such identifiers invariably requires domain-specific knowledge [66, p. 30]. Note that unstructured text may be present in tabular datasets and require special attention.<sup>29</sup>
- **Photos and video** may contain identifying information, such as printed names (e.g., name tags), as well as metadata in the file format. A range of biometric techniques also exists for matching photos of individuals against a dataset of photos and identifiers [66, p. 32].
- **Medical imagery** poses additional problems over photographs and video due to the presence of technical, medically-specific information. For example, identifying information may be present in the image itself (e.g., a photo may show an identifying

<sup>&</sup>lt;sup>29</sup>For an example of how unstructured text fields can damage the policy objectives and privacy assurances of a larger structured dataset, see Andrew Peterson's article, "Why the names of six people who complained of sexual assault were published online by Dallas police" [128].

scar or tattoo), an identifier may be "burned in" to the image area (e.g., an identification plate with a patient name is included in an X-Ray), or an identifier may be present in the file metadata. The body part in the image itself may also be recognized using a biometric algorithm and dataset [66, p. 35].

• Genetic sequences and other kinds of sequence information can be identified by using existing databanks that match sequences and identities. There is also evidence that genetic sequences from individuals who are not in datasets can be matched through genealogical triangulation – a process that uses genetic information and other information as quasi-identifiers to single out a specific identity [66, p. 36]. At present, there is no known method to reliably de-identify genetic sequences. Specific issues regarding the de-identification of genetic information is discussed in Sec. 4.3.6, "De-Identifying Genomic Information."

In many cases, data are complex and contain multiple modalities. Such mixtures may complicate risk determinations.

#### 4.3. De-Identification by Removing Identifiers and Transforming Quasi-Identifiers

De-identification based on removing identifiers and transforming quasi-identifiers is one of the most common approaches currently in use. It has the advantage of being conceptually straightforward, and there is a long institutional history of using this approach within both federal statistical agencies and the healthcare industry. This approach has the disadvantage of not being based on formal methods for ensuring privacy protection.

Below is a sample process for de-identifying data by removing identifiers and transforming quasi-identifiers:<sup>30</sup>

- 1. Determine the re-identification risk threshold. The organization determines acceptable risk for working with the dataset and possibly mitigating controls based on strong precedents and standards.<sup>31</sup>
- 2. Determine the information in the dataset that could be used to identify the data subjects. Identifying information can include:
  - **Direct identifiers,** such as names, phone numbers, and other information that unambiguously identifies an individual.
  - **Quasi-identifiers** that could be used in a linkage attack. Typically, quasi-identifiers identify multiple individuals and can be used to triangulate a specific individual.

<sup>&</sup>lt;sup>30</sup>This protocol is based on a protocol developed by Professors Khaled El Emam and Bradley Malin [58].

<sup>&</sup>lt;sup>31</sup>See the Federal Committee on Statistical Methodology's Data Protection Toolkit at https://nces.ed.gov/ fcsm/dpt.

- **High-dimensional data** [10] can be used to single out data records and, thus, constitute a unique pattern that could be identifying if the values exist in a secondary source to link against.<sup>32</sup>
- 3. Determine the direct identifiers in the dataset. An expert determines the elements in the dataset that only serve to identify the data subjects.
- 4. Mask (transform) direct identifiers. The direct identifiers are either removed or replaced with pseudonyms. Options for performing this operation are discussed in Sec. 4.3.1.
- 5. Perform threat modeling. The organization determines the additional information they might be able to use for re-identification, including both quasi-identifiers and non-identifying values that a data intruder might use for re-identification.
- 6. Determine minimal acceptable data accuracy. The organization determines what uses can or will be made with the de-identified data.
- 7. Determine the transformation process that will be used to manipulate the quasiidentifiers. Pay special attention to the data fields that contain dates and geographical information, removing or recoding as necessary.
- 8. Import (sample) data from the source dataset. Because the effort to acquire data from the source (identified) dataset may be substantial, some researchers recommend conducting a test data import run to assist in planning [58].
- 9. Review the results of the trial de-identification. Correct any coding or algorithmic errors that are detected.
- 10. Transform the quasi-identifiers for the entire dataset.
- 11. Evaluate the actual re-identification risk, which is calculated. As part of this evaluation, every aspect of the released dataset should be considered in light of the question, "Can *this* information be used to identify someone?"
- 12. Compare the actual re-identification risk with the threshold specified by the policymakers.
- 13. If the data do not pass the actual risk threshold, adjust the procedure and repeat Steps 11 and 12. For example, additional transformations may be required. Alternatively, it may be necessary to remove outliers. Removing data will of course impact data quality, but it will also protect the privacy of the individuals whose data have been removed.

<sup>&</sup>lt;sup>32</sup>For example, Narayanan and Shmatikov demonstrated that the set of movies that a person had watched could be used as an identifier given the existence of a second dataset of movies that had been publicly rated [109].

As noted on 13, this document uses the phrase *de-identification* to describe this process and recommends avoiding the phrase *anonymization*, which is typically used to indicate that the de-identification process cannot be reversed, and there is no technical mechanism to ensure that de-identified data cannot be re-identified.

#### 4.3.1. Removing or Transforming of Direct Identifiers

There are many possible processes for removing direct identifiers from a dataset, including:

- **Removal and replacement.** Replace identifiers with the value used by the database to indicate a missing value, such as NULL or NA.
- Masking. Replace identifiers with a repeating character, such as XXXXXX or 9999999.
- Encryption. Encrypt the identifiers with a strong encryption algorithm. After encryption, the key can be discarded to prevent decryption. However, if there is a desire to employ the same transformation at a later point in time, the key should be stored in a secure location that is separate from the de-identified dataset. Encryption used for this purpose carries special risks that need to be addressed with specific controls (see Sec. 4.3.2 for further information).
- Hashing with a keyed hash. A keyed hash is a special kind of hash function that produces different hash values for different keys. The hash key should have sufficient randomness to defeat a brute force attack aimed at recovering the hash key (e.g., SHA-256 HMAC [26] with a 256-bit randomly generated key). As with encryption, the key should be secret and should be discarded unless there is a desire for repeatability. Hashing used for this purpose carries special risks that need to be addressed with specific controls (see Sec. 4.3.2 below for further information). Hashing without a key generally does not confer security because an attacker can *brute force* all possible values to be hashed.
- **Replacement with keywords.** This approach transforms identifiers such as George Washington to PATIENT. Note that some keywords may be equally identifying, such as transforming George Washington to PRESIDENT.
- **Replacement with realistic surrogate values.** This approach transforms identifiers, such as George Washington, to surrogates that blend in, such as Abraham Polk.<sup>33</sup>

Encryption, hashing with a keyed hash, and replacement with realistic surrogate values are pseudonymization techniques. The technique used to remove direct identifiers should be clearly documented for users of the dataset – especially if the technique of replacement by

<sup>&</sup>lt;sup>33</sup>A study by Carrell et al. found that using realistic surrogate names in de-identified text like John Walker and 3900 Pennsylvania Ave instead of generic labels like PATIENT and ADDRESS could decrease or mitigate the risk of re-identifying the few names that remained in the text because "the reviewers were unable to distinguish the residual (leaked) identifiers from the...surrogates" [27].

realistic surrogate names is used – so that future data users have documentation that the dataset has been de-identified.

Carefully consider the application of pseudonyms given the source of the direct identifier. Applying this method to certain values, like last name, can subject the de-identified data to frequency distribution attacks for re-identification.

If the agency plans to make data available for longitudinal research and contemplates multiple data releases, then the transformation process should be repeatable, and the resulting transformed identities should be *pseudonyms*. The mapping between the direct identifier and the pseudonym is performed using a lookup table or a repeatable transformation. In either case, the release of the lookup table or the information used for the repeatable transformation will result in compromised identities. Thus, the lookup table or the information for the transformation must be highly protected. When using a lookup table, the pseudonym must be randomly assigned.

A significant risk of using a repeatable transformation is that a data intruder may be able to determine the transformation and, thus, gain the capability to re-identify all of the records in the dataset.

When multiple organizations use the same pseudonymization scheme, they can trade data and perform matching on the pseudonyms. This approach is sometimes called *privacypreserving record linkage* (PPRL). However, even when matching is probabilistic (as is the case with PPRL techniques that employ Bloom filters), this practice allows the organizations to re-identify each other's shared datasets. Some PPRL approaches perform record linkage within a secure data enclave to minimize the risk of unauthorized re-identification [111]. As an alternative, organizations can participate in a *private set intersection protocol*, of which there are many in the cryptographic literature [102, 45, 89].

# 4.3.2. Special Security Note Regarding the Encryption or Hashing of Direct Identifiers

The transformation of direct identifiers through encryption or hashing carries special risks, as errors in procedure or the release of the key used in the encryption or hashing operation can compromise identities for the entire dataset. There is no way to verify that a key has not been released.

If a hashing key is not used or is discovered by an attacker, it is possible for an attacker to perform a brute force search and determine the original values of identifiers that have been hashed.

When information is protected with encryption, the security of the encrypted data depends entirely on the security of the encryption key. If a key is improperly chosen, it may be possible for a data intruder to discover the key using a brute force search. Because there is no visual difference between data that are encrypted with a strong encryption key and data that are encrypted with a weak key, organizations must utilize administrative controls to ensure that keys are both unpredictable and suitably protected.

Because encryption may be reversed and both approaches may be the subject of a successful brute force attack, the use of encryption or hashing to protect direct identifiers is *not recommended* [66, 154].

# 4.3.3. De-Identifying Numeric Quasi-Identifiers

Once a determination is made regarding quasi-identifiers, they should be transformed. A variety of techniques are available to transform quasi-identifiers:

- **Top and bottom coding.** Outlier values that are above or below certain values are coded appropriately. For example, the Safe Harbor method under the HIPAA Privacy Rule calls for ages over 89 to be "aggregated into a single category of age 90 or older" [162, § 164.514 (b)(2)].
- **Micro aggregation.** Individual microdata are combined into small groups that preserve data analysis capabilities while providing for some disclosure protection.
- Generalize categories with small counts. When preparing contingency tables, several categories with small values may be combined. For example, rather than reporting that there are two people with blue eyes, one person with green eyes, and one person with hazel eyes, it may be reported that there are four people with blue, green, or hazel eyes.
- **Data suppression.** Cells in contingency tables with counts lower than a predefined threshold can be suppressed to prevent the identification of attribute combinations with small numbers [171].
- **Blanking and imputing.** Specific values that are highly identifying can be removed and replaced with imputed values.
- Attribute or record swapping. Attributes or data values are swapped within a set of similar records. For example, data that represent families in two similar towns within a county might be swapped. "Swapping has the additional quality of removing any 100-percent assurance that a given record belongs to a given household" [160, p. 31] while preserving the accuracy of regional statistics, such as sums and averages. In this case, the average number of children per family in the county would be unaffected by data swapping. However, swapping may damage or destroy important relationships within the data and introduce systematic biases, depending on how the swapping candidates are selected, so it must be performed carefully to avoid these issues.
- Noise addition. Also called "noise infusion," and "noise injection" (and occasionally "partially synthetic data"), this approach adds small random values to attributes.

For example, instead of reporting that a person is 84 years old, the person may be reported as being 79 years old. Noise addition increases variance in reported statistics and leads to regression dilution, also known as attenuation bias, in estimated regression coefficients and decreased correlations among attributes [47, 8]. When combined with a requirement for the non-negative reporting of attributes, such as age or population, noise addition may also introduce systematic bias since more values are increased in value than decreased.

These techniques (and others) are described in detail in several publications, including:

- **The Data Protection Toolkit (BETA).** A website maintained by the Federal Committee on Statistical Methodology for the purpose of promoting data access while protecting confidentiality throughout the federal statistical system [40], which can be found at https://nces.ed.gov/fcsm/dpt.
- The Anonymisation Decision-Making Framework (2nd Edition). By Mark Elliot, Elaine MacKey and Kieron O'Hara, UKAN, University of Manchester, Manchester, UK, 2020. This 119-page book provides tutorials and worked examples for de-identifying data and calculating risk [56].
- **IHE IT Infrastructure Handbook: De-Identification.** Integrating the Healthcare Enterprise, June 6, 2014. IHE offers a variety of guides, including one on de-identification at http://www.ihe.net/User\_Handbooks [78].

Swapping and noise addition both introduce noise into the dataset, such that records literally contain incorrect data. Certain kinds of noise addition have been mathematically proven to provide formal privacy guarantees. Swapping has no such guarantees.

All of these techniques impact data accuracy, but whether they impact data *utility* depends on the downstream uses of the data. For example, top-coding household incomes will not impact a measurement of the 90-10 quantile ratio, but it will impact a measurement of the top 1 % of household incomes [129].

Statistical agencies should document the specific statistical disclosure techniques that they used when performing statistical disclosure limitation. Where possible, statistical agencies should document the specific parameters used in data-protecting transformations [8]. This documentation should accompany the release of de-identified data. Without such transparency, data users may reach erroneous conclusions regarding their working data [72, 150, 76, 6].

#### 4.3.4. De-Identifying Dates

Dates can exist in many ways in a dataset. Dates may be in particular kinds of typed columns, such as a date of birth or the date of an encounter. Dates may be present as a number, such as the number of days since an epoch like January 1, 1900. Dates may be

present in free text narratives or in photographs (e.g., a photograph that shows a calendar or a picture of a computer screen with date information).

Several strategies have been developed for de-identifying dates:

- Under the Safe Harbor method of the HIPAA Privacy Rule, dates must be generalized to no greater specificity than the year (e.g., July 4, 1776, becomes 1776) [132, §164.514 (b)(2)].
- Dates within a single person's record can be systematically adjusted by a random amount. For example, the dates of a hospital admission and discharge might be systematically moved the same number of days a date of admission and discharge of July 4, 1776, and July 9, 1776, become Sept. 10, 1777, and Sept. 15, 1777, respectively [118]. However, this does not eliminate the risk that a data intruder will make inferences based on the interval between dates.
- In addition to a systematic shift, the intervals between dates can be perturbed to protect against re-identification attacks that involve identifiable intervals while still maintaining the order of events.
- Some dates cannot be arbitrarily changed without compromising data accuracy. For example, it may be necessary to preserve the day of the week, whether a day is a workday or a holiday, or a relationship to a holiday or event.
- Some ages can be randomly adjusted without impacting data accuracy while others cannot. For example, in many cases, the age of an individual can be randomly adjusted ±2 years if the person is over the age of 25 but not if their age is between one and three. However, individuals become eligible for specific benefits at specific ages, such as Social Security retirement at age 62, so changes to ages around these milestones may also result in data accuracy problems.

# 4.3.5. De-Identifying Geographical Locations and Geolocation Data

Geographical data can exist in many ways in a dataset. Geographical locations may be indicated by map coordinates (e.g., 39.1351966, -77.2164013), a street address (e.g., 100 Bureau Drive), or a postal code (e.g., 20899). Geographical locations can also be embedded in textual narratives.

Some geographical locations are less likely to be identifying (e.g., a crowded train station), while others may be highly identifying (e.g., a house in which a single person lives). Other locations may be identifying at some times of day and not others or during some months or some years. The amount of noise required to de-identify geographical locations significantly depends on the availability of external data, including geographical surveys. Identity may be shielded in an urban environment by adding  $\pm 100$  m, whereas a rural environment may require  $\pm 5$  km or more to introduce sufficient ambiguity.

A prescriptive de-identification rule – even one that accounts for varying population densities – may still be insufficient for de-identification if the rule fails to consider the interaction between geographic locations and other quasi-identifiers in the dataset. Randomized transformations should be made with caution to avoid the creation of inconsistencies in underlying data (e.g., moving the location of a residence along a coast into a body of water or across geopolitical boundaries).

Single locations may become identifying if they represent locations linked to a single individual that are recorded over time (e.g., a work/home commuting pair). Such behavioral time-location patterns can be quite distinct and allow for re-identification even with a small number of recorded locations per individual [107, 106]. In 2021, one study concluded that "[t]he risk of re-identification remains high even in country-scale location datasets" [60].

Data of higher resolution are typically more identifying. For example, in July 2021, the Catholic publication *The Pillar* published a report in which it had purchased the deidentified geolocation information for users of a homosexual dating platform. With these data, the journalists identified a prominent Catholic official as a user of the platform by simply matching the geolocation data to the official's residence. The official promptly resigned [130].

# 4.3.6. De-Identifying Genomic Information

Deoxyribonucleic acid (DNA) is the molecule inside human cells that carries the genetic instructions used for the proper functioning of living organisms. DNA present in the cell nucleus is inherited from both parents, while DNA present in the mitochondria is only inherited from an organism's mother. DNA is a repeating polymer that is made from four chemical bases: adenine (A), guanine (G), cytosine (C), and thymine (T). Human DNA consists of roughly 3 billion bases, of which 99 % are the same in all people [69].

Modern technology allows for the complete specific sequence of an individual's DNA to be determined within a certain accepted error threshold, and full-genome sequencing is increasingly common as costs have dropped significantly below \$1000 per genome in the United States. Even less expensive is the use of a DNA microarray to probe for the presence or absence of specific DNA sequences at predetermined points in the genome. This approach is typically used to determine the presence or absence of specific single nucleotide polymorphisms (SNPs) [68]. DNA sequences and SNPs are the same for monozygotic (identical) twins, individuals resulting from divided embryos, and clones. With these exceptions, it is believed that no two humans have the same complete DNA sequence. Individual SNPs may be shared by many individuals, but a sufficiently large number of SNPs that show sufficient variability is generally believed to produce a combination that is unique to an individual.

Thus, there are some sections of the DNA sequence and some combinations of SNPs that have high variability within the human population and others that have significant conservation between individuals within a specific population or group. When there is high variability, DNA sequences and SNPs can be used to match an individual with a historical sample that has been analyzed and entered into a dataset. The inheritability of genetic information has also allowed researchers to determine the surnames and even the complete identities of some individuals [74].

As the number of individuals who have their DNA and SNPs measured increases, scientists are realizing that the characteristics of DNA and SNPs in individuals may be more complicated than the preceding paragraphs imply. DNA changes as individuals age because of senescence, transcription errors, and mutation. DNA methylation, which can impact the functioning of DNA, also changes over time [19]. Individuals who are made up of DNA from multiple individuals – typically the result of the fusion of twins in early pregnancy – are known as *chimera* or *mosaic*. In 2015, a man in the United States failed a paternity test because the genes in his saliva were different from those in his sperm [87]. A human chimera was identified in 1953 because the person's blood contained a mixture of two blood types: A and O [48]. The incidence of human chimeras is unknown.

Because of the high variability inherent in DNA, complete DNA sequences may be identifiable by linking with an external dataset. Likewise, biological samples for which DNA can be extracted may be identifiable. Subsections of an individual's DNA sequence and collections of highly variable SNPs may be identifiable unless it is known that there are many individuals who share the region of DNA or those SNPs. Furthermore, genetic information may not only identify an individual but could also identify an individual's ancestors, siblings, and descendants. It is also possible to identify certain diseases and whether an individual is at risk for certain hereditary conditions. For example, the presence of the HER2 gene code is a marker for breast cancer risk.

## 4.3.7. De-Identifying Text Narratives and Qualitative Information

Researchers must devote specific attention when they de-identify text narratives and other kinds of qualitative information. Many approaches developed in the 1980s and 1990s that provided reasonable privacy assurances at the time may no longer provide adequate protection in an era with high-quality internet search and social media [126, 127, 125]. This is an area of active research.

## 4.3.8. Challenges Posed by Aggregation Techniques

Aggregation does not necessarily provide privacy protection, especially when data are presented in multiple data releases.

#### 4.3.8.1. Example

Consider a hypothetical example of a school that reports on its website the number of students performing below, at, and above grade level at the start of the school year (Table 1).

Reading Level at Start of School Year	# of Students
Below grade level	30-39
At grade level	50-59
Above grade level	20-29

**Table 1.** Reading levels at a hypothetical school, as measured by entrance examinations and reported at the start of the school year on October 1. (See example, Sec. 4.3.8)

Reading Level at Start of School Year	# of Students
Below grade level	30-39
At grade level	50-59
Above grade level	30-39

**Table 2.** Reading levels at a hypothetical school, as measured by entrance examinations and reported one month into the school year on November 1 after a single new student has transferred to the school. (See example, Sec. 4.3.8)

Then consider that a single new student enrolls at the school on October 15, and the school updates the table on its website (Table 2). Since the examination is only taken once, it is possible to infer that the student who joined the school is likely performing above grade level by comparing the two tables. This reveals protected information. Moreover, if a person who views both tables knows the specific student who enrolled in October, they have learned a private fact about that student.

Aggregation does not inherently protect privacy, and aggregation alone is not sufficient to provide formal privacy guarantees. Other ad hoc rules that have been proposed include the *threshold rule*, the *dominance rule*, and the *ambiguity rule*. However, as has been noted, "aggregated data provides a false sense of security" [15]. An alternative is to use aggregation primitives based on formal privacy, which can provide aggregations that have provable privacy guarantees while remaining highly accurate in many cases. Such methods work through the addition of carefully calibrated noise.

#### 4.3.9. Challenges Posed by High-Dimensional Data

Even after removing all of the unique identifiers and manipulating the quasi-identifiers, data can still be identifying if they are of sufficiently high dimensionality and if there is a way to link the supposedly non-identifying values to an identity.<sup>34</sup>

<sup>&</sup>lt;sup>34</sup>For example, consider a dataset of an anonymous survey that links responses from parents and their children. In such a dataset, a child might be able to find their parents' confidential responses by searching for their own responses and then following the link [109].

#### 4.3.10. Challenges Posed by Linked Data

Data can be linked in many ways. Pseudonyms allow data records from the same individual to be linked together over time. Family identifiers, such as distinctive family names or some kinds of genetic information, may allow data from parents to be linked with their children. Device identifiers allow data to be linked to physical devices and potentially link together all data coming from the same device. Data can also be linked to geographical locations.

Data linkage increases the risk of re-identification by providing more attributes that can be used to distinguish the true identity of a data record from others in the population. For example, survey responses that are linked together by household are more readily re-identified than survey responses that are not linked. Heart rate measurements may not be considered identifying, but, given a long sequence of tests, each individual in a dataset would have a unique constellation of heart rate measurements, and the dataset could be susceptible to being linked with another dataset that contains the same values.<sup>35</sup> Geographical location data can – when linked over time – create individual behavioral time-location patterns that can be used to classify and single out an individual within unlabeled data, even with a small number of recorded locations per individual [107, 106].

Dependencies between records may result in record linkages even when there is no explicit linkage identifier. For example, it may be that an organization has new employees take a proficiency test within seven days of being hired. This information would allow links to be drawn between an employee dataset that accurately reported an employee's start date and a training dataset that accurately reported the date that the test was administered, even if the sponsoring organization did not intend for the two datasets to be linkable.

## 4.3.11. Challenges Posed by Composition

In computer science, the term *composition* refers to combining multiple functions to create more complicated ones. One of the defining characteristics of complex systems is that they have unpredictable behavior, even when they are composed of very simple components. A challenge of composition is to develop approaches for limiting or eliminating such unpredictable behavior. Typically, this is done by proactively limiting the primitives that can be composed. De-identification is such a primitive that statisticians and data scientists must carefully control to ensure that the results of de-identification efforts can be composed. Without such controls, the results of composition can become unpredictable.

Specifically, it is important to understand whether the techniques used for de-identifying will retain their privacy guarantees when they are subject to composition. For example, if the same dataset is made available through two different de-identification regimes, what will happen to the privacy guarantees if the two downstream datasets are recombined? One of the primary advantages of differential privacy is that its operators are composable: if two

<sup>&</sup>lt;sup>35</sup>This is a different approach than characterizing an individual's heartbeat pattern so that it can be used as a biometric. In this case, it is a specific sequence of heartbeats that is recognized.

datasets are released with a privacy loss of  $\varepsilon = 1$  and  $\varepsilon = 1.5$ , then the releasing agency can compute that the total privacy loss that might be suffered by individuals in the dataset is no greater than  $\varepsilon = 2.5$ . This is not true of most other de-identification techniques, for which there is no straightforward approach to computing the maximum possible privacy loss that might result from a combination of two separate data releases.

Composition concerns can arise when:

- The same dataset is provided to multiple downstream users.
- Snapshots of a dataset are published on a periodic basis.
- Changes in computer technology result in new aspects of a dataset being made available.
- Legal proceedings require that aspects of the dataset (attributes or a subset of records) be made available without de-identification.

Privacy risk can result from unanticipated composition, which is one of the reasons that released datasets should be subjected to periodic review and reconsideration.

#### 4.3.12. Potential Failures of De-Identification

The de-identification process outlined in this section can fail to prevent a disclosure for a number of different reasons. In addition, failures of data *utility* can also occur, in which the de-identification process removes *too much* information, and the de-identified dataset is not useful for its intended purpose.

- If an **inappropriate risk threshold** is selected, then the risk of re-identification may be higher than intended. Agencies should consider risk thresholds carefully and select the most conservative threshold possible that achieves the utility goals of the release.
- If **direct** or **quasi-identifiers are missed**, then identifying information may remain in the de-identified dataset, leading to increased re-identification risk. Agencies should be mindful of the ways in which personal information can be used to identify individuals and in ambiguous situations assume that such information can be identifying when combined with other datasets.
- If **threats are missed** during threat modeling, then the re-identification risk could be higher than intended. In particular, if other datasets that could be linked with the de-identified dataset are not considered, then the risk could be much higher than anticipated. Agencies should carefully consider existing and future data releases during threat modeling.

- If the **selected transformations fail to remove identifying information**, then the risk of de-identification could be higher than intended. Agencies should select transformations with well-understood properties and a history of successful use.
- If the de-identified dataset **does not produce accurate results for its intended use**, then it may not satisfy the goals of the data release. Future data custodians may be forced to oversee additional data releases, and those future releases might be combined with the already released datasets in unforeseen ways. Agencies should understand how the de-identified data will be used and make sure to carefully evaluate its utility for those purposes before releasing it.

#### 4.3.13. Post-Release Monitoring

Following the release of a de-identified dataset, the releasing agency should monitor it to ensure that the assumptions made during the de-identification remain valid. This is because – absent the destruction of historical data – the identifiability of a dataset can increase over time. For example, the de-identified dataset may contain information that can be linked to an internal dataset that is later the subject of a data breach. In such a situation, the data breach could also result in the re-identification of the de-identified dataset. The de-identified dataset might also be linked to an external dataset released by a completely separate organization. Agencies have no control over the release of such datasets, and even monitoring may be challenging in this situation. In some cases, the de-identified dataset might be linked with privately held data, making monitoring impossible.

Agencies should develop an action plan that specifies what the agency should do if postrelease monitoring suggests the possibility of unwanted re-identification. For example, agencies may wish to use this information as grounds to determine the new probability of re-identification (Sec. 3.2.1) as a result of the new public information. Based on the results of such research, agencies may wish to revise their policies or even notify the public.

Agencies may wish to make releasing units responsible for post-release monitoring or to centralize the post-release monitoring in a single location. However, proper post-release monitoring requires knowledge of the datasets that have been released and the kinds of data that would allow for a re-identification attack. These requirements are likely to increase costs to organizations that wish to delegate post-release monitoring to other organizations or third parties. One way to decrease the requirement for post-release monitoring is to perform the de-identification using a privacy model that does not make assumptions about the background information available to the data intruder.

#### 4.4. Synthetic Data

An alternative to de-identifying using the technique presented in the previous section is to use the original dataset to create a synthetic dataset [46, p. 8].

Synthetic data can be created using two approaches:

Data adjective	Description
Datasets without formal guarantees:	
Partially synthetic	Data produced by selectively replacing rows, columns, or cells in an existing data set with values produced by a statistical model [96] or by the addition of unrelated statistical noise. This approach is sometimes called <i>blank-and-impute</i> (Sec. 4.4.1).
Datasets with formal guarantees if the original dataset is not used to create the data:	
Test	Data that resemble the original dataset in terms of structure and the range of values but for which there is no attempt to ensure that inferences drawn on the test data will be like those drawn on the original data. Test data may also include extreme values that are not in the original data but are present for testing software (Sec. 4.4.2).
Realistic	Better for clarity: Data that have a characteristic that is like the orig- inal data but (1) are not developed by modifying the original data and (2) contain no information that is privacy-sensitive (Sec. 4.4.3).
Datasets with formal guarantees when formal techniques are used:	
Fully synthetic	Data produced by applying the techniques of partial synthesis to ev- ery row, column, and cell such that there is no one-to-one mapping between the records of the original and synthetic datasets.

Table 3. Adjectives used for describing data in data releases (Sec. 4.4.4).

- 1. Sampling an existing dataset and either adding noise to specific cells that are likely to have a high risk of disclosure or replacing those cells with imputed values. This is known as a "partially synthetic" dataset (see Table 3).
- 2. Using the existing dataset to create a model and then using that model to create a synthetic dataset. This is known as a "fully synthetic" dataset (see Table 3).

In both cases, formal privacy techniques can be used to quantify the privacy protection offered by the synthetic dataset.

## 4.4.1. Partially Synthetic Data

A partially synthetic dataset is one in which an existing dataset is sampled, and either noise is added to specific cells that are likely to have a high risk of disclosure, or else the contents of those cells are replaced with imputed values that are typically based on probabilistic models. For example, data that belong to two families in adjoining towns may be swapped to protect the identity of the families. Alternatively, the data for an outlier variable may be removed and replaced with a range value that is incorrect (e.g., replacing the value "60" with the range "30-35"). It is considered best practice for the data publisher to indicate that some values have been modified or otherwise imputed but not to reveal the specific values that have been modified.

## 4.4.2. Test Data

It is also possible to create *test data* that are syntactically valid but do not convey accurate information when analyzed. Such data can be used for software development. When creating test data, it is useful for the names, addresses, and other information in the data to be conspicuously non-natural so that the test data are not inadvertently confused with true confidential data. For example, use the name "FIRSTNAME1 LASTNAME2" rather than "JOHN SMITH."

## 4.4.3. Realistic Test Data

Test data that can be mistaken for real data are sometimes called *realistic test data*. Such data may be required for some kinds of software testing or validation—for example, software that applies a statistical model to names in an attempt to identify typos or inadvertent repetitions. Provided that the realistic test data are not developed using confidential data or a model based on the confidential data, realistic test data will not compromise the content of confidential data. However, it can be difficult to develop such data, and it can be inadvertently confused with confidential data, potentially causing operational difficulties.

## 4.4.4. Fully Synthetic Data

A fully synthetic dataset is a dataset for which there is no one-to-one mapping between data in the original dataset and data in the de-identified dataset. One approach to creating a fully synthetic dataset is to use the original dataset to create a high-fidelity model – that is, a model with many parameters that is functionally close to the reality that it models – and then to use a simulation to produce individual data elements that are consistent with the model. Special efforts must be taken to maintain marginal and joint probabilities when creating partially or fully synthetic data.

Fully synthetic datasets cannot provide more information to the downstream user than was contained in the original model. Nevertheless, some users may prefer to work with the fully synthetic dataset instead of the model for a variety of reasons:

• Synthetic data provide users with the ability to develop queries and other techniques that can be applied to the real data without exposing real data to users during the development process. The queries and techniques can then be provided to the data owner, who can run them on the real data and provide the results to the users.

- Many hypotheses not represented exactly in the original model may be informed by the synthetic data because they are correlated with hypotheses (effects) that are in the model.
- Some users may place more trust in a synthetic dataset than in a model.
- When researchers form their hypotheses from synthetic data and then verify their findings on actual data, they can be protected from pretest estimation and false discovery bias [8, p. 257].

Because of the possibility of false discovery, analysts should be able to validate their discoveries against the original data to ensure that the things they discover are in the original data and not artifacts of the data generation process.

Both high-fidelity models and synthetic data generated from models may leak personal information that is potentially re-identifiable. The amount of leakage can be controlled using formal privacy models (e.g., differential privacy) that typically involve the introduction of noise. Section 4.4.7 describes the construction of fully synthetic data with differential privacy.

There are several advantages for agencies that choose to release de-identified data as a fully synthetic dataset:

- It can be very difficult to map records to actual people if the synthetic dataset is sufficiently large.
- The privacy guarantees can potentially be mathematically established and proven ( Sec. 4.4.7).
- The privacy guarantees can remain in force even if there are future data releases.

Fully synthetic data also have these disadvantages and limitations:

- It is not possible to create pseudonyms that map back to actual people because the records are fully fabricated.
- The data release may be less useful for accountability or transparency. For example, investigators equipped with a synthetic data release would be unable to find the actual "people" who make up the release because they would not actually exist.
- For traditional models (such as Gaussian mixture models), it may be difficult to find meaningful correlations or abnormalities in synthetic data that are not represented in the model. For example, if a model contains only main effects and first-order interactions, then all second-order interactions can only be estimated from the synthetic data to the extent that their design is correlated with the main or first-order interactions. For models based on modern deep learning techniques, it may be difficult to quantify the extent to which the model is memorizing (and potentially re-generating) the training data.

- Users of the data may not realize that the data are synthetic. Simply providing documentation that the data are fully synthetic may not be sufficient public notification since the dataset may be separated from the documentation. Instead, it is best to indicate in the data themselves that the values are synthetic. For example, names like "SYNTHETIC PERSON" or "FIRSTNAME1 LASTNAME1" may be placed in the data.
- Releasing a synthetic dataset may not be regarded by the public as a legitimate act of transparency, or the public may question the validity of the synthetic dataset based on its perceived lack of relationship to the original dataset. These concerns can be addressed through public education and by documenting the accuracy of the synthetic dataset.

In addition, it can be extremely challenging to construct the high-fidelity models that enable good synthetic datasets. The best known techniques for constructing these models are designed around ensuring that specific properties of the data (e.g., correlations between certain data attributes) are preserved. Models constructed this way may not necessarily reflect *other* properties that were present in the original data.

It is often possible to construct very high-fidelity models when the desirable properties of the synthetic data are known in advance (e.g., when it is known what questions future analysts will want to answer using the synthetic data) or when using modern deep learning techniques. Constructing synthetic data that faithfully represent *all* properties of the original data while enforcing strong privacy guarantees is impossible.

## 4.4.5. Synthetic Data with Validation

Agencies that share or publish synthetic data can optionally provide a verification service that takes queries or algorithms developed with synthetic data and applies them to actual data. The results of these queries or algorithms can then be compared with the results of running the same queries on the synthetic data, and the researchers can be warned if the results are significantly different. Alternatively, results can be provided to the researchers after the application of additional statistical disclosure limitation.

## 4.4.6. Synthetic Data and Open Data Policy

Releases of synthetic data can be confusing to the lay public.

- It may not be clear to data users that the synthetic data release is actually synthetic. Members of the public may assume that the synthetic data are simply an operational dataset that has had identifying columns suppressed.
- Synthetic data may contain synthetic individuals who appear similar to actual individuals in the population.

• Fully synthetic datasets do not have a zero-disclosure risk because they still contain information derived from non-public information about individuals. The disclosure risk may be greater when synthetic data are created with traditional statistical modeling or data imputing techniques rather than formal privacy models, such as differential privacy, which have provisions for tracking the accumulated privacy loss that results from multiple data operations, as discussed in Sec. 4.4.7.

#### 4.4.7. Creating a Synthetic Dataset with Differential Privacy

A growing number of mathematical algorithms have been developed for creating synthetic datasets that meet the mathematical definition of privacy provided by differential privacy [53]. Most of these algorithms will transform a dataset that contains private data into a new dataset containing synthetic data that provides reasonably accurate results in response to a variety of queries. However, there is no algorithm or implementation currently in existence that can be used by a person who is unskilled in the area of differential privacy. This is an area of active research.

The idea of differential privacy is that the result of a data analysis function  $\kappa$  applied to a dataset should not change very much if an arbitrary person *p*'s data are added to or removed from a dataset *D*. That is,  $\kappa(D) \approx \kappa(D-p)$ . The degree to which the two values are approximately equal is determined by the privacy loss parameter  $\varepsilon$ .

In the mathematical formulation of pure differential privacy,  $\varepsilon$  can range from 0 to  $\infty$ . When  $\varepsilon = 0$ , the output of  $\kappa$  does not depend on the input dataset. When  $\varepsilon = \infty$ , the output of  $\kappa$  is entirely dependent upon the input dataset, such that changing a single record results in an unambiguous measurable change in  $\kappa$ 's output. Thus, larger values of  $\varepsilon$  provide for more accuracy but result in increased privacy loss.

When  $\varepsilon$  is set appropriately, differential privacy limits the privacy loss that a data subject experiences from the use of their private data to the maximum privacy loss necessary for a given statistical purpose. Note that this particular notion of privacy does *not* protect all secrets about a person. It only protects the secrets that an observer would not have been able to learn if the person's data were not present in the dataset. Stated another way, differential privacy protects individuals from *additional harm that may result from their participation in the data analysis* but does not protect them from harm that would have occurred *even if their data were not present*. For example, if a study concludes that residents of Vermont overwhelmingly drive 4-wheel-drive vehicles, one might conclude that a *particular* Vermonter drives a 4-wheel-drive vehicle even if that individual did not participate in the study. Differential privacy does not attempt to prevent inferences of this type.

Many academic papers on differential privacy assume a value of 1.0 for  $\varepsilon$  but do not explain the rationale of the choice. Some researchers who work in the field of differential privacy have tried mapping existing privacy regulations to the choice of  $\varepsilon$ , but these efforts

invariably result in values of  $\varepsilon \neq 1$ . Principled approaches for setting  $\varepsilon$  are a subject of current academic research [93, 93, 92, 104].

There are relatively few scholarly publications regarding the deployment of differential privacy in real-world situations, and there are few papers that provide guidance on choosing appropriate values of  $\varepsilon$ . Thus, agencies that are interested in using differential privacy algorithms to allow for the querying of sensitive datasets or the creation of synthetic data should ensure that the techniques are appropriately implemented and that the privacy protections are appropriate for the desired application. Tools area now under development to help visualize and understand the error and risks associated with different privacy parameters.

Despite these difficulties, differential privacy has been successfully used in a growing number of real-world deployments, including the Census Bureau's OnTheMap interactive tool, the 2020 Census, and the College Scorecard website developed by the Internal Revenue Service and the U.S. Department of Education.

For additional information, please see the NIST Differential Privacy blog series at https:// www.nist.gov/itl/applied-cybersecurity/privacy-engineering/collaboration-space/focus-areas/ de-id/dp-blog, and the NIST de-identification tool location at https://www.nist.gov/itl/appliedcybersecurity/privacy-engineering/collaboration-space/focus-areas/de-id/tools.

# 4.5. De-Identifying with an Interactive Query Interface

Another model for granting public access to de-identified agency information is to construct an interactive query interface that allows members of the public or qualified investigators to run queries over the agency's dataset. This option has been developed by several agencies, and there are many ways that it can be implemented. For example:

- If the queries are run on actual data, the results can be altered through the addition of noise to protect privacy, potentially satisfying a formal privacy model, such as differential privacy. Alternatively, individual queries can be reviewed by agency staff to verify that privacy thresholds are maintained.
- Queries can be run on synthetic data. In this case, the agency can also run queries on the actual data and warn the external researchers if the queries run on synthetic data deviate significantly from the queries run on the actual data (ensuring that the warning itself does not compromise the privacy of some individual).
- Query interfaces can be made freely available on the public internet, or they can be made available in a restricted manner to qualified researchers operating in secure locations.

A significant privacy risk with interactive queries is that each query results in additional privacy loss [44].<sup>36</sup> That is, the query interface alone will not protect privacy but should

<sup>&</sup>lt;sup>36</sup>If a finite privacy loss budget is allocated, the data controller needs to respond by increasing the amount of noise added to each response, accepting a higher level of privacy risk, or ceasing to answer questions as the

be combined with additional privacy protections. For example, query interfaces should incorporate privacy mechanisms, such as adding noise to results with differential privacy, and log both queries and query results in order to deter and detect malicious use.

When formal privacy is desired, an advantage of synthetic data is that the privacy loss budget can be spent on creating the synthetic dataset rather than on responding to interactive queries. This approach can also result in consistent query results for all users of the query interface.

#### 4.6. Validating a De-Identified Dataset

Agencies should validate datasets after they are de-identified to ensure that the resulting dataset meets the agency's goals in terms of both data usefulness and privacy protection.

#### 4.6.1. Validating Data Usefulness

De-identification can decrease the usefulness of the resulting dataset. It is, therefore, important to ensure that the de-identified dataset is still useful for the intended application. Otherwise, there is no reason to go through the expense of de-identification and added risk of releasing the de-identified data.

There are several approaches to validating data usefulness. For example, insiders can perform statistical calculations on both the original dataset and the de-identified dataset and compare the results to see if the de-identification resulted in unacceptable changes. Agencies can engage trusted outsiders to examine the de-identified dataset and determine whether the data could be used for the intended purpose.

Recognizing that there is an inherent trade-off between data accuracy and privacy protection, agencies can adopt accuracy goals for the data that they make available to a broad audience. An accuracy goal specifies how accurate the data must be in order to be fit for an intended use. Limiting data accuracy to this goal is an important technique for protecting the privacy of data subjects.

## 4.6.2. Validating Privacy Protection

There are several approaches to validating the privacy protection provided by de-identification, including:

- Examining the resulting data files to make sure that no identifying information is unintentionally included in file data or metadata.
- Examining the resulting data files to make sure that the data satisfy k-anonymity, if such a standard is desired.

budget nears exhaustion. This can result in equity issues if the first users to query the dataset obtain better answers than later users.

- Critically evaluating all default assumptions used by software that performs data modification or modeling.
- Conducting a *motivated intruder test* to see if reasonably competent outside individuals can perform re-identification using publicly available datasets, commercially available datasets, or even private datasets that might be available to certain data intruders. Motivations for an intruder can include prurient interest, causing embarrassment or harm, revealing private facts about public figures, or engaging in a reputation attack. Details for how to conduct a motivated intruder test can be found in *Anonymisation: Managing data protection risk code of practice*, published by the United Kingdom's Information Commissioner's Office [81].
- Providing the team conducting the motivated intruder test with some confidential agency data to understand how a data intruder might be able to take advantage of data leaked as a result of a breach or a hostile insider.

Ideally, studies should report re-identification results for such motivated intruder tests for both vulnerable populations and the general population.

These approaches do not provide provable guarantees on the protection offered by formal privacy techniques, but they may be useful as part of an overall agency risk assessment.<sup>37</sup> Applications that require provable privacy guarantees should rely on formal privacy methods, such as differential privacy, when planning their data releases.

Validating the privacy protection of de-identified data is greatly simplified by using validated de-identification software, as discussed in Sec. 5, "Re-Identification Studies."

## 4.6.3. Re-Identification Studies

Re-identification studies are motivated intruder tests. These studies can identify issues that would allow external actors to successfully re-identify de-identified data. Re-identification studies look for vulnerabilities in a dataset that could be used for re-identifying data subjects. They do not determine whether someone with intimate knowledge of a specific respondent can find that respondent in the database. The only way to protect a single specific individual perceived to be at high risk of re-identification is through data perturbation (e.g., noise addition) or information reduction (e.g., removing the observation altogether).

<sup>&</sup>lt;sup>37</sup>Although other documents that discuss de-identification use the term *risk assessment* to refer to a specific calculation of ambiguity using the k-anonymity de-identification model, this document uses the term *risk assessment* to refer to a much broader process. Specifically, risk assessment is defined as, "The process of identifying, estimating, and prioritizing risks to organizational operations (including mission, functions, image, reputation), organizational assets, individuals, other organizations, and the Nation, resulting from the operation of an information system. Part of risk management incorporates threat and vulnerability analyses and considers mitigations provided by security controls planned or in place. Synonymous with risk analysis" [149].

The key statistic calculated in re-identification studies is the *conditional re-identification rate*. This statistic is a proxy for disclosure risk. The rate is the number of confirmed links between the dataset and another dataset divided by the number of putative (suspected) links expressed as a percentage. If the conditional re-identification rate falls above an agreed upon threshold for any publication strata, it suggests that the data should not be released outside of a controlled environment.

Re-identification studies are often an iterative process. If a re-identification study uncovers problems with the de-identified data, the data curator can engage with subject-matter experts, make changes to the dataset, and perform another re-identification study. Changes to the dataset might involve coarsening linking variables, eliminating highly disclosive linking variables from the microdata to be released, or coarsening strata. This continues until the study concludes that the de-identified data can be disseminated.

There are broadly two types of re-identification studies:

- 1. **Micro (or targeted) re-identification studies**, where one looks for a specific person. A well-known example is that of former Governor William Weld of Massachusetts, whose medical records in a hospital discharge summary record were linked to voter records [18]. As noted earlier, some individual targets are supremely hard to protect as there is often extensive publicly available information about them.
- 2. Macro (or wholesale) re-identification studies, where one seeks to re-identify a large number of individuals. Such studies can be used to understand the overall risk or identify specific potential vulnerabilities, especially in datasets with structures on multiple scales or that are highly heterogeneous, such as the U.S. Census Bureau's simulated reconstruction-abetted re-identification attack on the 2010 Census [75] and the study of re-identification risk of a clinical study report anonymized under European Medicines Agency (EMA) Policy 0070 and Health Canada Regulations [21]. Alternatively, such studies can be performed to embarrass or discredit the organization releasing the data. Such studies rely on linking easily procurable external data to the protected microdata that are being released. A variety of metrics can be calculated to uncover putative links, and several methods can be used to confirm putative links.

Formal privacy parameters often appear opaque and elusive to non-theoreticians. Subjectmatter experts and decision-makers more clearly understand disclosure risk after reviewing the results of re-identification studies.

External intruders may attempt to calculate for themselves re-identification rates as part of an academic review of the agency's work. They may even purport to have successfully linked their external data to a de-identified dataset. However, external intruders do not have access to the confidential data on which the de-identified data were based, so there is no way for the external intruders to validate their work: the calculations may be low or high, and the linkages may be correct or incorrect. By conducting a re-identification study a priori, those who seek to disseminate the de-identified data know how successful the external intruder's re-identification attempt was if both parties have access to the same external internal data.

The conditional re-identification rate is identical to the metric of *precision* in the record linkage and health science literature. It represents the ratio of true positives to the sum of true positives and false positives. Data owners should not be alarmed if an external organization reports a relatively high suspected re-identification rate as long as they know that the conditional re-identification rate is low [59, 77, 139].

Confirmed re-identification rates are defined in Sec. 3.2.1 as *re-identification probabilities*. On its own, a low confirmed re-identification probability does not indicate that an organization should disseminate a de-identified dataset. Even when a confirmed rate is low, a high *conditional* rate should direct an organization to not disseminate the de-identified microdata.

Re-identification studies may identify problems that can direct improvements to any organization's disclosure avoidance methods. Re-identification studies are not designed to replace legacy or modern provable privacy methods but to act as a quality control to validate that the methods – old and new – protect as they were designed.

## 5. Software Requirements, Evaluation, and Validation

Agencies should clearly define the requirements for de-identification algorithms and the software that implements those algorithms. They should be sure that the algorithms that they intend to use are validated, that the software implements the algorithms as expected, and that the data that result from the operation of the software are correct.

Today, there a growing number of algorithms and tools for performing de-identification, data masking, and other privacy-preserving operations. NIST maintains a list of some of these tools<sup>38</sup>. Such tools are also increasingly being evaluated in academic literature [144] and by NIST [135, 1]. Although there are no widely accepted performance standards or certification procedures at present, NIST is conducting a series of Collaborative Challenges "designed to spur research, innovation, and understanding of data deidentification techniques." Details of the NIST Collaborative Challenges program can be found at https://www.nist.gov/itl/applied-cybersecurity/privacy-engineering/collaboration-space/challenges/collaborative-0.

#### 5.1. Evaluate the Privacy-Preserving Techniques

Software evaluation should begin with a determination of the privacy preserving techniques used by the software. The agency should determine that the algorithm is appropriate for the task at hand and that it has not been superseded by a new algorithm or approach that provides a more appropriate risk/utility trade-off.

There have been decades of research in the field of statistical disclosure limitation and de-identification, and understanding in the field has evolved over time. Agencies should not base their technical evaluation of a technique solely on the fact that the technique has been published in peer-reviewed literature or that the agency has a long history of using the technique and has not experienced any problems. Instead, it is necessary to evaluate proposed techniques through the totality of scientific experience and with regard to current threats.

Traditional statistical disclosure limitation and de-identification techniques base their risk assessments - in part - on an expectation of what kinds of data are available to a data intruder to conduct a linkage attack. Where possible, these assumptions should be documented and published along with a description of the privacy-preserving techniques that were used to transform the datasets prior to release so that they can be reviewed by external experts and the scientific community.

<sup>&</sup>lt;sup>38</sup>https://www.nist.gov/itl/applied-cybersecurity/privacy-engineering/collaboration-space/focus-areas/de-id/tools

Because our understanding of privacy technology and the capabilities of privacy attacks are rapidly evolving, techniques that have been previously established should be periodically reviewed. New vulnerabilities may be discovered in techniques that have been previously accepted. Alternatively, new techniques may be developed that allow agencies to reevaluate the trade-offs they have made with respect to privacy risk and data usability.

#### 5.2. De-Identification Tools

A de-identification tool is a program that is involved in the creation of de-identified datasets.

#### 5.2.1. De-Identification Tool Features

De-identification tools may perform many functions, including:

- Detecting identifying information
- Calculating re-identification risk
- Performing de-identification
- Mapping identifiers to pseudonyms
- Providing for the selective revelation of pseudonyms

De-identification tools may handle a variety of data modalities. For example, tools may be designed for tabular data or for multimedia. Tools may attempt to de-identify all data types or be developed for specific modalities. A potential risk of using de-identification tools is that a tool could be equipped to handle some but not all of the different modalities in a dataset. For example, a tool could de-identify the categorical information in a table according to a de-identification standard but might not detect or attempt to address the presence of identifying information in a text field. For this reason, de-identification tools should be validated for the specific kinds of data that the agency intends to use.

#### 5.2.2. Data Provenance and File Formats

Output files created by de-identification tools and data masking tools can record provenance information, such as metadata regarding input datasets, the de-identification methods used, and the resulting decrease in data accuracy. Output files can also be explicitly marked to indicate that they have been de-identified. For example, de-identification profiles that are part of the Digital Imaging and Communications in Medicine (DICOM) specification indicate which elements are direct versus quasi-identifiers and which de-identification algorithms have been employed [43, Appendix E, "Attribute Confidentiality Profiles"].

## 5.2.3. Data Masking Tools

Data masking tools are programs that can remove or replace designated fields in a dataset while maintaining relationships between tables. These tools can be used to remove direct

identifiers but generally cannot identify or modify quasi-identifiers in a manner consistent with a privacy policy or risk analysis.

Data masking tools were developed to allow software developers and testers access to datasets that contain realistic test data while providing minimal privacy protection. Absent additional controls or data manipulations, data masking tools should not be used for the de-identification of datasets that are intended for public release nor as the sole mechanism to ensure confidentiality in non-public data sharing.

## 5.3. Evaluating De-Identification Software

Once techniques are evaluated and approved, agencies should ensure that the techniques are faithfully executed by their chosen software. Privacy software evaluation should consider the trade-off between data usability and privacy protection. Privacy software evaluation should also seek to detect and minimize the chances of tool error and user error.

For example, agencies should verify:

- Correctness. The software properly implements the chosen algorithms.
- **Containment.** The software does not leak identifying information in expected or unexpected ways, such as through the inaccuracies of floating-point arithmetic or the differences in execution time (if observable to a data intruder).
- Usability. The software can be operated efficiently and with minimal error, and users can detect and correct errors when they happen.

Agencies should also evaluate the performance of the de-identification software, such as:

- Efficiency. How long does it take to run on a dataset of a typical size?
- Scalability. How much does it slow down when moving from a dataset of N to 100N?
- **Repeatability.** If the tool is run twice on the same dataset, are the results similar? If two different people run the tool, do they get similar results?
- **Transparency.** Is the tool's algorithm documented? Is the tool's source code available? Is it possible for interested researchers or members of the public to obtain the tool and test it for themselves? These characteristics are common for open-source software but may not be present in proprietary software.

Ideally, software should be able to track the accumulated privacy leakage from multiple data releases.

#### 5.4. Evaluating Data Accuracy

The field of statistical disclosure limitation (SDL) has developed approaches for gauging the impact of SDL techniques on microdata [172]. The literature examines the mathe-

matical impact of SDL procedures (e.g., sampling, recoding, suppression, rounding, and noise addition) and computes the possible impact on various statistical measurements. A growing body of evidence indicates the need for agencies to evaluate the accuracy of the de-identified data to verify that the accuracy is sufficient for the intended use.

For example:

- Researchers at the Massachusetts Institute of Technology (MIT) and Harvard applied k-anonymity de-identification to educational data collected by a massive open online course operated by MITx and HarvardX on the edX platform and found that de-identification resulted in meaningful biases that changed the meaning of some statistics. In one case, de-identification decreased the reported number of enrolled female students from 29 % to 26 % because of the need to suppress attributes for specific microdata [39].
- Researchers at the University of Wisconsin and the Marshfield Clinic Research Foundation performed an experiment in which they created a machine learning statistical model for Warfarin dosing based on clinical data. They showed that while differential privacy could prevent training data extraction (also known as "model inversion") from a trained model, levels of noise that offered sufficient privacy protection also resulted in decreased statistical performance in their simulated clinical trials. Using their vintage-2013 differential privacy models, they found that "for privacy budgets effective at preventing attacks, patients would be exposed to increased risk of stroke, bleeding events, and mortality" [63].

Approaches for evaluating data accuracy include [91]:

- Demonstrating that machine learning algorithms trained on the de-identified data can accurately predict the original data and vice versa
- Verifying that statistical distributions do not incur undue bias because of the deidentification procedure
- Publishing sufficient information about the statistical properties of the disclosure limitation methods to permit the correction of inferences using those properties

Agencies can create or adopt standards regarding the accuracy of de-identified data. If data accuracy cannot be well-maintained along with data privacy goals, then the release of data that are inaccurate for statistical analyses could potentially result in incorrect scientific conclusions and incorrect policy decisions.

#### 6. Conclusion

Government agencies can use de-identification technology to make datasets available to researchers and the public while minimizing the compromise of privacy of the people contained within the data.

There are currently three primary models available for de-identification:

- 1. Agencies can make data available with traditional de-identification techniques that rely on the suppression of identifying information (direct identifiers) and the manipulation of information that partially identifies (quasi-identifiers).
- 2. Agencies can create synthetic datasets.
- 3. Agencies can make data available through a query interface.

These models can be mixed within a single dataset to provide different kinds of access for different users or intended uses.

Privacy protection can be strengthened when agencies employ formal models for privacy protection, such as differential privacy, because the mathematical models that these systems use are designed to ensure privacy protection irrespective of future data releases or developments in re-identification technology. However, the mathematics underlying these systems is very new, and there is little experience within the Government in using these systems. Thus, agencies should understand the implications of these systems before deploying them in place of traditional de-identification approaches that do not offer formal privacy guarantees.

Agencies that use de-identification should establish appropriate governance structures to support de-identification, data release, and post-release monitoring. Such structures will typically include a Disclosure Review Board as well as appropriate education, training, and research efforts.

A summary of this document's advice for practitioners appears in Figure 5.

In closing, it is important to remember that different jurisdictions may have different standards and policies regarding the definition and use of de-identified data. Information that is considered de-identified in one jurisdiction may be regarded as being identifiable in another.

- **Governance and Management (Section 3)** Managing de-identification includes identifying the goals of the de-identification process and considering risks to participants in the data release. To guide this process, this document describes several tools:
  - Consider all phases of the **data life cycle** (Sec. 3.3).
  - Consider different **data sharing models** (Sec. 3.4), including complementary protections like data use agreements, synthetic data, and enclaves.
  - Leverage the Five Safes (Sec. 3.5), a methodology for evaluating risk.
  - Form a **Disclosure Review Board** (Sec. 3.6) to oversee the implementation of de-identification policies.
  - Follow existing **de-identification standards** when possible (Sec. 3.7).
- **Technical Steps (Section 4)** The technical process of de-identification should leverage the best practices developed over the past several decades. In particular, NIST recommends that agencies:
  - Conduct a **data survey** (Sec. 4.2) to identify de-identification requirements specific to the data.
  - Identify **identifiers** and **quasi-identifiers** in the data, and select a method for de-identifying each one (Sec. 4.3).
  - Consider the existing **auxiliary data** (Sec. 4.3) that could be used to enable a re-identification attack.
  - Practice **defense in depth** by combining security measures with deidentification when possible, and consider using **synthetic data** (Sec. 4.4) or an **interactive query interface** (Sec. 4.5).
  - When possible, use **formal privacy techniques** to quantify privacy loss associated with the release of de-identified data (Sec. 4.4.7).
  - Validate the **utility** and **privacy** of the de-identified data (Sec. 4.6). In particular, establish accuracy goals for de-identification so that the data are not more accurate than required for the intended purpose.

**Software (Section 5)** In general, agencies should:

- Utilize automated, repeatable, software-based approaches for performing deidentification.
- Carefully consider the software used to implement de-identification to ensure that the algorithms used have been validated and that the software correctly implements those algorithms.
- Consider the efficiency, scalability, and repeatability properties of software tools, and evaluate the accuracy of the tool's output.

Fig. 5. Advice for Practitioners: A Summary

#### References

- [1] July 27, 2020. URL: https://www.nist.gov/blogs/cybersecurity-insights/differentialprivacy-privacy-preserving-data-analysis-introduction-our.
- [2] 115th Congress (2017–2018). Public Law 115-435: The Foundations for Evidence-Based Policymaking Act of 2018. 2018. URL: https://www.congress.gov/bill/115thcongress/house-bill/4174.
- [3] 45 CFR 164 Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule Safe Harbor method Standard: De-identification f protected health information.
- [4] 81 FR 49689: Revision of OMB Circular No. A-130, "Managing Information as a Strategic Resource. July 28, 2016. URL: https://www.cio.gov/policies-andpriorities/circular-a-130/.
- [5] 95th Congress. Public Law 95-416. Oct. 5, 1978. URL: https://www.census.gov/ history/pdf/NARA\_Legislation.pdf.
- [6] John Abowd et al. "The 2020 Census Disclosure Avoidance System TopDown Algorithm". In: *Harvard Data Science Review* Special Issue 2 (June 24, 2022). URL: https://hdsr.mitpress.mit.edu/pub/7evz361i.
- [7] John M. Abowd and Michael B.Hawes. "Confidentiality Protection in the 2020 US Census of Population and Housing". In: *Annual Review of Statistics and Its Application* 10.1 (2023). DOI: 10.1146/annurev-statistics-010422-034226. URL: https://doi.org/10.1146/annurev-statistics-010422-034226.
- [8] John M. Abowd and Ian M. Schmutte. *Economic Analysis and Statistical Disclo-sure Limitation*. Mar. 19, 2015. URL: https://www.brookings.edu/bpea-articles/economic-analysis-and-statistical-disclosure-limitation/.
- John M. Abowd and Lars Vilhuber. "How Protective are Synthetic Data?" In: *Lecture Notes in Computer Science: Privacy in Statistical Databases* 5262 (2008), pp. 239–246. URL: https://link.springer.com/chapter/10.1007/978-3-540-87471-3\_20.
- [10] Charu C. Aggarwal. "On K-Anonymity and the Curse of Dimensionality". In: *Proceedings of the 31st International Conference on Very Large Data Bases*. VLDB '05. Trondheim, Norway: VLDB Endowment, 2005, pp. 901–909. ISBN: 1595931546.
- [11] J. Trent Alexander, Michael Davern, and Betsey Stevenson. "Inaccurate age and sex data in the census PUMS files: Evidence and implications". In: *Public Opinion Quarterly* 74 (3 2010), pp. 551–569. URL: https://doi.org/10.1093/poq/nfq033.

- [12] Micah Altman et al. "Towards a Modern Approach to Privacy-Aware Government Data Releases". In: *Berkeley Technology Law Journal* 30 (3), pp. 1967–2072. URL: http://papers.ssrn.com/sol3/papers.cfm?abstract\_id=2779266.
- [13] AMD. AMD Secure Encrypted Virtualization (SEV). Last accessed July 13, 2022. 2022. URL: https://developer.amd.com/sev/.
- [14] Olivia Angiuli, Joe Blitzstein, and Jim Waldo. "How to De-Identify Your Data".
  In: *Commun. ACM* 58.12 (Nov. 2015), pp. 48–55. ISSN: 0001-0782. DOI: 10.1145/ 2814340. URL: https://doi.org/10.1145/2814340.
- [15] Luk Arbuckle. "Aggregated data provides a false sense of security". In: *Privacy Tech* (Apr. 27, 2020).
- [16] Luk Arbuckle and Felix Ritchie. "The Five Safes of Risk-Based Anonymization". In: *IEEE Security & Privacy* 17.5 (2019), pp. 84–89. DOI: 10.1109/MSEC.2019. 2929282.
- [17] ASTM International. ASTM E1869-04 (Reapproved 2014) Standard Guide for Confidentiality, Privacy, Access, and Data Security Principles for Health Information Including Electronic Health Records. 2014.
- [18] Daniel Barth-Jones. The 'Re-Identification' of Governor William Weld's Medical Information: A Critical Re-Examination of Health Data Identification Risks and Privacy Protections, Then and Now. July 2012. URL: https://ssrn.com/abstract= 2076397%20or%20http://dx.doi.org/10.2139/ssrn.2076397.
- [19] Hans T Bjornsson et al. "Intra-individual Change Over Time in DNA Methylation with Familial Clustering". In: JAMA 299 (24 June 25, 2008), pp. 2877–2833. URL: https://pubmed.ncbi.nlm.nih.gov/18577732/.
- [20] Kaitlin Boeckl, ed. *NIST Privacy Risk Assessment Methodology (PRAM)*. Jan. 16, 2020. URL: https://www.nist.gov/privacy-framework/nist-pram.
- [21] Janice Branson et al. "Evaluating the re-identification risk of a clinical study report anonymized under EMA Policy 0070 and Health Canada Regulations". In: *Trials* 21.1 (Feb. 18, 2020), p. 200. DOI: 10.1186/s13063-020-4120-y. URL: https://doi.org/10.1186/s13063-020-4120-y.
- [22] Sean Brooks et al. An introduction to privacy engineering and risk management in federal systems. Gaithersburg, MD, 2017. DOI: 10.6028/NIST.IR.8062. URL: https://nvlpubs.nist.gov/nistpubs/ir/2017/NIST.IR.8062.pdf.
- [23] Mark Bun and Thomas Steinke. "Concentrated Differential Privacy: Simplifications, Extensions, and Lower Bounds". In: *CoRR* abs/1605.02065 (2016). arXiv: 1605.02065. URL: http://arxiv.org/abs/1605.02065.
- [24] Sylvia M. Burwell. Open Data Policy-Managing Information as an Asset. May 9, 2013. URL: https://obamawhitehouse.archives.gov/sites/default/files/omb/ memoranda/2013/m-13-13.pdf.

- [25] George Bush. Executive Order 13402:Strengthening Federal Efforts to Protect Against Identity Theft. May 10, 2006. URL: https://www.gpo.gov/fdsys/pkg/FR-2006-05-15/pdf/06-4552.pdf.
- [26] G. Camarillo, C. Holmberg, and Y. Gao. *Re-INVITE and Target-Refresh Request Handling in the Session Initiation Protocol (SIP)*. RFC 6141 (Proposed Standard). Internet Engineering Task Force, Mar. 2011. URL: www.ietf.org/rfc/rfc6141.txt.
- [27] David Carrell et al. "Hiding in plain sight: Use of realistic surrogates to reduce exposure of protected health information in clinical text". In: *Journal of the American Medical Informatics Association : JAMIA* 20 (2 July 2012), pp. 342–348. DOI: 10.1136/amiajnl-2012-001034.
- [28] Ann Cavoukian. Privacy by Design: The 7 Foundational Principles. Ontario, CA, Jan. 2011. URL: https://www.ipc.on.ca/wp-content/uploads/Resources/7foundationalprinciples. pdf.
- [29] Census Bureau Data Stewardship Program. DS025: Organization of the Disclosure Review Board. Dec. 19, 2019. URL: https://www2.census.gov/foia/ds\_policies/ ds025.pdf.
- [30] Malcolm Chisholm. "7 Phases of a Data Life Cycle". In: *Information Management* (July 9, 2015). URL: http://www.information-management.com/news/data-management/Data-Life-Cycle-Defined-10027232-1.html.
- [31] A. Church. "A Note on the 'Entscheidungsproblem'". In: *Journal of Symbolic Logic* 1 (1936), pp. 40–41.
- [32] Aloni Cohen. "Attacks on Deidentification's Defenses". In: 31st USENIX Security Symposium (USENIX Security 22). Boston, MA: USENIX Association, Aug. 2022, pp. 1469–1486. ISBN: 978-1-939133-31-1. URL: https://www.usenix.org/ conference/usenixsecurity22/presentation/cohen.
- [33] Aloni Cohen and Kobbi Nissim. "Towards formalizing the GDPR's notion of singling out". In: *Proceedings of the National Academy of Sciences* 117.15 (2020), pp. 8344–8352. DOI: 10.1073/pnas.1914598117. eprint: https://www.pnas.org/doi/ pdf/10.1073/pnas.1914598117. URL: https://www.pnas.org/doi/abs/10.1073/pnas. 1914598117.
- [34] Commission on Evidence-Based Policymaking. *The Promise of Evidence-Based Policymaking*. Sept. 2017. URL: https://www.acf.hhs.gov/opre/project/commission-evidence-based-policymaking-cep.
- [35] Donna Daily. "Disclosure Avoidance Protections for the American Community Survey". In: *Random Samplings* (Dec. 14, 2022). URL: https://www.census.gov/ newsroom/blogs/random-samplings/2022/12/disclosure-avoidance-protectionsacs.html.
- [36] Tore Dalenius. "Finding a needle in a haystack or identifying anonymous census records". In: *Journal of Official Statistics* 2 (3 1986), pp. 329–336.

- [37] Tore Dalenius. "Finding a Needle in a Haystack, or Identifying Anonymous Census Records". In: *Journal of Official Statistics* 2 (3 1986), pp. 329–336.
- [38] Tore Dalenius. "Towards a methodology for statistical disclosure control". In: *Statistik Tidskrift* 15 (1977), pp. 429–444.
- [39] Jon P. Daries et al. "Privacy, Anonymity, and Big Data in the Social Sciences". In: *Communications of the ACM* 57 (6 Sept. 2014), pp. 56–63.
- [40] Data Protection Toolkit: Report and Resources on Statistical Disclosure Limitation Methodology and Tiered Data Access (formerly "Statistical Policy Working Paper #22"), rev. 2022.01. Nov. 28, 2022. URL: https://nces.ed.gov/fcsm/dpt.
- [41] Tess DeBlanc-Knowles et al. National Strategy to Advance Privacy-Preserving Data Sharing and Analytics. Mar. 2023. URL: https://www.whitehouse.gov/wpcontent/uploads/2023/03/National-Strategy-to-Advance-Privacy-Preserving-Data-Sharing-and-Analytics.pdf.
- [42] Tanvi Desai, Felix Ritchie, and Richard Welpton. Economics Working Paper Series 1601. 2016. URL: http://dx.doi.org/10.13140/RG.2.1.3661.1604.
- [43] DICOM Standards Committee. DICOM PS3.15 2016e Security and System Management Profiles. 2016. URL: http://dicom.nema.org/medical/dicom/current/ output/html/part15.html#chapter\_E.
- [44] Irit Dinur and Kobbi Nissim. "Revealing Information While Preserving Privacy". In: Proceedings of the Twenty-second ACM SIGMOD-SIGACT-SIGART Symposium on Principles of Database Systems. PODS '03. San Diego, California: ACM, 2003, pp. 202–210. ISBN: 1-58113-670-6. DOI: 10.1145/773153.773173. URL: doi.acm.org/10.1145/773153.773173.
- [45] Changyu Dong, Liqun Chen, and Zikai Wen. "When Private Set Intersection Meets Big Data: An Efficient and Scalable Protocol". In: *Proceedings of the 2013 ACM SIGSAC Conference on Computer and Communications Security*. CCS '13. Berlin, Germany: Association for Computing Machinery, 2013, pp. 789–800. ISBN: 9781450324779. DOI: 10.1145/2508859.2516701. URL: https://doi.org/10.1145/2508859.2516701.
- [46] Jörg Drechsler, Stefan Bender, and Susanne Rässler. Comparing fully and partially synthetic datasets for statistical disclosure control in the German IAB Establishment Panel (Working paper 11). New York, 2007. URL: http://fdz.iab.de/342/ section.aspx/Publikation/k080530j05.
- [47] George T. Duncan, Mark Elliot, and Juan-José Salazar-Gonzalez. *Statistical Confidentiality: Principles and Practice*. Springer, 2011, p. 113.
- [48] I. Dunsford et al. "A human blood-group chimera". In: *British Medical Journal* 81 (July 11, 1953). URL: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2028470/.

- [49] Cynthia Dwork. "Differential Privacy". In: 33rd International Colloquium on Automata, Languages and Programming, part II (ICALP 2006). Vol. 4052. Lecture Notes in Computer Science. Springer Verlag, July 2006, pp. 1–12. ISBN: 3-540-35907-9. URL: https://www.microsoft.com/en-us/research/publication/differentialprivacy/.
- [50] Cynthia Dwork and Moni Naor. "On the Difficulties of Disclosure Prevention in Statistical Databases or The Case for Differential Privacy". In: *Journal of Privacy* and Confidentiality 2.1 (Sept. 2010), pp. 93–107. DOI: 10.29012/jpc.v2i1.585. URL: https://journalprivacyconfidentiality.org/index.php/jpc/article/view/585.
- [51] Cynthia Dwork and Aaron Roth. "The Algorithmic Foundations of Differential Privacy". In: *Foundations and Trends in Theoretical Computer Science*. Vol. 9. 3–4. NOW, 2014, pp. 211–407.
- [52] Cynthia Dwork et al. "Calibrating Noise to Sensitivity in Private Data Analysis".
  In: *Theory of Cryptography*. Ed. by Shai Halevi and Tal Rabin. Berlin, Heidelberg: Springer Berlin Heidelberg, 2006, pp. 265–284. ISBN: 978-3-540-32732-5.
- [53] Cynthia Dwork et al. "Calibrating Noise to Sensitivity in Private Data Analysis". In: *Proceedings of the Third Conference on Theory of Cryptography*. TCC'06. New York, NY: Springer-Verlag, 2006, pp. 265–284. ISBN: 3540327312. DOI: 10.1007/ 11681878\_14. URL: doi.org/10.1007/11681878\_14.
- [54] Department of Education (ED) Disclosure Review Board (DRB). The Data Disclosure Decision. Version 1.0. 2015. URL: https://s3.amazonaws.com/sitesusa/wpcontent/uploads/sites/1151/2016/10/The-Data-Disclosure-Decision-Departmentof-Education-Case-Study\_Mar-2015.pdf.
- [55] M J. Elliot and A. Dale. *Scenarios of attack: the data intruder's perspective on statistical disclosure risk.* English. 1999.
- [56] Mark Elliot, Elaine Mackey, and Kieron O'Hara. The Anonymisation Decision-Making Framework: European Practitioners' Guide. Oxford Road, Manchester, UK: UKAN, University of Manchester, 2020. URL: https://ukanon.net/framework/.
- [57] El Emam. Methods for the de-identification of electronic health records for genomic research. 2011. URL: https://genomemedicine.biomedcentral.com/articles/10. 1186/gm239.
- [58] K. El Emam and B. Malin. "Appendix B: Concepts and Methods for De-Identifying Clinical Trial Data". In: Sharing Clinical Trial Data: Maximizing Benefits, Minimizing Risk. Washington, DC: Institute of Medicine of the National Academies, The National Academies Press, 2015.
- [59] Khaled El Emam and Luk Arbuckle. *Anonymizing Health Data: Case Studies and Methods to Get you Started*. Sebastopol, CA: O'Reilly Media, 2013.

- [60] Ali Farzanehfar, Florimond Houssiau, and Yves-Alexandre de Montjoye. "The risk of re-identification remains high even in country-scale location datasets". In: *Patterns* 2.3 (2021), p. 100204. ISSN: 2666-3899. DOI: https://doi.org/10.1016/j. patter.2021.100204. URL: https://www.sciencedirect.com/science/article/pii/ S2666389921000143.
- [61] I. P. Fellegi. "On the Question of Statistical Confidentiality". In: *Journal of the American Statistical Association* 67.337 (1972), pp. 7–18. DOI: 10.1080/01621459. 1972.10481199.
- [62] Matthew Fredrikson et al. "Privacy in Pharmacogenetics: An End-to-End Case Study of Personalized Warfarin Dosing". In: 23rd USENIX Security Symposium. San Diego, CA, Aug. 20, 2014. URL: https://www.usenix.org/system/files/ conference/usenixsecurity14/sec14-paper-fredrikson-privacy.pdf.
- [63] Matthew Fredrikson et al. "Privacy in Pharmacogenetics: An End-to-End Case Study of Personalized Warfarin Dosing". In: *Proceedings of the 23rd USENIX Conference on Security Symposium*. SEC'14. San Diego, CA: USENIX Association, 2014, pp. 17–32. ISBN: 9781931971157.
- [64] Katherine L. Frohlich and Louise Potvin. "Transcending the known in public health practice: the inequality paradox: the population approach and vulnerable populations". In: *Am J Public Health* 98 (2 Feb. 2008), pp. 216–21. DOI: 10.2105/AJPH. 2007.114777.
- [65] Simson Garfinkel. De-Identification of Personally Identifiable Information. Tech. rep. NIST IR 8053. National Institute of Science and Technology, Nov. 2015. URL: http://nvlpubs.nist.gov/nistpubs/ir/2015/NIST.IR.8053.pdf.
- [66] Simson L. Garfinkel. De-identification of personal information. 2015. DOI: 10. 6028/NIST.IR.8053. URL: https://nvlpubs.nist.gov/nistpubs/ir/2015/NIST.IR.8053. pdf.
- [67] Simson L. Garfinkel. Government Data De-Identification Stakeholder's Meeting June 29, 2016 Meeting Report. 2016. DOI: 10.6028/NIST.IR.8150. URL: https: //nvlpubs.nist.gov/nistpubs/ir/2016/NIST.IR.8150.pdf.
- [68] Genetics Home Reference. What are single nucleotide polymorphisms (SNPs)? Last access June 16, 2022. 2022. URL: https://ghr.nlm.nih.gov/primer/genomicresearch/ snp.
- [69] Genetics Home Reference. *What is DNA*. Last access June 16, 2022. 2022. URL: https://ghr.nlm.nih.gov/primer/basics/dna.
- [70] Craig Gentry. "A Fully Homomorphic Encryption Scheme". AAI3382729. PhD thesis. Stanford, CA, USA, 2009. ISBN: 9781109444506.
- [71] Glossary of Statistical Terms. OECD, 2007. URL: https://stats.oecd.org/glossary/ detail.asp?ID=4884.

- [72] Ruobin Gong, Erica L. Groshen, and Salil Vadhan. "Harnessing the Known Unknowns: Differential Privacy and the 2020 Census". In: *Harvard Data Science Review* Special Issue 2 (June 24, 2022). URL: https://hdsr.mitpress.mit.edu/pub/ fgyf5cne.
- [73] E. Green and F. Richie. "Data Access Project: Final Report". In: (June 2016). URL: https://eprints.uwe.ac.uk/31874.
- [74] Melissa Gymrek et al. "Identifying Personal Genomes by Surname Inference". In: *Science* 339 (6117 Jan. 2013), pp. 321–329.
- [75] Michael Hawes. The Census Bureau's Simulated Reconstruction-Abetted Re-identification Attack on the 2010 Census. May 7, 2021. URL: https://www.census.gov/data/ academy/webinars/2021/disclosure-avoidance-series/simulated-reconstructionabetted-re-identification-attack-on-the-2010-census.html.
- [76] Michael B. Hawes. "Implementing Differential Privacy: Seven Lessons From the 2020 United States Census". In: *Harvard Data Science Review* 2.2 (Apr. 30, 2020). URL: https://hdsr.mitpress.mit.edu/pub/dgg03vo6.
- [77] TN Herzog, FJ Scheuren, and WE Winkler. *Data Quality and Record Linkage Techniques*. New York/London: Springer, 2007.
- [78] IHE IT Infrastructure Technical Committee. IHE IT Infrastructure Handbook. June 6, 2014. URL: https://www.ihe.net/wp-content/uploads/uploadedFiles/Documents/ ITI/IHE\_ITI\_Handbook\_De-Identification\_Rev1.1\_2014-06-06.pdf.
- [79] IHE IT Infrastructure Technical Committee. IHE IT Infrastructure Handbook: De-Identification. Integrating the Healthcare Enterprise, Mar. 14, 2014. URL: https: //ihe.net/uploadedFiles/Documents/ITI/IHE\_ITI\_Handbook\_De-Identification\_ Rev1.0\_2014-03-14.pdf.
- [80] Clay Johnson III. OMB Memorandum M-07-16: Safeguarding Against and Responding to the Breach of Personally Identifiable Information. Replaced by M-17-12. May 2007. URL: https://georgewbush-whitehouse.archives.gov/omb/ memoranda/fy2007/m07-16.pdf.
- [81] Information Commissioner's Office. Anonymisation: code of practice, managing data protection risk. 2012. URL: https://ico.org.uk/media/1061/anonymisationcode.pdf.
- [82] ISO. ISO/IEC 27559:2022 Information security, cybersecurity and privacy protection — Privacy enhancing data de-identification framework. 2022. URL: https: //www.iso.org/standard/71677.html.
- [83] *ISO 26324:2012, Information and documentation Digital object identifier system.* Geneva, Switzerland, 2012. URL: https://www.iso.org/standard/43506.html.
- [84] ISO/IEC 24760-1:2011, Information technology Security techniques A framework for identity management – Part 1: Terminology and concepts. 2011.

- [85] *ISO/TS 25237:2008(E) Health Informatics Pseudonymization.* Geneva, Switzerland, 2008.
- [86] Auguste Kerckhoffs. "II. Desiderata De La Cryptographie Militaire". In: *Journal des sciences militaires* IX (Jan. 1883), pp. 5–38.
- [87] Shehab Khan. ""Human chimera": Man fails paternity test because genes in his saliva are different to those in sperm". In: *The Independent* (Oct. 24, 2015).
- [88] Daniel Kifer et al. "Bayesian and Frequentist Semantics for Common Variations of Differential Privacy: Applications to the 2020 Census". In: arXiv preprint arXiv:2209.03310 (2022).
- [89] Vladimir Kolesnikov et al. "Efficient Batched Oblivious PRF with Applications to Private Set Intersection". In: *Proceedings of the 2016 ACM SIGSAC Conference on Computer and Communications Security*. CCS '16. Vienna, Austria: Association for Computing Machinery, 2016, pp. 818–829. ISBN: 9781450341394. DOI: 10. 1145/2976749.2978381. URL: https://doi.org/10.1145/2976749.2978381.
- [90] Leah Krehling. *De-Identification Guideline*. Tech. rep. WL-2020-01. Department of Electrical and Computer Engineering, Western University, 2020, p. 45.
- [91] Sandra Lechner and Winfried Pohlmeier. "To Blank or Not to Blank? A Comparison of the Effects of Disclosure Limitation Methods on Nonlinear Regression Estimates". In: *Privacy in Statistical Databases, Lecture Notes in Computer Science* 3050 (2004), pp. 187–200.
- [92] Jaewoo Lee and Chris Clifton. "Differential Identifiability". In: Proceedings of the 18th ACM SIGKDD International Conference on Knowledge Discovery and Data Mining. KDD '12. Beijing, China: Association for Computing Machinery, 2012, pp. 1041–1049. ISBN: 9781450314626. DOI: 10.1145/2339530.2339695. URL: https://doi.org/10.1145/2339530.2339695.
- [93] Jaewoo Lee and Chris Clifton. "How Much Is Enough? Choosing ε for Differential Privacy". In: *Information Security*. Ed. by Xuejia Lai, Jianying Zhou, and Hui Li. Berlin, Heidelberg: Springer Berlin Heidelberg, 2011, pp. 325–340. ISBN: 978-3-642-24861-0.
- [94] Ninghui Li, Tiancheng Li, and Suresh Venkatasubramanian. "t-Closeness: Privacy Beyond k-Anonymity and l-Diversity". In: 2007 IEEE 23rd International Conference on Data Engineering. 2007, pp. 106–115. DOI: 10.1109/ICDE.2007.367856.
- [95] Yehuda Lindell. "Secure Multiparty Computation". In: Commun. ACM 64.1 (Dec. 2020), pp. 86–96. ISSN: 0001-0782. DOI: 10.1145/3387108. URL: https://doi.org/ 10.1145/3387108.
- [96] Roderick JA Little. "Statistical analysis of masked data". In: *Journal of Official Statistics* 9 (2 1993), pp. 407–426.

- [97] M. Altman M et al. "Towards a Modern Approach to Privacy-Aware Government Data Release". In: *Berkeley Journal of Technology Law Internet* (2016). URL: https: //lawcat.berkeley.edu/record/1127405?ln=en.
- [98] Ashwin Machanavajjhala et al. "1-diversity: Privacy beyond k-anonymity". In: *Proc.* 22nd Intnl. Conf. Data Engg. (ICDE). 2006.
- [99] Ashwin Machanavajjhala et al. "Privacy: Theory meets Practice on the Map". In:
  2008 IEEE 24th International Conference on Data Engineering. 2008, pp. 277–286. DOI: 10.1109/ICDE.2008.4497436.
- [100] Management and Budget Office. Statistical Policy Directive No. 1: Fundamental Responsibilities of Federal Statistical Agencies and Recognized Statistical Units. Dec. 2, 2014. URL: https://www.federalregister.gov/documents/2014/12/02/2014-28326/statistical-policy-directive-no-1-fundamental-responsibilities-of-federalstatistical-agencies-and.
- [101] Sean Martin. When De-identifying Patient Information, Follow the HITRUST Framework. Sept. 8, 2016. URL: https://hitrustalliance.net/de-identifying-patientinformation-follow-hitrust-framework/.
- [102] Daniel A. Mayer et al. "Implementation and Performance Evaluation of Privacy-Preserving Fair Reconciliation Protocols on Ordered Sets". In: *Proceedings of the First ACM Conference on Data and Application Security and Privacy*. CODASPY '11. San Antonio, TX, USA: Association for Computing Machinery, 2011, pp. 109– 120. ISBN: 9781450304665. DOI: 10.1145/1943513.1943529. URL: https://doi.org/ 10.1145/1943513.1943529.
- [103] E McCallister, T Grance, and K A Scarfone. Guide to protecting the confidentiality of Personally Identifiable Information (PII). Gaithersburg, MD, 2010. DOI: 10.6028/NIST.SP.800-122. URL: https://nvlpubs.nist.gov/nistpubs/Legacy/SP/ nistspecialpublication800-122.pdf.
- [104] Luise Mehner, Saskia Nuñez von Voigt, and Florian Tschorsch. "Towards Explaining Epsilon: A Worst-Case Study of Differential Privacy Risks". In: 2021 IEEE European Symposium on Security and Privacy Workshops (EuroS&PW). 2021, pp. 328–331. DOI: 10.1109/EuroSPW54576.2021.00041.
- [105] William K. Michener et al. "Participatory design of DataONE—Enabling cyberinfrastructure for the biological and environmental sciences". In: *Ecological Informatics* 11 (2012). Data platforms in integrative biodiversity research, pp. 5–15. ISSN: 1574-9541. DOI: https://doi.org/10.1016/j.ecoinf.2011.08.007. URL: https://www.sciencedirect.com/science/article/pii/S1574954111000768.
- [106] Yves-Alexandre de Montjoye et al. "Unique in the Crowd: The Privacy Bounds of Human Mobility". In: *Nature Scientific Reports* 3 (1376 2013).
- [107] Yves-Alexandre de Montjoye et al. "Unique in the Shopping Mall: On the Reidentifiability of Credit Card Metadata". In: *Science* 347 (536 2015).

- [108] Arvind Narayanan and Ed Felten. No silver bullet: De-identification still doesn't work. Working Paper. July 9, 2014. URL: http://randomwalker.info/publications/ no-silver-bullet-de-identification.pdf.
- [109] Arvind Narayanan and Vitaly Shmatikov. "Robust De-anonymization of Large Sparse Datasets". In: 2008 IEEE Symposium on Security and Privacy (sp 2008). 2008, pp. 111–125. DOI: 10.1109/SP.2008.33.
- [110] National Center for Environmental Health. *Planning for an Emergency: Strategies for Identifying and Engaging At-Risk Groups*. Centers for Disease Control, 2015. URL: https://www.cdc.gov/nceh/hsb/disaster/atriskguidance.pdf.
- [111] National COVID Cohort Collaborative. *N3C Privacy-Preserving Record Linkage*. Last accessed February 18, 2023. 2023. URL: https://covid.cd2h.org/PPRL.
- [112] NIST Big Data Interoperability Framework: Volume 1, Definitions. 2015. DOI: 10. 6028/NIST.SP.1500-1. URL: https://nvlpubs.nist.gov/nistpubs/SpecialPublications/ NIST.SP.1500-1.pdf.
- [113] NIST Privacy Framework: A Tool for Improving Privacy Through Enterprise Risk Management, Version 1.0. Gaithersburg, MD, 2022. DOI: 10.6028/NIST.CSWP.10. URL: https://nvlpubs.nist.gov/nistpubs/CSWP/NIST.CSWP.01162020.pdf.
- [114] Christine M. O'Keefe and James O. Chipperfield. "A Summary of Attack Methods and Confidentiality Protection Measures for Fully Automated Remote Analysis Systems". In: *International Statistical Review / Revue Internationale de Statistique* 81.3 (2013), pp. 426–455. ISSN: 03067734, 17515823. URL: http://www.jstor.org/ stable/43299645 (visited on 06/28/2022).
- [115] Barack Obama. *Executive Order 13642—Making Open and Machine Readable the New Default for Government Information*. May 9, 2013. URL: https://obamawhitehouse. archives.gov/the-press-office/2013/05/09/executive-order-making-open-andmachine-readable-new-default-government-.
- [116] OECD Director of Public Governance. *OECD Open, Useful and Re-usable data* (*OURdata*) *Index: 2019.* 2020. URL: https://www.oecd.org/gov/digital-government/ ourdata-index-policy-paper-2020.pdf.
- [117] OECD Legal Instruments. Recommendation of the Council on Health Data Governance. Dec. 12, 2016. URL: https://legalinstruments.oecd.org/en/instruments/ OECD-LEGAL-0433.
- [118] Office of Civil Rights, US Department of Health and Human Services. Guidance Regarding Methods for De-identification of Protected Health Information in Accordance with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule. Nov. 26, 2012. URL: http://www.hhs.gov/hipaa/for-professionals/ privacy/special-topics/de-identification/.

- [119] Office of Civil Rights, US Department of Health and Human Services. Individuals' Right under HIPAA to Access their Health Information 45 CFR § 164.524. Last accessed June 17, 2022. 2022. URL: https://www.hhs.gov/hipaa/for-professionals/ privacy/guidance/access/index.html.
- [120] Office of Management and Budget. *Circular A110 Revised 11/19/93, as further amended 9/30/99.* URL: https://obamawhitehouse.archives.gov/omb/circulars\_a110/.
- [121] Office of Management and Budget. *Statistical Programs and Standards*. 2022. URL: https://www.whitehouse.gov/omb/information-regulatory-affairs/statistical-programs-standards/.
- [122] Office of Safeguards, US Internal Revenue Service. Publication 1075: Tax Information Security Guidelines For Federal, State and Local Agencies. 2021. URL: https://www.irs.gov/pub/irs-pdf/p1075.pdf.
- [123] Paul Ohm. "Broken Promises of Privacy: Responding to the Surprising Failure of Anonymization". In: UCLA Law Review 57 (July 13, 2012), pp. 1701–1778.
- [124] OHRP-Guidance on Research Involving Private Information or Biological Specimens. Aug. 16, 2008. URL: http://www.hhs.gov/ohrp/policy/cdebiol.html.
- [125] Joanne Pascale and Thomas Mayer. "Alternative Methods for Exploring Confidentiality Issues Related to Dependent Interviewing". In: (Dec. 11, 2002).
- [126] Joanne Pascale et al. Issue Paper on Disclosure Review for Information Products with Qualitative Research Findings. Mar. 2, 2020. URL: https://www.census.gov/ library/working-papers/2020/adrm/rsm2020-01.html.
- Joanne Pascale et al. "Protecting the Identity of Participants in Qualitative Research". In: *Journal of Survey Statistics and Methodology* 10.3 (Jan. 2022), pp. 549–567. ISSN: 2325-0984. DOI: 10.1093/jssam/smab048. eprint: https://academic.oup.com/jssam/article-pdf/10/3/549/44275508/smab048.pdf. URL: https://doi.org/10.1093/jssam/smab048.
- [128] Andrew Peterson. "Why the names of six people who complained of sexual assault were published online by Dallas police". In: *The Washington Post* (Apr. 29, 2016). URL: https://www.washingtonpost.com/news/the-switch/wp/2016/04/29/why-thenames-of-six-people-who-complained-of-sexual-assault-were-published-onlineby-dallas-police/.
- [129] Thomas Piketty and Emmanuel Saez. "Income Inequality in the United States 1913-1998". In: *Quarterly Journal of Economics* 118 (1 2003), pp. 1–41.
- [130] "Pillar Investigates: USCCB gen sec Burrill resigns after sexual misconduct allegations". In: *The Pillar* (July 2021). URL: https://www.pillarcatholic.com/p/pillarinvestigates-usccb-gen-sec.

- [131] Sandro Pinto and Nuno Santos. "Demystifying Arm TrustZone: A Comprehensive Survey". In: ACM Comput. Surv. 51.6 (Jan. 2019). ISSN: 0360-0300. DOI: 10.1145/ 3291047. URL: https://doi.org/10.1145/3291047.
- [132] Private Lives and Public Policies: Confidentiality and Accessibility of Government Statistics. Panel on Confidentiality and Data Access, National Research Council, 1993, p. 288. URL: http://www.nap.edu/catalog/2122/.
- [133] Public Law 93-579: The Privacy Act of 1974. 88 Stat. 1896, 5 U.S.C. § 552a. 1974.
- [134] William H. Rehnquist. *Department of State v. Washington Post Co., 456 U.S. 595* (1982). 1982. URL: https://www.loc.gov/item/usrep456595/.
- [135] Diane Ridgeway et al. Challenge Design and Lessons Learned from the 2018 Differential Privacy Challenges. 2021. DOI: 10.6028/NIST.TN.2151. URL: https: //nvlpubs.nist.gov/nistpubs/TechnicalNotes/NIST.TN.2151.pdf.
- [136] Felix Ritchie. "Microdata access and privacy: What have we learned over twenty years?" In: *Journal of Privacy and Confidentiality* 11.1 (Feb. 2021). DOI: 10.29012/ jpc.766. URL: https://journalprivacyconfidentiality.org/index.php/jpc/article/view/ 766.
- [137] Pierangela Samarati and Latanya Sweeney. "Protecting privacy when disclosing information: k-anonymity and its enforcement through generalization and suppression". In: *Proceedings of the IEEE Symposium on Research in Security and Privacy* (May 1998).
- [138] Pierangela Samarti. "Protecting Respondents' Identities in Microdata Release". In: *IEEE Transactions on Knowledge and Data Engineering* 13 (6 Nov. 2001), pp. 1010–1027.
- [139] M Scaiano et al. "unified framework for evaluating the risk of re-identification of text de-identification tools". In: *Journal of Biomedical Informatics* 63 (Oct. 2016), pp. 174–183.
- [140] Matthias Schunter. "Intel Software Guard Extensions: Introduction and Open Research Challenges". In: *Proceedings of the 2016 ACM Workshop on Software PROtection*. SPRO '16. Vienna, Austria: Association for Computing Machinery, 2016, p. 1. ISBN: 9781450345767. DOI: 10.1145/2995306.2995307. URL: https://doi.org/10.1145/2995306.2995307.
- [141] M Seastrom. "Licensing". In: *Confidentiality, Disclosure and Data Access: Theory and Practical Application for Statistical Agencies*. Ed. by P. Doyle et al. Elsevier Science, 2001.
- [142] Ben Snaith, Peter Wells, and Anna Scott. *Data's value: how and why should we measure it?* Aug. 9, 2018. URL: https://www.theodi.org/article/datas-value-how-and-why-should-we-measure-it/.

- [143] Philip Steel and Jon Sperling. The Impact of Multiple Geographies and Geographic Detail on Disclosure Risk: Interactions between Census Tract and ZIP Code Tabulation Geography. 2001. URL: https://www.census.gov/content/dam/Census/ library/working-papers/2001/adrm/steel-sperling-2001.pdf.
- [144] Jackson M. Steinkamp et al. "Evaluation of Automated Public De-Identification Tools on a Corpus of Radiology Reports". In: *Radiol Artif Intell* 2 (6 Oct. 14, 2020). URL: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8082401/.
- [145] John Paul Stevens. U.S. Dept. of Justice v. Reporters Committee For Freedom of Press, 489 U.S. 749 (1989). 1988. URL: https://www.loc.gov/item/usrep489749/.
- [146] John Paul Stevens. United States Department of State v. Ray et al., 502 U.S. 164 (1991). 1991. URL: https://www.loc.gov/item/usrep502164/.
- [147] Kevin Stine et al. Volume I: guide for mapping types of information and information systems to security categories. Gaithersburg, MD, 2008. DOI: 10.6028/ NIST. SP. 800 - 60v1r1. URL: https://nvlpubs.nist.gov/nistpubs/Legacy/SP/ nistspecialpublication800-60v1r1.pdf.
- [148] Tim Stobierski. In: *Business Insights* (Feb. 2, 2021). URL: https://online.hbs.edu/ blog/post/data-life-cycle.
- [149] Gary Stoneburner, Alice Goguen, and Alexis Feringa. *Risk management guide for information technology systems: recommendations of the National Institute of Stan-dards and Technology*. Gaithersburg, MD, 2002. DOI: 10.6028/NIST.SP.800-30. URL: https://nvlpubs.nist.gov/nistpubs/Legacy/SP/nistspecialpublication800-30.pdf.
- [150] Teresa A. Sullivan. "Coming to Our Census: How Social Statistics Underpin Our Democracy (and Republic)". In: *Harvard Data Science Review* 2.1 (Jan. 31, 2020). URL: https://hdsr.mitpress.mit.edu/pub/1g1cbvkv.
- [151] Latanya Sweeney. "k-anonymity: a model for protecting privacy". In: International Journal on Uncertainty, Fuzziness and Knowledge-based Systems 10 (5 2002), pp. 557–570.
- [152] Latanya Sweeney. "k-anonymity: a model for protecting privacy". In: Int. J. Uncertain. Fuzziness Knowl.-Based Syst. 10 (5 Oct. 2002), pp. 557–570. URL: http: //dx.doi.org/10.1142/S0218488502001648.
- [153] Latanya Sweeney. "Weaving Technology and Policy Together to Maintain Confidentiality". In: *Journal of Law, Medicine and Ethics* 25 (1997), pp. 98–110.
- [154] Vanessa Teague, Chris Culnane, and Dr Ben Rubinstein. "The Simple Process Of Re-Identifying Patients In Public Health Records". In: *Engineering & Technology* (Dec. 18, 2017). URL: https://pursuit.unimelb.edu.au/articles/the-simple-processof-re-identifying-patients-in-public-health-records.

- [155] "The Debate Over 'Re-Identification' Of Health Information: What Do We Risk?" In: *Health Affairs Blog* (Aug. 10, 2012). DOI: 10.1377/hblog20120810.021952. URL: https://www.healthaffairs.org/do/10.1377/forefront.20120810.021952.
- [156] Title V of the E-Government Act of 2002: Confidential Information Protection and Statistical Efficiency Act (CIPSEA) PL 107–347,116 Stat. 2899, 44 USC § 101 Section 502(8).
- [157] TransCelerate Biopharma, Inc. Data De-identification and Anonymization of Individual Patient Data in Clinical Studies—A Model Approach. 2013.
- [158] Michael Carl Tschantz and Jeannette M. Wing. Formal Methods for Privacy. Tech. rep. CMU-CS-09-154. Pittsburg, PA: Carnegie Mellon University, Aug. 2009. URL: http://reports-archive.adm.cs.cmu.edu/anon/2009/CMU-CS-09-154.pdf.
- [159] A. M. Turing. "On Computable Numbers, with an Application to the Entscheidungsproblem". In: *Proceedings of the London Mathematical Society, Series 2* (42 1936), pp. 230–265.
- [160] US Census Bureau. *Census Confidentiality and Privacy: 1790-2002.* 2003. URL: https://www.census.gov/prod/2003pubs/conmono2.pdf.
- [161] US Census Bureau. *The "72-Year Rule"*. Jan. 26, 2022. URL: https://www.census. gov/history/www/genealogy/decennial\_census\_records/the\_72\_year\_rule\_1.html.
- [162] US Congress. Public Law 104-191: Health Insurance Portability and Accountability Act of 1996 (HIPAA). Aug. 1996. URL: https://www.congress.gov/bill/104thcongress/house-bill/3103.
- [163] US Congress. *Public Law 114-185: FOIA Improvement Act of 2016.* 2016. URL: https://www.congress.gov/114/plaws/publ185/PLAW-114publ185.pdf.
- [164] US Congress. *The Freedom Of Information Act, 5 U.S.C.* § 552. 2022. URL: https://www.justice.gov/oip/freedom-information-act-5-usc-552.
- [165] US Department of Health and Human Services. 45 CFR Part 46: Federal Policy for the Protection of Human Subjects. Jan. 19, 2017. URL: https://www.govinfo.gov/ content/pkg/FR-2017-01-19/pdf/2017-01058.pdf.
- [166] US Department of Health and Human Services. Guidance Regarding Methods for De-identification of Protected Health Information in Accordance with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule. 2012. URL: https://www.hhs.gov/hipaa/for-professionals/privacy/special-topics/deidentification/index.html.
- [167] Joel Havermann, plaintiff—Appellant v. Carolyn W. Colvin, Acting Commissioner of the Social Security Administration, Defendant—Appellee, No. 12-2453, US Court of Appeals for the Fourth Circuit, 537 Fed. Appx. 142; 2013 US App. Aug 1, 2013. Joel Havemann v. Carolyn W. Colvin, Civil No. JFM-12-1325. 2015 US Dist. LEXIS 27560. Mar. 6, 2015.

- [168] Russell T. Vought. Phase 1 Implementation of the Foundations for Evidence-Based Policymaking Act of 2018: Learning Agendas, Personnel, and Planning Guidance. URL: https://www.whitehouse.gov/wp-content/uploads/2019/07/M-19-23.pdf.
- [169] Isabel Wagner and David Eckhoff. "Technical Privacy Metrics: A Systematic Survey". In: ACM Comput. Surv. 51.3 (June 2018). ISSN: 0360-0300. DOI: 10.1145/3168389. URL: https://doi.org/10.1145/3168389.
- [170] Charlie Warzel and Stuart A. Thompson. "How Your Phone Betrays Democracy". In: *The New York Times* (Dec. 2019). URL: https://www.nytimes.com/interactive/ 2019/12/21/opinion/location-data-democracy-protests.html.
- [171] Cathy Wasserman and Eric Ossiander. *Department of Health Agency Standards for Reporting Data with Small Numbers*. May 2018. URL: https://doh.wa.gov/sites/default/files/legacy/Documents/1500//SmallNumbers.pdf.
- [172] Leon Willenborg and Ton de Waal. "Chapter 3 Data Analytic Impact of SDC Techniques on Microdata". In: *Elements of Statistical Disclosure Control* (2012), pp. 72–92.

#### Appendix A. Standards

- ASTM E1869-04(2014) Standard Guide for Confidentiality, Privacy, Access, and Data Security Principles for Health Information Including Electronic Health Records
- DICOM PS3.15 2016d Security and System Management Profiles Chapter E Attribute Confidentiality Profiles, DICOM Standards Committee, NEMA 2016. http://dicom.nema.org/medical/dicom/current/output/html/part15.html#chapter\_E
- HITRUST De-Identification Working Group (2015, March). De-Identification Framework: A Consistent, Managed Methodology for the De-Identification of Personal Data and the Sharing of Compliance and Risk Information. Frisco, TX: HITRUST. Retrieved from https://hitrustalliance.net/de-identification-license-agreement/
- ISO 8000-2:2012(E) Data quality Part 2: Vocabulary, 2012. ISO, Geneva, Switzerland. 2012.
- ISO/IEC 27559:2022 Privacy enhancing data de-identification framework. ISO, Geneva, Switzerland. 2022.
- ISO/IEC 20889:2018, Information technology Security techniques Privacy enhancing data de-identification techniques. ISO, Geneva, Switzerland. 2018.
- ISO/IEC 27000:2014 Information technology Security techniques Information security management systems Overview and vocabulary. ISO, Geneva, Switzerland. 2012.
- ISO/IEC 24760-1:2011 Information technology Security techniques A framework for identity management – Part 1: Terminology and concepts. ISO, Geneva, Switzerland. 2011.
- ISO/TS 25237:2008(E) Health Informatics Pseudonymization. ISO, Geneva, Switzerland. 2008.
- IHE IT Infrastructure Handbook, De-Identification, Integrating the Healthcare Enterprise, June 6, 2014. http://www.ihe.net/User\_Handbooks/

#### Appendix A.1. NIST Publications

• NIST Privacy Framework: A Tool for Improving Privacy Through Enterprise Risk Management, Version 1.0. Gaithersburg, MD, 2022. DOI: 10.6028/NIST.CSWP.10. URL: https://nvlpubs.nist.gov/nistpubs/CSWP/NIST.CSWP.01162020.pdf

- Kevin Stine et al. *Volume I: guide for mapping types of information and information systems to security categories.* Gaithersburg, MD, 2008. DOI: 10.6028/NIST.SP.800-60v1r1. URL: https://nvlpubs.nist.gov/nistpubs/Legacy/SP/nistspecialpublication800-60v1r1.pdf
- Simson L. Garfinkel. *De-identification of personal information*. 2015. DOI: 10.6028/ NIST.IR.8053. URL: https://nvlpubs.nist.gov/nistpubs/ir/2015/NIST.IR.8053.pdf
- Simson L. Garfinkel. *Government Data De-Identification Stakeholder's Meeting June 29, 2016 Meeting Report.* 2016. DOI: 10.6028/NIST.IR.8150. URL: https://nvlpubs.nist.gov/nistpubs/ir/2016/NIST.IR.8150.pdf

#### Appendix A.2. Other U.S. Government Publications

- Census Confidentiality and Privacy: 1790-2002, US Census Bureau, 2003. https://www.census.gov/prod/2003pubs/conmono2.pdf
- Coded Private Information or Specimens Use in Research (2008), Guidance, U.S. Department of Health & Human Services, Office of Human Research Protections, October 16, 2008 http://www.hhs.gov/ohrp/policy/cdebiol.html
- *Data De-identification: An Overview of Basic Terms*, Privacy Technical Assistance Center, US Department of Education. May 2013. http://ptac.ed.gov/sites/default/ files/data\_deidentification\_terms.pdf
- *Data Disclosure Decision*, Department of Education (ED) Disclosure Review Board (DRB), A Product of the Federal CIO Council Innovation Committee. Version 1.0, 2015.
- Data Protection Toolkit: Report and Resources on Statistical Disclosure Limitation, Methodology and Tiered Data Access (formerly "Statistical Policy Working Paper #22"), rev. 2022.01 (11/28/2022).https://nces.ed.gov/fcsm/dpt
- Disclosure Avoidance Techniques at the US Census Bureau: Current Practices and Research, Research Report Series (Disclosure Avoidance #2014-02), Amy Lauger, Billy Wisniewski, and Laura McKenna, Center for Disclosure Avoidance Research, US Census. Bureau, September 26, 2014. https://www.census.gov/srd/CDAR/cdar2014-02\_Discl\_Avoid\_Techniques.pdf
- Frequently Asked Questions Disclosure Avoidance, Privacy Technical Assistance Center, U.S. Department of Education. October 2012 (revised July 2015). http://ptac.ed.gov/sites/default/files/FAQ\_Disclosure\_Avoidance.pdf
- Guidance Regarding Methods for De-identification of Protected Health Information in Accordance with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, U.S. Department of Health & Human Services, Office for Civil Rights,

November 26, 2012. http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/ De-identification/hhs\_deid\_guidance.pdf

- Data Release Policy for Vital Statistics Micro-data Files, U.S. Centers for Disease Control and Prevention, April 1, 2019. http://www.cdc.gov/nchs/nvss/dvs\_data\_release. htm
- Linking Data for Health Services Research: A Framework and Instructional Guide. Dusetzina SB, Tyree S, Meyer AM, Meyer A, Green L, Carpenter WR. (Prepared by the University of North Carolina at Chapel Hill under Contract No. 290-2010-000141.) AHRQ Publication No. 14-EHC033-EF. Rockville, MD: Agency for Healthcare Research and Quality; September 2014.
- National Center for Health Statistics Data Release and Access Policy for Micro-data and Compressed Vital Statistics File, Centers for Disease Control, April 26, 2011. http://www.cdc.gov/nchs/nvss/dvs\_data\_release.htm
- National Center for Health Statistics Policy on Micro-Data Dissemination, Centers for Disease Control, July 2002. https://www.cdc.gov/nchs/data/nchs\_microdata\_release\_policy\_4-02a.pdf
- National Strategy to Advance Privacy-Preserving Data Sharing and Analytics, A report by the Fast-Track Action Committee on Advancing Privacy-Preserving Data Sharing and Analytics Networking and Information Technology Research and Development Subcommittee of the National Science and Technology Council, March 2023 https://www.whitehouse.gov/wp-content/uploads/2023/03/National-Strategy-to-Advance-Privacy-Preserving-Data-Sharing-and-Analytics.pdf
- *OHRP-Guidance on Research Involving Private Information or Biological Specimens (2008)*, Department of Health & Human Services, Office of Human Research Protections (OHRP), August 16, 2008. http://www.hhs.gov/ohrp/policy/cdebiol.html
- OMB Circular A-130, Managing Information as a Strategic Resource, July 2016.
- Privacy and Confidentiality Research and the U.S. Census Bureau, Recommendations Based on a Review of the Literature, Thomas S. Mayer, Statistical Research Division, US Bureau of the Census. February 7, 2002. https://www.census.gov/ library/working-papers/2002/adrm/rsm2002-01.html

# Selected Publications by Other Governments

- Privacy business resource 4: De-identification of data and information, Office of the Australian Information Commissioner, Australian Government, April 2014. http://www.oaic.gov.au/ima resources/privacy-business-resources/privacy\_business\_resource\_4.pdf
- *Opinion 05/2014 on Anonymisation Techniques*, Article 29 Data Protection Working Party, 0829/14/EN WP216, Adopted on 10 April 2014.

- Anonymisation: Managing data protection risk, Code of Practice 2012, Information Commissioner's Office. https://ico.org.uk/media/for-organisations/documents/1061/anonymisationcode.pdf. 108 pages.
- *The Anonymisation Decision-Making Framework*, Mark Elliot, Elaine Mackey, Kieron O'Hara and Caroline Tudor, UKAN, University of Manchester, July 2016. http://ukanon.net/ukan-resources/ukan-decision-making-framework/

# **Reports and Books**

- *The Algorithmic Foundations of Differential Privacy*, Cynthia Dwork and Aaron Roth, (Foundations and Trends in Theoretical Computer Science). Now Publishers, August 11, 2014. https://www.cis.upenn.edu/~aaroth/privacybook.html
- Anonymizing Health Data, Khaled El Emam and Luk Arbuckle, O'Reilly, 2013.
- *Building an Anonymization Pipeline*, Luk Arbuckle and Khaled El Emam, O'Reilly, 2020.
- Confidentiality, Disclosure and Data Access: Theory and Practical Applications for Statistical Agencies, P. Doyle and J. Lane, North-Holland Publishing, Dec 31, 2001.
- *Guide to the De-Identification of Personal Health Information*, Khaled El Emam, CRC Press, 2013.
- Private Lives and Public Policies: Confidentiality and Accessibility of Government Statistics (1993), George T. Duncan, Thomas B. Jabine, and Virginia A. de Wolf, Editors; Panel on Confidentiality and Data Access; Commission on Behavioral and Social Sciences and Education; Division of Behavioral and Social Sciences and Education; National Research Council, 1993. https://dx.doi.org/10.17226/2122
- Sharing Clinical Trial Data: Maximizing Benefits, Minimizing Risk, Committee on Strategies for Responsible Sharing of Clinical Trial Data, Board on Health Sciences Policy, Institute of Medicine of the National Academies, The National Academies Press, Washington, DC. 2015.
- *Statistical Confidentiality: Principles and Practice*, George T. Duncan, Mark Elliot, Juan-José Salazar-Gonzalez, Springer, 2011.
- *Statistical Disclosure Control*, Anco Hundepool, Josep Domingo-Ferrer, Luisa Franconi, Sarah Giessing, Eric Schulte Nordholt, Keith Spicer, Peter-Paul de Wolf, Wiley, September 2012.
- Statistical Disclosure Control for Microdata: Methods and Applications in R, Matthias Templ, Springer, 2017.
- Statistical Disclosure Control for Microdata: A Practice Guide for sdcMicro, Thijs Benschop and Matthew Welch, The World Bank, 2019.

# **How-To Articles**

- Leah Krehling, De-Identification Guideline, WHISPERLAB, Technical Report WL-2020-01, Department of Electrical and Computer Engineering, Western University, 2020.
- Olivia Angiuli, Joe Blitstein, and Jim Waldo, How to De-Identify Your Data, Communications of the ACM, December 2015.
- Jörg Drechsler, Stefan Bender, Susanne Rässler, Comparing fully and partially synthetic datasets for statistical disclosure control in the German IAB Establishment Panel. 2007, United Nations, Economic Commission for Europe. Working paper, 11, New York, 8 p.
- Ebaa Fayyoumi and B. John Oommen, A survey on statistical disclosure control and micro-aggregation techniques for secure statistical databases. 2010, *Software Practice and Experience*. 40, 12 (November 2010), 1161-1188. DOI=10.1002/spe.v40:12 https://dx.doi.org/10.1002/spe.v40:12
- Jingchen Hu, Jerome P. Reiter, and Quanli Wang, Disclosure Risk Evaluation for Fully Synthetic Categorical Data, Privacy in Statistical Databases, pp. 185-199, 2014. https://link.springer.com/chapter/10.1007/978-3-319-11257-2\_15
- Matthias Templ, Bernhard Meindl, Alexander Kowarik and Shuang Chen, Introduction to Statistical Disclosure Control (SDC), IHSN Working Paper No. 007, International Household Survey Network, August 2014. http://www.ihsn.org/home/sites/ default/files/resources/ihsn-working-paper-007-Oct27.pdf
- Natalie Shlomo, Statistical Disclosure Control Methods for Census Frequency Tables, International Statistical Review (2007), 75, 2, 199-217. https://www.jstor.org/ stable/41508461

### Appendix B. List of Symbols, Abbreviations, and Acronyms

Selected acronyms and abbreviations used in this paper are defined below.

ACM Association for Computing Machinery

AHRQ Agency for Healthcare Research and Quality

AMD Advanced Micro Devices

ARM Advanced RISC Machines (formerly Acron RISC Machine)

**ARMP** Average Record Matching Probability

**ASTM** ASTM (formerly the American Society for Testing and Materials)

**CED-DA** Center for Enterprise Dissemination-Disclosure Avoidance

**CFR** Code of Federal Regulations

CIO Chief Information Officer

CIPSEA The Confidential Information Protection and Statistical Efficiency Act of 2002

**CNSS** Committee on National Security Systems

**CNSSI** Committee on National Security Systems Instruction

**CPU** Central Processing Unit

**CRC** (formerly the Chemical Rubber Company)

**DCMA** Defense Contract Management Agency

**DICOM** Digital Imaging and Communications in Medicine

**DOI** Digital Object Identifier

**DRB** Disclosure Review Board

**DUA** Data Use Agreement

EDDRB Department of Education Disclosure Review Board

FCSM Federal Committee on Statistical Methodology

**FHE** Fully-Homomorphic Encryption

FISMA Federal Information Security Modernization Act

FOIA Freedom of Information Act

- HHS Health and Human Services
- HIPAA Health Insurance Portability and Accountability Act
- **HITRUST** (formerly the Health Industry Trust Alliance)
- **IAB** Institut für Arbeitsmarkt-und Berufsforschung (Germany's Institute for Employment and Research)
- **ICSP** Interagency Council on Statistical Policy
- IEC International Electrotechnical Commission
- **IHE** Integrating the Healthcare Enterprise
- **IHSN** International Household Survey Network
- **IRB** Institutional Review Board
- **IRS** Internal Revenue Service
- **ISO** (formerly International Organization for Standardization)
- **ISO/TS** ISO Technical Standard
- ITL Information Technology Laboratory
- KIRP Known Inclusion Re-Identification Probability
- MCC Millennium Challenge Corporation
- MIT Massachusetts Institute of Technology
- MPC Multi-Party Computation
- NEMA National Electrical Manufacturers Association
- NIST National Institute of Standards and Technology
- NIST IR National Institute of Standards and Technology Interagency or Internal Report
- NIST SP National Institute of Standards and Technology Special Publication
- **OECD** Organisation for Economic Cooperation and Development
- **OHRP** Office for Human Research Protections
- **OMB** Office of Management and Budget
- **OPRE** Office of Planning, Research and Evaluation
- **PEC** Privacy-Enhancing Cryptography
- PHI Protected Health Information
- PII Personally Identifiable Information

NIST SP 800-188 September 2023

**PUF** Public Use File

**RMP** Record-Matching Probability

**SDC** Statistical Disclosure Control

**SDL** Statistical Disclosure Limitation

SHA Secure Hash Algorithm

SLA Service-Level Agreement

**SME** Subject-Matter Expert

**TEE** Trusted Execution Environments

**UIRP** Unknown Inclusion Re-Identification Probability

**UKAN** United Kingdom Advocacy Network

WHISPERLAB Western Information Security and Privacy Research Laboratory

### Appendix C. Glossary

Selected terms used in the publication are defined below. Where noted, the definition is sourced from another publication.

- **accuracy** Closeness of computations or estimates to the exact or true values that the statistics were intended to measure. (OECD Glossary)
- **ambiguity rule** See *p*,*q rule*.
- **anonymity** Condition in identification whereby an entity can be recognized as distinct, without sufficient identity information to establish a link to a known identity. (ISO/IEC 24760-1:2011)
- **anonymization** A process that removes the association between the identifying dataset and the data subject. (ISO 25237-2008)
- anticipated re-identification rate When an organization contemplates performing re-identification, the re-identification rate that the resulting de-identified data are likely to have.
- attacker A person who seeks to exploit potential vulnerabilities of a system.
- **attribute** Characteristic or property of an entity that can be used to describe its state, appearance, or other aspect. (ISO/IEC 24760-1:2011)[84]
- attribute disclosure Re-identification event in which an entity learns confidential information about a data principal, without necessarily identifying the data principal. (ISO/IEC 20889:2018)
- **brute force attack** In cryptography, an attack that involves trying all possible combinations to find a match.
- characteristic Distinguishing feature. (ISO 8000-2:2012(E))
- **coded** 1. Identifying information (such as name or social security number) that would enable the investigator to readily ascertain the identity of the individual to whom the private information or specimens pertain has been replaced with a number, letter, symbol, or combination thereof (i.e., the code); 2. A key to decipher the code exists, enabling linkage of the identifying information to the private information or specimens. [124]
- **confidentiality** Data confidentiality is a property of data, usually resulting from legislative measures, which prevents it from unauthorized disclosure. (OECD Glossary of Statistical Terms)

- **control** Measure that is modifying risk. Note: controls include any process, policy, device, practice, or other actions that modify risk. (ISO/IEC 27000:2014)
- **correct re-identifications** Putative re-identifications that correctly infer an individual's identity and associated data.
- **covered entity** Under HIPAA, a health plan, a health care clearinghouse, or a health care provider that conducts certain health care transactions electronically (e.g., billing). (HIPAA Privacy Rule)
- **data** Re-interpretable representation of information in a formalized manner suitable for communication, interpretation, or processing. (ISO 8000-2:2012(E))
- **data accuracy** Closeness of agreement between a property value and the true value. (ISO 8000-2:2012(E)
- **data dictionary** Collection of data dictionary entries that allows lookup by entity identifier. (ISO 8000-2:2012(E))
- **data dictionary entry** Description of an entity type containing, at a minimum, an unambiguous identifier, a term, and a definition. (ISO 8000-2:2012(E))
- **data intruder** A data user who attempts to disclose information about a population through identification or attribution. (OECD Glossary of Statistical Terms)
- **data life cycle** The set of processes in an application that transform raw data into actionable knowledge. (NIST SP 1500-1)
- data subjects Persons to whom data refer. (ISO/TS 25237:2008)
- **data use agreement** Executed agreement between a data provider and a data recipient that specifies the terms under which the data can be used.
- data universe All possible data within a specified domain.
- dataset A collection of data.
- **dataset with identifiers** A dataset that contains information that directly identifies individuals.
- dataset without identifiers A dataset that does not contain direct identifiers.
- **de-identification** A general term for any process of removing the association between a set of identifying data and the data subject.[85]
- **de-identification model** An approach to the application of data de-identification techniques that enables the calculation of re-identification risk. (ISO/IEC 20889:2018)
- **de-identification process** A general term for any process of removing the association between a set of identifying data and the data principal. (ISO/TS 25237:2008)

- **de-identified information** Records that have had enough PII removed or obscured such that the remaining information does not identify an individual, and there is no reasonable basis to believe that the information can be used to identify an individual.
- **differential privacy** A rigorous mathematical definition of disclosure that considers the risk that an individual's confidential data may be learned as a result of a mathematical analysis based on that data being made publicly available.
- **direct identifier** An attribute that alone enables unique identification of a data principal within a specific operational context.<sup>39</sup> (ISO/IEC 20889:2018)
- direct identifying data Data that directly identify a single individual. (ISO/TS 25237:2008)
- disclosure Divulging of, or provision of access to, data. (ISO/TS 25237:2008)
- **disclosure limitation** Statistical methods used to hinder anyone from identifying an individual respondent or establishment by analyzing published data, especially by manipulating mathematical and arithmetical relationships among the data. p. 21][160]
- **disassociability** Enabling the processing of PII or events without association to individuals or devices beyond the operational requirements of the system. (NISTIR 8062)
- **dominance rule** Synonym of the (n,k) rule. (OECD Glossary of Statistical Terms)
- effectiveness The extent to which planned activities are realized and planned results achieved. (ISO/IEC 27000:2014)
- entity An item inside or outside an information and communication technology system, such as a person, an organization, a device, a subsystem, or a group of such items that has recognizably distinct existence. (ISO/IEC 24760-1:2011)
- **expert determination** Within the context of de-identification, refers to the Expert Determination method for de-identifying protected health information in accordance with the HIPAA Privacy Rule de-identification standard.
- **Federal Committee on Statistical Methodology (FCSM)** An interagency committee dedicated to improving the quality of Federal statistics. The FCSM was created by the Office of Management and Budget (OMB) to inform and advise OMB and the Interagency Council on Statistical Policy (ICSP) on methodological and statistical issues that affect the quality of Federal data. (fscm.sites.usa.gov)
- **genomic information** Information based on an individual's genome, such as a sequence of DNA or the results of genetic testing.

<sup>&</sup>lt;sup>39</sup>Here and throughout, the operational context includes the information that the entity processing (e.g., deidentifying) the data possesses, together with information that third parties and potential attackers can possess or that is in the public domain (ISO/IEC 20889:2018).

- **harm** Any adverse effects that would be experienced by an individual (i.e., that may be socially, physically, or financially damaging) or an organization if the confidentiality of PII were breached.
- **Health Insurance Portability and Accountability Act of 1996 (HIPAA)** A federal statute that called on the federal Department of Health and Human Services to establish regulatory standards to protect the privacy and security of individually identifiable health information. See https://www.hhs.gov/hipaa/for-professionals/index.html.
- **HIPAA Privacy Rule** Establishes national standards to protect individuals' medical records and other personal health information and applies to health plans, health care clearinghouses, and those health care providers that conduct certain health care transactions electronically. (HIPAA Privacy Rule, 45 CFR 160, 162, 164). See https: //www.hhs.gov/hipaa/for-professionals/privacy/index.html.
- **identification** The process of using claimed or observed attributes of an entity to single out the entity among other entities in a set of identities. (ISO/TS 25237:2008)
- **identifier** Set of attributes in a dataset that enables unique identification of a data principal within a specific operational context. (ISO/TS 20889:2018)
- **identifying information** information that can be used to distinguish or trace an individual's identity, either alone or when combined with other information that is linked or linkable to a specific individual. (OMB M-17-12)
- **imputation** A procedure for entering a value for a specific data item where the response is missing or unusable. (OECD Glossary of Statistical Terms)
- **inference** Refers to the ability to deduce the identity of a person associated with a set of data through "clues" contained in that information. This analysis permits determination of the individual's identity based on a combination of facts associated with that person even though specific identifiers have been removed, like name and social security number. (ASTM E1869-04)[17]
- information Knowledge concerning objects, such as facts, events, things, processes, or ideas, including concepts, that within a certain context has a particular meaning. (ISO 8000-2:2012(E))
- **k-anonymity** A technique "to release person-specific data such that the ability to link to other information using the quasi-identifier is limited" [151]. The k-anonymity technique achieves this through suppression of identifiers and output perturbation, although recent work has shown that the k-anonymity mechanism can be reversed in some instances [32].
- **l-diversity** A refinement to the k-anonymity approach that assures that groups of records specified by the same identifiers have sufficient diversity to prevent inferential disclosure. [98]

- **masking** The process of systematically removing a field or replacing it with a value in a way that does not preserve the analytic utility of the value, such as replacing a phone number with asterisks or a randomly generated pseudonym. [59]
- **motivated intruder test** The 'motivated intruder' is taken to be a person who starts without any prior knowledge but who wishes to identify the individual from whose personal data the anonymised data have been derived. This test is meant to assess whether the motivated intruder would be successful. [81]
- (n,k) rule A cell is regarded as confidential, if the n largest units contribute more than k % to the cell total, e.g., n=2 and k=85 means that a cell is defined as risky if the two largest units contribute more than 85 % to the cell total. The n and k are given by the statistical authority. In some NSOs [national statistical office] the values of n and k are confidential. (OECD Glossary of Statistical Terms)
- **noise** A convenient term for a series of random disturbances borrowed through communication engineering, from the theory of sound. In communication theory, noise results in the possibility of a signal sent, x, being different from the signal received, y, and the latter has a probability distribution conditional upon x. If the disturbances consist of impulses at random intervals, it is sometimes known as "shot noise." (OECD Glossary of Statistical Terms)
- **noise addition** A de-identification technique that modifies a dataset by adding random values to the values of a selected attribute. (ISO/TS 20889:2018)
- noise infusion See noise addition.
- noise injection See noise addition.
- non-deterministic noise A random value that cannot be predicted.
- **non-ignorable bias** In the context of de-identification, a bias that results from the suppression or redaction of data based on the value of the suppressed data.
- **non-public personal information** Information about a person that is not publicly known; called "private information" in some other publications.
- **p,q rule** It is assumed that out of publicly available information the contribution of one individual to the cell total can be estimated to within q per cent (q=error before publication); after the publication of the statistic the value can be estimated to within p percent (p=error after publication). In the (p,q) rule the ratio p/q represents the information gain through publication. If the information gain is unacceptable, the cell is declared as confidential. The parameter values p and q are determined by the statistical authority and, thus, define the acceptable level of information gain. In some [National Statistical Organizations] the values of p and q are confidential. (OECD Glossary of Statistical Terms)

- **personal data** Any information relating to an identified or identifiable natural person (*data subject*). (ISO/TS 25237:2008)
- **personal identifier** Information with the purpose of uniquely identifying a person within a given context. (ISO/TS 25237:2008)
- personal information See personal data.
- **personally identifiable information (PII)** Information that can be used to distinguish or trace an individual's identity, either alone or when combined with other information that is linked or linkable to a specific individual. (A-130)
- **perturbation-based methods** Perturbation-based methods falsify the data before publication by introducing an element of error purposely for confidentiality reasons. This error can be inserted in the cell values after the table is created, which means the error is introduced to the output of the data and will, therefore, be referred to as output perturbation, or the error can be inserted in the original data on the microdata level, which is the input of the tables one wants to create; the method with then be referred to as data perturbation – input perturbation being the better but uncommonly used expression. Possible methods are: rounding; random perturbation; [and] disclosure control methods for microstatistics applied to macrostatistics. (OECD Glossary of Statistical Terms)
- **privacy** Freedom from intrusion into the private life or affairs of an individual when that intrusion results from undue or illegal gathering and use of data about that individual. (ISO/IEC 2382-8:1998, definition 08-01-23)
- **privacy loss** A measure of the extent to which a data release may reveal information that is specific to an individual.
- privacy loss budget An upper bound on the cumulative total privacy loss for individuals.
- **privacy risk** The likelihood that individuals will experience problems resulting from data processing, and the impact should they occur. (NIST Privacy Framework Version 1.0)
- **property value** Instance of a specific value together with an identifier for a data dictionary entry that defines a property. (ISO 8000-2:2012(E))
- protected health information (PHI) Individually identifiable health information: (1) Except as provided in paragraph (2) of this definition, that is: (i) Transmitted by electronic media; (ii) Maintained in electronic media; or (iii) Transmitted or maintained in any other form or medium. (2) *Protected health information* excludes individually identifiable health information in: (i) Education records covered by the Family Educational Rights and Privacy Act, as amended, 20 USC. 1232g; (ii) Records described at 20 USC. 1232g(a)(4)(B)(iv); and (iii) Employment records held by a

covered entity in its role as employer. (HIPAA Privacy Rule, 45 CFR 160.103). See https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html.

- **pseudonym** Personal identifier that is different from the normally used personal identifier. (ISO/TS 25237:2008)
- **pseudonymization** De-identification technique that replaces an identifier (or identifiers) for a data principal with a pseudonym in order to hide the identity of that data principal. (ISO/TS 20889:2018)
- putative re-identifications Apparent re-identifications that may or may not be correct.
- **quality** Degree to which a set of inherent characteristics fulfils requirements. (ISO 8000-2:2012(E))
- **quasi-identifier** A variable that can be used to identify an individual through association with another variable.
- **re-identification** A process by which information is attributed to de-identified data in order to identify the individual to whom the de-identified data relate. (OECD-LEGAL-0433)[117]
- **re-identification precision** The ratio of correct re-identifications to the sum of correct and incorrect apparent re-identifications.
- **re-identification probability** The probability that an individual's identity will be correctly inferred by an outside party using information contained in a de-identified dataset.
- re-identification rate The percentage of records in a dataset that can be re-identified.
- **re-identification risk** The likelihood that a third party can re-identify data subjects in a de-identified dataset.
- **recipient** Natural or legal person, public authority, agency, or any other body to whom data are disclosed. (ISO/TS 25237:2008)
- **redaction** The removal of information from a document or dataset for legal or security purposes.
- **requirement** A need or expectation that is stated, generally implied or obligatory. (ISO 8000-2:2012(E))
- **risk** A measure of the extent to which an entity is threatened by a potential circumstance or event, and typically a function of: (i) the adverse impacts that would arise if the circumstance or event occurs; and (ii) the likelihood of occurrence. (CNSSI No. 4009)
- **risk assessment** The process of identifying, estimating, and prioritizing risks to organizational operations (including mission, functions, image, reputation), organizational assets, individuals, other organizations, and the Nation, resulting from the operation

of an information system. Part of risk management, incorporates threat and vulnerability analyses, and considers mitigations provided by security controls planned or in place. Synonymous with risk analysis. (NIST SP 800-39)

- Safe Harbor Within the context of de-identification, refers to the Safe Harbor method for de-identifying protected health information in accordance with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule. See https://www.hhs.gov/hipaa/for-professionals/privacy/special-topics/de-identification/index.html.
- **statistical disclosure limitation (also statistical disclosure control)** The set of methods to reduce the risk of disclosing information on individuals, businesses or other organizations. Such methods are only related to the dissemination step and are usually based on restricting the amount of or modifying the data released. (OECD Glossary of Statistical Terms)
- suppression One of the most commonly used ways of protecting sensitive cells in a table is via suppression. It is obvious that in a row or column with a suppressed sensitive cell, at least one additional cell must be suppressed, or the value in the sensitive cell could be calculated exactly by subtraction from the marginal total. For this reason, certain other cells must also be suppressed. These are referred to as secondary suppressions. (OECD Glossary of Statistical Terms)
- **synthetic data generation** A process in which seed data are used to create artificial data that have some of the statistical characteristics of the seed data.
- **threshold rule** Usually, with the threshold rule, a cell in a table of frequencies is defined to be sensitive if the number of respondents is less than some specified number. Some agencies require at least five respondents in a cell, others require three. When thresholds are not respected, an agency may restructure tables and combine categories or use cell suppression, rounding or the confidentiality edit, or provide other additional protection in order to satisfy the rule. (OECD Glossary of Statistical Terms)
- validation model The synthetic data user is provided with some statistics computed directly on the confidential data using the same statistical formulas that were applied to the synthetic data.
- **verification model** The synthetic data user is provided with statistics that measure the similarity of the synthetic data result to the same output computed from the confidential data.