Responsible Data Science Applied Ethics (2)

April 28, 2025 **Lucas Rosenblatt**

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Center for Data Science



human subjects research



The Belmont Report



Belmont Report: Summary

THE BELMONT REPORT

Office of the Secretary

Ethical Principles and Guidelines for the Protection of Human Subjects of Research

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research

April 18, 1979

- Boundaries between research and practice
- Ethical principles Respect for Persons Beneficence Justice
- Applications



Boundaries between research & practice

 Research seeks generalizable knowledge, practice includes everyday treatment and activities

"For the most part, the term "practice" refers to interventions that are designed solely to enhance the wellbeing of an individual patient or client and that have a reasonable expectation of success. The purpose of medical or behavioral practice is to provide diagnosis, preventive treatment or therapy to particular individuals ... By contrast, the **term "research' designates an activity designed to test an hypothesis**, permit conclusions to be drawn, and thereby to develop or contribute to generalizable knowledge (expressed, for example, in theories, principles, and statements of relationships). Research is usually described in a formal protocol that sets forth an objective and a set of procedures designed to reach that objective."

• Argues that ethical principles of Belmont Report apply only to research



Principles: Autonomy / Respect for Persons

Individuals should be treated as autonomous agents

"To **respect autonomy** is to give weight to autonomous persons' considered opinions and choices while refraining from obstructing their actions unless they are clearly detrimental to others. To show lack of respect for an autonomous agent is to repudiate that person's considered judgments, to deny an individual the freedom to act on those considered judgments, or to **withhold information necessary to make a considered judgment**, when there are no compelling reasons to do so. "



Principles: Autonomy / Respect for Persons

Persons with diminished autonomy are entitled to protection

"In some situations, however, application of the principle is not obvious. The involvement of prisoners as subjects of research provides an instructive example. On the one hand, it would seem that the principle of respect for persons requires that prisoners not be deprived of the opportunity to volunteer for research. On the other hand, under prison conditions they may be subtly coerced or unduly influenced to engage in research activities for which they would not otherwise volunteer. Respect for persons would then dictate that prisoners be protected. Whether to allow prisoners to "volunteer" or to "protect" them presents a dilemma. **Respecting persons, in most hard cases, is often a matter of balancing competing claims urged by the principle of respect itself.** "



Principles: Beneficence

Do not harm

Maximize possible benefits and minimize possible harm

"The Hippocratic maxim "do no harm" has long been a fundamental principle of medical ethics. **Claude Bernard extended it to the realm of research, saying that one should not injure one person regardless of the benefits that might come to others.** However, even avoiding harm requires learning what is harmful; and, in the process of obtaining this information, persons may be exposed to risk of harm. Further, the Hippocratic Oath requires physicians to benefit their patients "according to their best judgment." **Learning what will in fact benefit may require exposing persons to risk.** The problem posed by these imperatives is to decide when it is justifiable to seek certain benefits despite the risks involved, and when the benefits should be foregone because of the risks."

Principles: Justice

Who ought to receive the benefits of research and bear its burdens?

"Questions of justice have long been associated with social practices such as punishment, taxation and political representation. Until recently these questions have not generally been associated with scientific research. However, they are foreshadowed even in the earliest reflections on the ethics of research involving human subjects. For example, during the 19th and early 20th centuries the **burdens of serving as research subjects fell largely upon poor ward patients, while the benefits of improved medical care flowed primarily to private patients.**..."

Principles: Justice

Who ought to receive the benefits of research and bear its burdens?

".... Subsequently, the exploitation of unwilling prisoners as research subjects in Nazi concentration camps was condemned as a particularly flagrant injustice. In this country, in the 1940's, the **Tuskegee syphilis study** used disadvantaged, rural black men to study the untreated course of a disease that is by no means confined to that population. These subjects were deprived of demonstrably effective treatment in order not to interrupt the project, long after such treatment became generally available. "

Applications: Informed Consent

"Respect for persons requires that subjects, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them. This opportunity is provided when adequate standards for informed consent are satisfied.

While the importance of informed consent is unquestioned, **controversy prevails over the nature and possibility** of an informed consent. Nonetheless, there is widespread agreement that **the consent process can be analyzed as containing three elements: information, comprehension and voluntariness.** ..."

Applications: Informed Consent

Information, Comprehension, Voluntariness

"Most codes of research establish specific items for disclosure intended to assure that subjects are given sufficient information. These items generally include: the research procedure, their purposes, risks and anticipated benefits, alternative procedures (where therapy is involved), and a statement offering the subject the opportunity to ask questions and to withdraw at any time from the research.

... A special problem of consent arises where informing subjects of some pertinent aspect of the research is likely to impair the validity of the research. ... In all cases of research involving incomplete disclosure, such research is justified only if it is clear that (1) incomplete disclosure is truly necessary to accomplish the goals of the research, (2) there are no undisclosed risks to subjects that are more than minimal, and (3) there is an adequate plan for debriefing subjects, when appropriate, and for dissemination of research results to them. "

Applications: Informed Consent

Information, Comprehension, Voluntariness

"The manner and context in which information is conveyed is as important as the information itself. For example, **presenting information in a disorganized and rapid fashion, allowing too little time for consideration or curtailing opportunities for questioning, all may adversely affect a subject's ability to make an informed choice.**

Because the subject's ability to understand is a function of intelligence, rationality, maturity and language, it is **necessary to adapt the presentation of the information to the subject's capacities**. Investigators are responsible for ascertaining that the subject has comprehended the information. "

Recall: Racial bias in resume screening

Are Emily and Greg More Employable Than Lakisha and Jamal? A Field Experiment on Labor Market Discrimination

September 2004

Marianne Bertrand

Sendhil Mullainathan

AMERICAN ECONOMIC REVIEW VOL. 94, NO. 4, SEPTEMBER 2004 (pp. 991-1013)

We study race in the labor market by sending fictitious resumes to help-wanted ads in Boston and Chicago

newspapers. To manipulate perceived race, resumes are randomly assigned African-American- or White-sounding names.

White names receive 50 percent more callbacks for

interviews. Callbacks are also more responsive to resume quality for White names than for African-American ones. The racial gap is uniform across occupation, industry, and employer size. We also find little evidence that employers are inferring social class from the names. Differential treatment by race still appears to still be prominent in the U. S. labor market.

Back to Informed Consent

Research question: Does an employer unlawfully discriminate against applicants based on membership in protected groups?

Employers don't provide consent, in fact, they are actively deceived!

Field experiments to study discrimination are legally permissible if:

- 1. the harm to employers is limited, and
- 2. there is great social benefit to having a reliable measure of discrimination, **and**
- 3.other methods of measuring discrimination are weak; and
- 4. deception does not strongly violate the norms of that setting.

Assessment of risks and benefits

"Risks and benefits of research may affect the **individual subjects**, the **families** of the individual subjects, and **society** at large (or special groups of subjects in society).

In balancing these different elements, the **risks and benefits affecting the immediate research subject** will normally carry special weight.

Beneficence thus requires that we protect against risk of harm to subjects and also that we be concerned about the loss of the substantial benefits that might be gained from research. "

Selection of subjects

Just as the principle of **respect for persons** finds expression in the requirements for consent, and the principle of **beneficence** in risk/benefit assessment, the principle of **justice** gives rise to moral requirements that there be fair procedures and outcomes in the selection of research subjects.

- **Individual justice** in the selection of subjects would require that researchers exhibit fairness: thus, they should not offer potentially beneficial research only to some patients who are in their favor or select only "undesirable" persons for risky research.
- Social justice requires that distinction be drawn between classes of subjects that ought, and ought not, to participate in any particular kind of research, based on the ability of members of that class to bear burdens and on the appropriateness of placing further burdens on already burdened persons.

The Menlo Report



The Menlo Report: Summary

The Menlo Report

Ethical Principles Guiding Information and Communication Technology Research

August 2012

... the Menlo Report calls on researchers to **move beyond the narrow definition of "research involving human subjects" from the Belmont Report** to a more general notion of "research with human-harming potential."

A principles-based approach means that **researchers should not hide behind a narrow, legal definition of "research involving human subjects**," even if IRBs allow it. Rather, they should adopt a more general notion of "research with human-harming potential" and they should subject all of their own research with human-harming potential to ethical consideration.

The Menlo Report: Summary

Principle	Application
Respect for Persons	Participation as a research subject is voluntary, and follows from informed consent; Treat individuals as autonomous agents and respect their right to determine their own best interests; Respect individuals who are not targets of research yet are impacted; Individuals with diminished autonomy, who are incapable of deciding for themselves, are entitled to protection.
Beneficence	Do not harm; Maximize probable benefits and minimize probable harms; Systematically assess both risk of harm and benefit.
Justice	Each person deserves equal consideration in how to be treated, and the benefits of research should be fairly distributed according to individual need, effort, societal contribution, and merit; Selection of subjects should be fair, and burdens should be allocated equitably across impacted subjects.
Respect for Law and Public Interest	Engage in legal due diligence; Be transparent in methods and results; Be accountable for actions.

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Respect for law and public interest

- Implicit in the Belmont Reports' application of Beneficence, but deserves explicit consideration
- In Information and Communication Technology Research (ICTR), included as a separate principle with two applications - *Compliance* and *Transparency and Accountability*

"The second application refers to **transparency of methodologies and results**, and accountability for actions. Transparency and accountability serve vital roles in many ICTR contexts where it is challenging or impossible to identify stakeholders (e.g., attribution of sources and intermediaries of information), to understand interactions between highly dynamic and globally distributed systems and technologies, and consequently to **balance associated harms and benefits**. A lack of transparency and accountability risks undermining the credibility of, trust and confidence in, and ultimately support for, ICT research."

Respect for law and public interest

- Implicit in the Belmont Reports' application of Beneficence, but deserves explicit consideration
- In Information and Communication Technology Research (ICTR), included as a separate principle with two applications - *Compliance* and *Transparency and Accountability*

"Accountability demands that research methodology, ethical evaluations, data collected, and results generated should be documented and made available responsibly in accordance with balancing risks and benefits. Data should be available for legitimate research, policy-making, or public knowledge, subject to appropriate collection, use, and disclosure controls informed by the Beneficence principle. The appropriate format, scope and modality of the data exposure will vary with the circumstances, as informed by Beneficence determinations."

case studies



Reminder: ethical frameworks

Deontologists focus on *means*, consequentialists focus on *ends*

Transplant: A doctor has five patients dying of organ failure and one healthy patient whose organs can save all five. A **consequentialist doctor is required to kill** the healthy patient to obtain his organs. This complete focus on ends, without regard to means, is flawed.

NB: putting a price on human life

NB: reasoning under uncertainty

Time bomb: A police office captured a terrorist who knows the location of a ticking time bomb that will kill millions of individuals if it detonates. A **deontological police officer would not lie** to trick a terrorist into revealing the location of the bomb. This complete focus on means, without regards to ends, also is flawed.

https://www.bitbybitbook.com/en/1st-ed/ethics/

Case study prompts

Deontologists focus on *means*, consequentialists focus on *ends*

- Give a consequentialist and a deontological interpretation of these case studies
- Explain the role of respect for persons, beneficence, and justice for each case study
- Discuss whether informed consent is required and how you would design it

https://www.bitbybitbook.com/en/1st-ed/ethics/

Case study: Emotional contagion

Experimental evidence of massive-scale emotional contagion through social networks



Proceedings of the National Academy of Sciences of the United States of America

Adam D. I. Kramer, Jamie E. Guillory, and Jeffrey T. Hancock

PNAS June 17, 2014 111 (24) 8788-8790; first published June 2, 2014 https://doi.org/10.1073/pnas.1320040111

Edited by Susan T. Fiske, Princeton University, Princeton, NJ, and approved March 25, 2014 (received for review October 23, 2013)

Significance

We show, via a massive (N = 689,003) experiment on Facebook, that emotional states can be transferred to others via emotional contagion, leading people to experience the same emotions without their awareness. We provide experimental evidence that emotional contagion occurs without direct interaction between people (exposure to a friend expressing an emotion is sufficient), and in the complete absence of nonverbal cues.



Case study: Emotional contagion

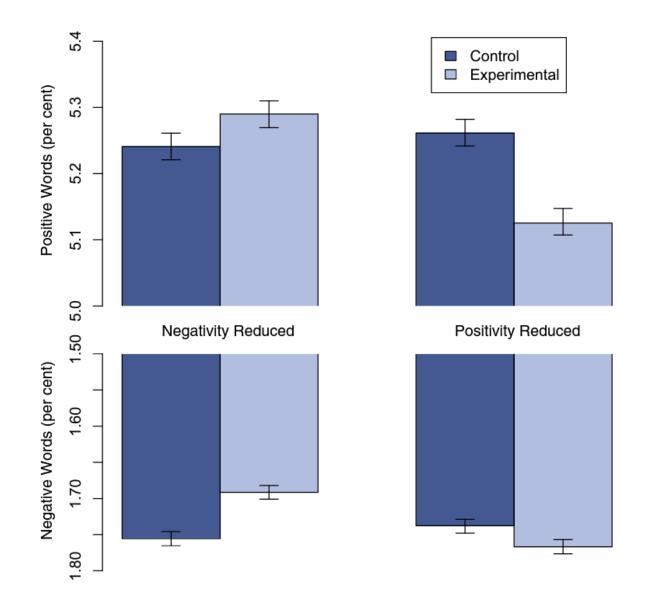


Fig. 1. Mean number of positive (*Upper*) and negative (*Lower*) emotion words (percent) generated people, by condition. Bars represent standard errors.



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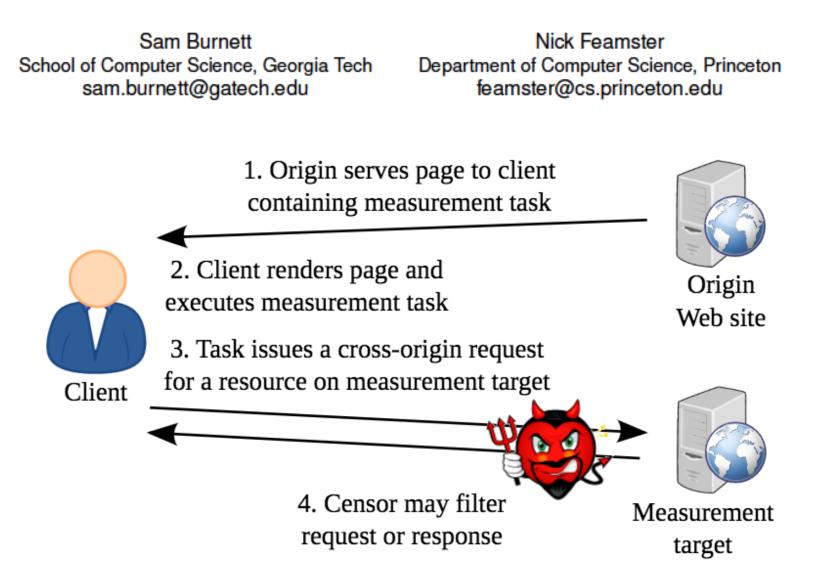
Case study: Emotional contagion

- **Criticism** in the research community, in the press
 - users were not consented to participate in the study
 - there was no third-party review of study design -Facebook did not even have an IRB at the time
- Result
 - PNAS placed a disclaimer on the article
 - Facebook instituted an internal ethics review board

Did Facebook stop running these types of experiments?

Case study: Encore

Encore: Lightweight Measurement of Web Censorship with Cross-Origin Requests



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Case study: Encore

Encore: Lightweight Measurement of ACM SIGCOMM 2015 Web Censorship with Cross-Origin Requests

Sam Burnett School of Computer Science, Georgia Tech sam.burnett@gatech.edu Nick Feamster Department of Computer Science, Princeton feamster@cs.princeton.edu

"...We present Encore, a system that harnesses cross-origin requests to **measure Web filtering** from a diverse set of vantage points without requiring users to install custom software, enabling longitudinal measurements from many vantage points. We explain how Encore **induces Web clients to perform cross-origin requests** that measure Web filtering, design a distributed platform for scheduling and collecting these measurements, show the feasibility of a global-scale deployment with a pilot study and an **analysis of potentially censored Web content**, identify several cases of filtering in six months of measurements, and **discuss ethical concerns** that would arise with widespread deployment."

Case study: Encore

Encore: Lightweight Measurement of ACM SIGCOMM 2015 Web Censorship with Cross-Origin Requests

Sam Burnett School of Computer Science, Georgia Tech sam.burnett@gatech.edu Nick Feamster Department of Computer Science, Princeton feamster@cs.princeton.edu

Statement from the SIGCOMM 2015 Program Committee: The SIGCOMM 2015 PC appreciated the technical contributions made in this paper, but found the paper controversial because some of the experiments the authors conducted raise ethical concerns. The controversy arose in large part because the networking research community does not yet have widely accepted guidelines or rules for the ethics of experiments that measure online censorship. In accordance with the published submission guidelines for SIGCOMM 2015, had the authors not engaged with their Institutional Review Boards (IRBs) or had their IRBs determined that their research was unethical, the PC would have rejected the paper without review. But the authors did engage with their IRBs, which did not flag the research as unethical. The PC hopes that discussion of the ethical concerns these experiments raise will advance the development of ethical guidelines in this area. It is the PC's view that future guidelines should include as a core principle that researchers should not engage in experiments that subject users to an appreciable risk of substantial harm absent informed consent. The PC endorses neither the use of the experimental techniques this paper describes nor the experiments the authors conducted.

Case study: 2014 Ebola outbreak



- Public health officials wanted information about the mobility of people in the most heavily infected countries in order to help control the outbreak
- Mobile phone companies had detailed call records that could have provided some of this information
- Yet ethical and legal concerns bogged down researchers' attempts to analyze the data

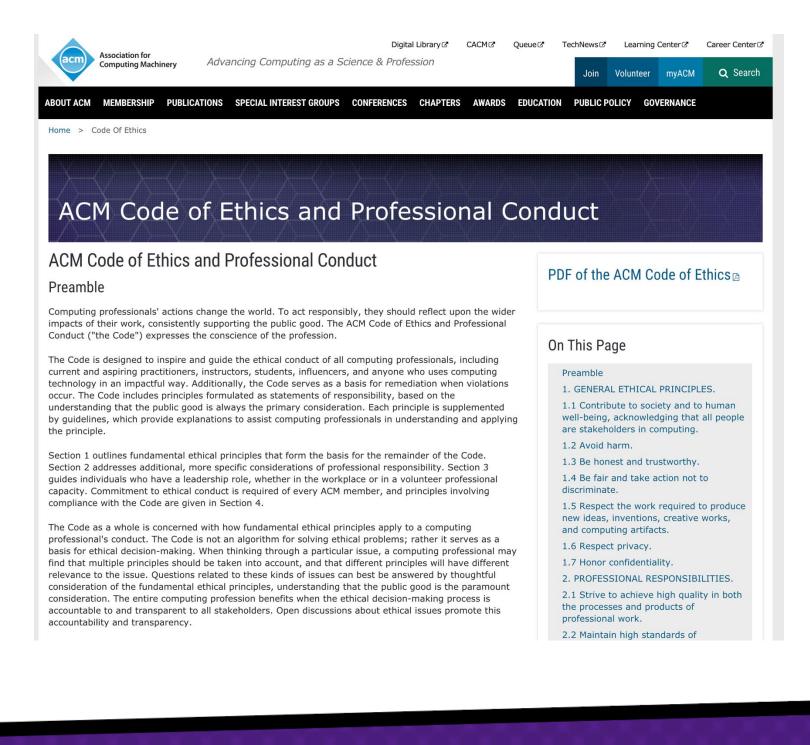
If we, as a community, can develop ethical norms and standards that are shared by th researchers and the public—and I think we can do this—then we can harness the capabilities of the digital age in ways that are responsible and beneficial to society.

https://www.bitbybitbook.com/en/1st-ed/ethics/

professional responsibility



The ACM Code of Ethics



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tps://www.acm.org/binaries/content/assets/about/acm-code-of-ethics-bool

The ACM Code of Ethics

General ethical principles

- Contribute to society and to human well-being, acknowledging that all people are stakeholders in computing
- Avoid harm
- Be honest and trustworthy
- Be fair and take action not to discriminate
- Respect the work required to produce new ideas, inventions, creative works, and computing artifacts
- Respect privacy
- Honor confidentiality

Personal responsibility?

NATURE | NEWS

Italian seismologists cleared of manslaughter

Appeals court says six scientists did not cause deaths in 2009 L'Aquila earthquake and cuts sentence of a government official.

Alison Abbott & Nicola Nosengo

10 November 2014

 International weekly journal of science

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Six seismologists accused of misleading the public about the risk of an earthquake in Italy were cleared of manslaughter on 10 November. An appeals court overturned their six-year prison sentences and reduced to two years the sentence for a government official who had been convicted with them.

The magnitude-6.3 earthquake struck the historic town of L'Aquila in the early hours of 6 April 2009, killing more than 300 people.



Personal responsibility?

NATURE | NEWS

Italian seismologists cleared of manslaughter

Appeals court says six scientists did not cause deaths in 2009 L'Aquila earthquake and cuts sentence of a government official.

Alison Abbott & Nicola Nosengo

10 November 2014

The finding by a three-judge appeals court prompted many L'Aquila citizens who were waiting outside the courtroom to react with rage, shouting "shame" and saying that the Italian state had just acquitted itself, local media reported. But it **comes as a relief to scientists around the world who had been following the unprecedented case with alarm**.

"We don't want to have to be worried about the possibility of being prosecuted if we give advice on earthquakes," says seismologist Ian Main of the University of Edinburgh, UK. "That would discourage giving honest opinion."

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laws & regulation



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GDPR		
Chapter 1 (Art. 1 – 4) General provisions	~	General Data Protection Regulation
Chapter 2 (Art. 5 – 11) Principles	~	GDPR
Chapter 3 (Art. 12 – 23) Rights of the data subject	~	Welcome to gdpr-info.eu. Here you can find the official PDF of the Regulation (EU) 2016/679
Chapter 4 (Art. 24 – 43) Controller and processor	~	(General Data Protection Regulation) in the current version of the OJ L 119, 04.05.2016; cor. OJ L 127, 23.5.2018 as a neatly arranged website. All Articles of the GDPR are linked with suitable
Chapter 5 (Art. 44 – 50) Transfers of personal data to third countries or international organisations	~	recitals. The European Data Protection Regulation is applicable as of May 25th, 2018 in all member states to harmonize data privacy laws across Europe. If you find the page useful, feel
Chapter 6 (Art. 51 – 59) ndependent supervisory authorities	~	free to support us by sharing the project.
Chapter 7 (Art. 60 – 76)	*	Quick Access
Chapter 8 (Art. 77 – 84) Remedies, liability and penalties	~	Chapter 1 - 1 2 3 4
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GDPR: scope and definitions

Article 2: Material Scope

- This Regulation applies to the processing of personal data wholly or partly by automated means and to the processing other than by automated means of personal data which form part of a filing system or are intended to form part of a filing system.
 Article 4: Definitions
 - **'personal data**' means any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person;
 - **'processing'** means any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction;

GDPR: scope and definitions

Article 4: Definitions

- 'controller' means the natural or legal person, public authority, agency or other body which, alone or jointly with others, determines the purposes and means of the processing of personal data; where the purposes and means of such processing are determined by Union or Member State law, the controller or the specific criteria for its nomination may be provided for by Union or Member State law;
- **'processor'** means a natural or legal person, public authority, agency or other body which processes personal data on behalf of the controller;
- 'consent' of the data subject means any freely given, specific, informed and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her;

GDPR: informed consent

Art. 7 GDPR Conditions for consent

- Where processing is based on consent, the controller shall be able to demonstrate that the data subject has consented to processing of his or her personal data.
- 2. ¹ If the data subject's consent is given in the context of a written declaration which also concerns other matters, the request for consent shall be presented in a manner which is clearly distinguishable from the other matters, in an intelligible and easily accessible form, using clear and plain language. ² Any part of such a declaration which constitutes an infringement of this Regulation shall not be binding.



GDPR: informed consent

- 3. ¹ The data subject shall have the right to withdraw his or her consent at any time. ² The withdrawal of consent shall not affect the lawfulness of processing based on consent before its withdrawal. ³ Prior to giving consent, the data subject shall be informed thereof. ⁴ It shall be as easy to withdraw as to give consent.
- 4. When assessing whether consent is freely given, utmost account shall be taken of whether, *inter alia*, the performance of a contract, including the provision of a service, is conditional on consent to the processing of personal data that is not necessary for the performance of that contract.

Chapter 3 **Rights of the data subject**

Section 1	-	Transparency and modalities
Article 12	_	Transparent information, communication and modalities for the exercise of the rights of the data subject
Section 2	_	Information and access to personal data
Article 13	-	Information to be provided where personal data are collected from the data subject
Article 14	_	Information to be provided where personal data have not been obtained from the data subject
Article 15	_	Right of access by the data subject

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Chapter 3 **Rights of the data subject**

Section 3	-	Rectification and erasure
Article 16	_	Right to rectification
Article 17	_	Right to erasure ('right to be forgotten')
Article 18	_	Right to restriction of processing
Article 19	-	Notification obligation regarding rectification or erasure of personal data or restriction of processing
Article 20	_	Right to data portability
Section 4	_	Right to object and automated individual decision-making
Article 21	_	Right to object
Article 22	_	Automated individual decision-making, including profiling

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Recital 58 The principle of transparency*

¹ The principle of transparency requires that any information addressed to the public or to the data subject be concise, easily accessible and easy to understand, and that clear and plain language and, additionally, where appropriate, visualisation be used. ² Such information could be provided in electronic form, for example, when addressed to the public, through a website. ³ This is of particular relevance in situations where the proliferation of actors and the technological complexity of practice make it difficult for the data subject to know and understand whether, by whom and for what purpose personal data relating to him or her are being collected, such as in the case of online advertising. ⁴ Given that children merit specific protection, any information and communication, where processing is addressed to a child, should be in such a clear and plain language that the child can easily understand.

Technical challenges

Transparency, Fairness, Data Protection, Neutrality: Data Management Challenges in the Face of New Regulation

SERGE ABITEBOUL, Inria & Ecole Normale Supérieure, France JULIA STOYANOVICH, New York University, USA

- Legal frameworks: the EU's General Data Protection Regulation (GDPR), the New York City Automated Decision Systems (ADS) law, the Indian Net Neutrality Regulatory Framework
- Common threads:
- data subject's **informed consent** to data collection and processing
- right to an **explanation** of decision-making processes and results
- data rights: correction, deletion, portability of personal data



that's all, folks!



Exam review



Format (approximate)

- There will be ~4 questions, and each question will have multiple parts.
- The exam is designed to take around 60-75 minutes to complete. We may give you more time.
- There will be no "trick" questions: exam questions will feel like slightly easier written HW questions.

Format (exact)

- You will be allowed to have the lecture notes, either on your laptop or printed out.
- You may use your laptops to search through notes / slides if you wish.
- We will ask that you turn off your WIFI during the exam, and we will walk around and monitor your laptop use.
- You are NOT allowed to use an LLM (even a locally hosted one) to help with writing / reasoning on the exam. If we find you attempting to do this, you will immediately receive a 0 on the exam.

Best ways to prepare

- The best way to prepare for the exam is to review lecture slides and HW problems!
- As you will have access to the lecture slides, don't worry about memorizing anything...
- Instead, focus on being able to reason about the content, and apply the techniques / logic to similar situations.



fairness

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Some slides to be sure you know

Falaah will go over in lab:

- Slides 14-32 in <u>Lecture 2</u>
- Slides 16-25 in <u>Lecture 3</u>



ML pipelines



Some slides to be sure you know

Falaah will go over in lab:

- Slides 39-47 in Lecture 5/6
- Slides 56-65



interpretability

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Slide review

- <u>https://dataresponsibly.github.io/rds25/assets/lecture_7_interpretability.p</u>
 <u>df</u>
- <u>https://dataresponsibly.github.io/rds25/assets/lecture_8_2025.pdf</u>



privacy

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Slide review

- <u>https://dataresponsibly.github.io/rds25/assets/lecture_10_spring_2025.p</u>
 <u>df</u>
- <u>https://dataresponsibly.github.io/rds25/assets/lecture_11_privacy.pdf</u>



Responsible Data Science

Anonymity and privacy

Thank you!





Center for Data Science

