



# An introduction to data ethics

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# Sources of inspiration

- ▶ Coursera MOOC from the University of Geneva (2018): *Le Bien, le Juste, l'Utile. Introduction aux éthiques philosophiques*
- ▶ edX MOOC from the University of Michigan (2018): *Data Science Ethics*
- ▶ *Ethical IT Innovation* (2016). S. Spiekermann. CRC Press.
- ▶ *L'éthique aux interfaces entre biologie/santé et sciences de l'information* (2016). H. Chneiweiss. (with his approval)
- ▶ *L'éthique appliquée* (2010). M. Marzano. PUF
- ▶ Wikipedia

## Motivation and Goal

A Question of Time

"All your data are belong to us"

This is NOT a checklist

To finish

# Why should you care?

- ▶ because you are a citizen
- ▶ because ethical products sell better [Spiekermann, 2015]
- ▶ because if you don't as data scientists, others with less knowledge will

# What this course will (hopefully) bring you

No ready-made solution

BUT

tools to think by yourself

# Your work

A wide range of topics

- ▶ Self-driving car (EN) → traceability, passive vigilance
- ▶ Chatbot Tay (EN) → ML in the wild
- ▶ YouTube (EN) → algorithm transparency, bias
- ▶ Social credit in China (EN) → consent, privacy
- ▶ Vocal assistants (EN) → gender bias
- ▶ Automatic sentencing (EN) → racial bias
- ▶ Wearables (EN) → consent, privacy

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Who's dealing with it?

Is (techno)Science Necessarily Good?

(some) Turning Points in the XXth century

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# A very old question (the oldest?) in a brave new world



From Lysippe — Eric Gaba (User:Sting),  
July 2005., CC BY-SA 2.5

Ethics is a domain from...



What discipline/domain thinks a lot about ethics?



## (some) French institutions dealing with ethics

- ▶ **CNIL**: Commission Nationale de l'Informatique et des Libertés
- ▶ **CCNE**: Comité consultatif national d'éthique
- ▶ **CERNA**: Commission de réflexion sur l'éthique de la recherche en sciences et technologies du numérique d'Allistene
- ▶ **COMETS**: Comité d'éthique du CNRS
- ▶ **CEI**: Comité d'éthique de l'Inserm
- ▶ **COERLE**: Comité opérationnel d'évaluation des risques légaux et éthiques

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Is (the outcome of) science necessarily good?

Are there things that are possible to do that we agree we should not?



(c) <https://www.starwars.com/databank/clone-troopers>

Is (the way we do) science necessarily good?

Are there things that are possible to do that we agree we should not?



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# The Nuremberg Code

originated before, but finalized during "the Doctors' Trial" (1947)



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10 main principles, including:

- ▶ Respect of the subject:
  - ▶ informed consent
  - ▶ freedom to quit the experiment
- ▶ Beneficence:
  - ▶ favorable risks/benefits balance
- ▶ Justice:
  - ▶ positive results for society

# The Belmont Report [Bel, 1979]

originated from "Tuskegee Syphilis Experiment" (1932-1972)



By National Archives Atlanta, GA

# The Belmont Report [Bel, 1979]

originated from "Tuskegee Syphilis Experiment" (1932-1972)



The report includes 3 main principles:

- ▶ Respect of the subject:
  - ▶ informed consent
- ▶ Beneficence:
  - ▶ favorable risks/benefits balance
- ▶ Justice:
  - ▶ fair selection of the subjects

**Tableau 1. Bref historique des textes fondateurs de l'éthique et exemples des raisons de leur rédaction**

Codes éthiques fondateurs	Code de Nuremberg (traduction française in <sup>27</sup> )	Déclaration d'Helsinki	Rapport Belmont
Quand, où ?	1947, Etats-Unis	1964, Finlande (dernière révision de 2000)	1978, Etats-Unis
Qui ?	Juges du Tribunal militaire américain de Nuremberg	Association médicale mondiale (AMM)	Commission nationale américaine pour la protection des sujets humains dans la recherche biomédicale et comportementale
Pourquoi ? Précisions	<ul style="list-style-type: none"> <li>• Expériences des médecins nazis sur des prisonniers en camp de concentration</li> <li>• Trois officiels nazis et vingt médecins impliqués, dont :               <ul style="list-style-type: none"> <li>– Heinrich Himmler : mécène et directeur de la médecine nazie, parfois surnommé « le meurtrier du Siècle ». Met en œuvre la solution finale</li> <li>– Josef Mengele : tortures, sévices corporels lors d'expériences médicales absurdes et inhumaines entraînant souvent la mort, à Auschwitz</li> <li>– Aribert Heim : vivisection humaine sur les détenus de Mauthausen</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Fait suite aux atrocités de la Seconde Guerre mondiale</li> <li>• AMM : association internationale de médecins (fondée en 1947 à Paris) dont le but humanitaire est de mettre en place les normes les plus rigoureuses dans le domaine de la médecine, l'éthique et l'enseignement médical</li> </ul>	<ul style="list-style-type: none"> <li>• Création le 12 juillet 1974 du National research act (Loi publique 93348 sur la recherche)</li> <li>• Tuskegee : expériences sur la syphilis (1932-1972, Etats-Unis) : ouvriers agricoles noirs et pauvres, non traités par les médecins (diagnostic donné : « mauvais sang ») pour observer l'évolution de la maladie, et ce même après l'efficacité avérée du traitement à la pénicilline. L'expérience cesse en 1972, lorsque le Washington Star<sup>28</sup> révèle l'affaire. N'a jamais donné de résultats concluants</li> <li>• Willowbrook : étude sur l'hépatite (1950-1960, Etats-Unis) : virus délibérément inoculé à des enfants placés en établissements psychiatriques. Selon le formulaire de consentement signé par les parents, est administré un vaccin et non le virus. Justification d'alors : ces enfants seraient infectés de toute manière ; en participant à l'étude, ils seraient mieux soignés.</li> </ul>
Principes généraux	<ul style="list-style-type: none"> <li>• Bienfaisance : rapport risque/ bénéfice favorable</li> <li>• Respect du sujet de recherche : consentement volontaire, capacité de consentir, possibilité de quitter l'essai</li> <li>• Justice : utilité pour la société</li> </ul>	<ul style="list-style-type: none"> <li>• Bienfaisance : rapport risque/ bénéfice favorable</li> <li>• Respect du sujet de recherche : consentement informé</li> <li>• Justice : distinction entre recherche thérapeutique ou non</li> <li>• Responsabilité : pas uniquement au chercheur, avis extérieur nécessaire (comité d'éthique)</li> </ul>	<ul style="list-style-type: none"> <li>• Bienfaisance : rapport risque/bénéfice favorable (distinction entre risques « minimes » et risques « plus que minimes »)</li> <li>• Respect du sujet de recherche : consentement éclairé</li> <li>• Justice : sélection équitable des sujets</li> </ul>
Forme	Dix principes fondamentaux	Loi consensuelle, nombreux paragraphes	Paragraphes agencés en trois catégories éthiques et applications

Motivation and Goal

A Question of Time

"All your data are belong to us"

Definitions

Data vs data

What Happens to Data?

Back to Consent

This is NOT a checklist

To finish

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# Ethics?





soft law

SINCE 1828

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ethics

DICTIONARY | THESAURUS

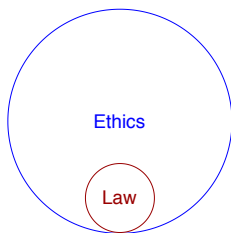


## Definition of ETHIC

- ethics** *plural in form but singular or plural in construction* : the discipline dealing with what is good and bad and with moral duty and obligation
- a** : a set of moral principles : a theory or system of moral values • the present-day materialistic *ethic* • an old-fashioned work *ethic* —often used in plural but singular or plural in construction • an elaborate *ethics* • Christian *ethics*  
**b** *ethics plural in form but singular or plural in construction* : the principles of conduct governing an individual or a group • professional *ethics*  
**c** : a guiding philosophy  
**d** : a consciousness of moral importance • forge a conservation *ethic*
- ethics** *plural* : a set of moral issues or aspects (such as rightness) • debated the *ethics* of human cloning

<https://www.merriam-webster.com/dictionary/ethics>

# Ethics is not law



**Law:** sets minimum standards (rules and regulations)

VS

**Ethics:** sets maximum standards (guidelines)

# What do you know about ethics?

- ▶ well-known ethical issues?
- ▶ ethical institutions?
- ▶ famous thinkers?
- ▶ well-known texts/documents about ethics? turning points?



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WORD OF THE DAY

VIDEO

W

data

DICTIONARY

THESAURUS

# data

noun, plural in form but singular or plural in construction, often attributive

da·ta | \ 'dā-tə,  'da- also 'dä-  \

## Definition of *data*

- 1 : factual information (such as measurements or statistics) used as a basis for reasoning, discussion, or calculation

// the *data* is plentiful and easily available

— H. A. Gleason, Jr.

// comprehensive *data* on economic growth have been published

— N. H. Jacoby

- 2 : information in digital form that can be transmitted or processed
- 3 : information output by a sensing device or organ that includes both useful and irrelevant or redundant information and must be processed to be meaningful

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## Art. 4 GDPR Definitions

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For the purposes of this Regulation:

- (1) '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;

<https://gdpr-info.eu/art-4-gdpr/>

# Sensitive Data

specifically protected ?

Art. 9 GDPR

## Processing of special categories of personal data

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1. Processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation shall be prohibited.

<https://gdpr-info.eu/art-9-gdpr/>

# Sensitive Data: exceptions

2. Paragraph 1 shall not apply if one of the following applies:
  - (a) the data subject has given explicit consent to the processing of those personal data for one or more specified purposes, except where Union or Member State law provide that the prohibition referred to in paragraph 1 may not be lifted by the data subject;
  - (b) processing is necessary for the purposes of carrying out the obligations and exercising specific rights of the controller or of the data subject in the field of employment and social security and social protection law in so far as it is authorised by Union or Member State law or a collective agreement pursuant to Member State law providing for appropriate safeguards for the fundamental rights and the interests of the data subject;
  - (c) processing is necessary to protect the vital interests of the data subject or of another natural person where the data subject is physically or legally incapable of giving consent;

<https://gdpr-info.eu/art-9-gdpr/>



# Sensitive Data: exceptions again

- (d) processing is carried out in the course of its legitimate activities with appropriate safeguards by a foundation, association or any other not-for-profit body with a political, philosophical, religious or trade union aim and on condition that the processing relates solely to the members or to former members of the body or to persons who have regular contact with it in connection with its purposes and that the personal data are not disclosed outside that body without the consent of the data subjects;
- (e) processing relates to personal data which are manifestly made public by the data subject;
- (f) processing is necessary for the establishment, exercise or defence of legal claims or whenever courts are acting in their judicial capacity;
- (g) processing is necessary for reasons of substantial public interest, on the basis of Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject;

<https://gdpr-info.eu/art-9-gdpr/>

# Sensitive Data: exceptions again again

- (h) processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services on the basis of Union or Member State law or pursuant to contract with a health professional and subject to the conditions and safeguards referred to in paragraph 3;
- (i) processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy;

<https://gdpr-info.eu/art-9-gdpr/>

# Sensitive Data: exceptions again again again

- (j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with [Article 89\(1\)](#) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

<https://gdpr-info.eu/art-9-gdpr/>

# Pseudonymisation vs anonymisation

Pseudonymisation:

- ▶ reversible
- ▶ informed consent legally compulsory

**Ex:** *Mr X has been arrested for murder.*

**But:** *The son of the most well-known ophthalmologist in Orléans is schizophrenic.*

vs

Anonymisation:

- ▶ irreversible
- ▶ no consent needed (information should be given, though)

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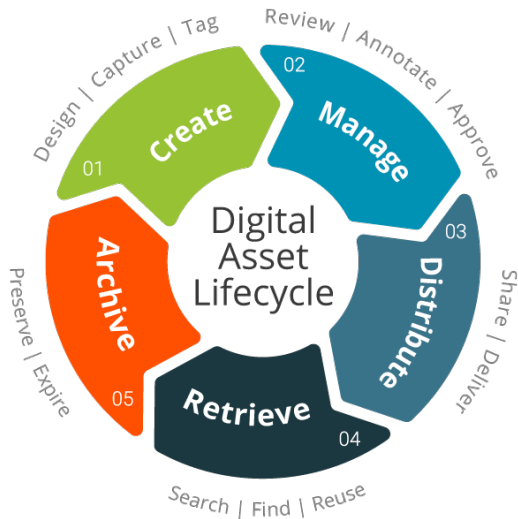
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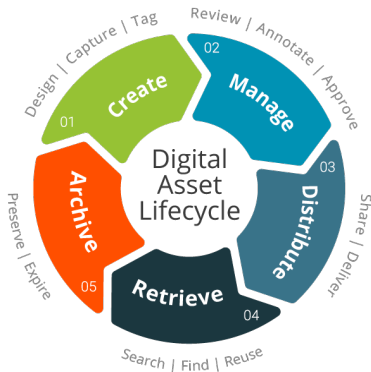
To finish

# Data Lifecycle



Haztowichp - CC BY-SA

# Ethical Hot Spots?

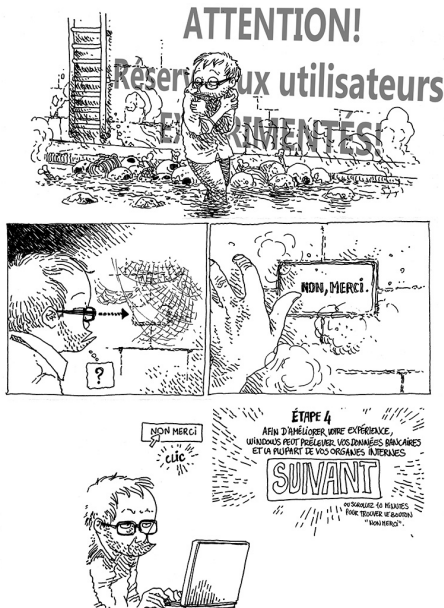


Haztowichp - CC BY-SA

Exercise your "ethical" brain

Identify the potential ethical "hot spots" in the data lifecycle (take a concrete example to illustrate)

# What Consent Means (or not), by ©Boulet





# Informed Consent

The Nuremberg Code (1947) states that consent can be voluntary **only if**:

- ▶ participants are **able** to consent
- ▶ they are **free from coercion**
- ▶ they **comprehend** the risks and benefits involved

# Art. 7 GDPR: Conditions for consent (1/2)

## Art. 7 GDPR Conditions for consent

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1. 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. <sup>1</sup> 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. <sup>2</sup> Any part of such a declaration which constitutes an infringement of this Regulation shall not be binding.

<https://gdpr-info.eu/art-7-gdpr/>

## Art. 7 GDPR: Conditions for consent (2/2)

3. <sup>1</sup> The data subject shall have the right to withdraw his or her consent at any time. <sup>2</sup> The withdrawal of consent shall not affect the lawfulness of processing based on consent before its withdrawal. <sup>3</sup> Prior to giving consent, the data subject shall be informed thereof. <sup>4</sup> 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.

<https://gdpr-info.eu/art-7-gdpr/>

# Consequences in Practice

There is **no** consent if no decision is made:

- ▶ opt in vs opt out
- ▶ importance of the default settings
- ▶ possibility to withdraw one's consent at anytime



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

# Exercise

Exercise your "ethical" brain

Go on the [Facebook homepage](#) (disconnect if you are connected) and evaluate to what extent the consent of a new user is informed.

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Why not?

Data Ethics Decision Aid

EU Ethical guidelines for trustworthy AI

To finish

## Reminder: beyond Grids

Grids are attractive:

- ▶ simple
- ▶ illusion of exhaustiveness

But they are far from enough:

*" Neither the risk analysis informed by engineering practice, nor the socially informed engineering practice can be replaced by the other." [Gurses et al., 2011]*

# Making the Most of Grids

1. start thinking/discussing **without** them
2. use them as a complement
3. do not limit your thinking because you checked all the list in the grid



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## DEDA.app

The DEDA app addresses the different phases of a data project with individual questions. Depending on the user's answers, DEDA responds with new questions, addresses concerns and points to action points. It also documents the users approach to the ethical issues. The resulting report can be used to further scrutinize the ethical compliance of a data project and/or be archived for documentation, transparency and accountability.

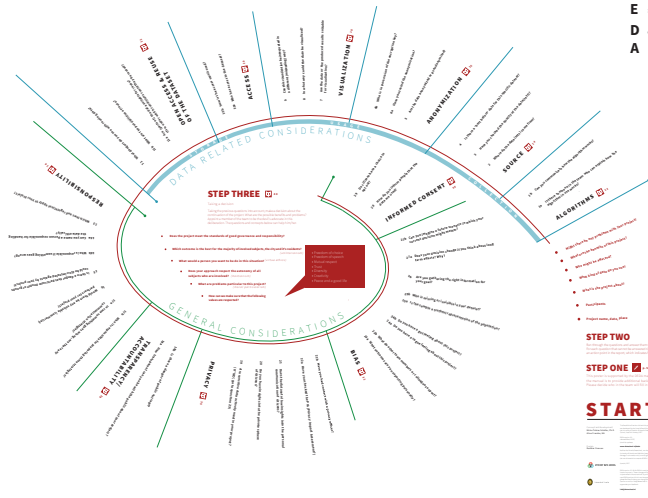
**ACCESS DEDA.APP**



<https://dataschool.nl/deda/deda-app/?lang=en>

# The Worksheet

**D**ata  
**E**thics  
**D**ecision  
**A**id



Here

# Using DEDA

Just Do It

Take the survey for the case you presented

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# Ethical guidelines for trustworthy AI

<https://ec.europa.eu/digital-single-market/en/news/ethics-guidelines-trustworthy-ai>

4 ethical principles:

1. Respect for human autonomy
2. Prevention of harm
3. Fairness
4. Explicability

+ tensions between them and decisions made should be documented and argued

# Respect for human autonomy

<https://ec.europa.eu/digital-single-market/en/news/ethics-guidelines-trustworthy-ai>

*"AI systems should not unjustifiably subordinate, coerce, deceive, manipulate, condition or herd humans. Instead, they should be designed to augment, complement and empower human cognitive, social and cultural skills. The allocation of functions between humans and AI systems should follow human-centric design principles and leave meaningful opportunity for human choice. **This means securing human oversight over work processes in AI systems.**"*

*"the less oversight a human can exercise over an AI system, the more extensive testing and stricter governance is required"*

# Prevention of harm

<https://ec.europa.eu/digital-single-market/en/news/ethics-guidelines-trustworthy-ai>

*"AI systems should neither cause nor exacerbate harm or otherwise adversely affect human beings. This entails the protection of human dignity as well as mental and physical integrity. AI systems and the environments in which they operate must be safe and secure. [...] Particular attention must also be paid to situations where AI systems can cause or exacerbate adverse impacts due to asymmetries of power or information, such as between employers and employees, businesses and consumers or governments and citizens. "*



# Fairness

<https://ec.europa.eu/digital-single-market/en/news/ethics-guidelines-trustworthy-ai>

*"The development, deployment and use of AI systems must be fair. [...] Moreover, the use of AI systems should never lead to people being deceived or unjustifiably impaired in their freedom of choice. Additionally, fairness implies that AI practitioners should respect the principle of proportionality between means and ends, and consider carefully how to balance competing interests and objectives. The procedural dimension of fairness entails the ability to contest and seek effective redress against decisions made by AI systems and by the humans operating them. In order to do so, **the entity accountable for the decision must be identifiable, and the decision-making processes should be explicable.**"*

# Explicability

<https://ec.europa.eu/digital-single-market/en/news/ethics-guidelines-trustworthy-ai>

*"This means that **processes need to be transparent**, the capabilities and purpose of AI systems openly communicated, and decisions – to the extent possible – explainable to those directly and indirectly affected. [...] The degree to which explicability is needed is highly dependent on the context and the severity of the consequences if that output is erroneous or otherwise inaccurate."*

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WYHTR: What You Have To Remember



- ▶ it's a question of time (spent questioning/thinking)
- ▶ others have thought about it before (get inspired)
- ▶ no ready-made solution
- ▶ checklists are bad (they prevent you from thinking by yourself)



(1979).

The belmont report : Ethical principles and guidelines for the protection of human subjects of research.



Chenaud, C., Gigon, F., Ricou, B., and Merlani, P. (2008).

Le consentement éclairé pour la recherche aux soins intensifs en suisse : quelle solution ?

Rev Med Suisse, 4:2691–2695.



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Engineering privacy by design.

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Spiekermann, S. (2015).

Ethical IT Innovation: A Value-Based System Design  
Approach.

CRC Press.