



Data Ethics: DIY

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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

"All your data are belong to us"

Definitions

Motivation and Goal

A Bit of Practice

A Question of Time

To finish

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Ethics?

soft law

The screenshot shows the Merriam-Webster dictionary website. At the top, there is a navigation bar with links for JOIN MWU, GAMES, BROWSE THESAURUS, WORD OF THE DAY, VIDEO, and WORDS AT P. Below the navigation bar, the Merriam-Webster logo is displayed with the text "SINCE 1828". A search bar contains the word "ethics", with a dropdown menu showing "DICTIONARY" and "THESAURUS". On the left side of the main content area, there is a vertical sidebar with social media sharing icons for Facebook, Twitter, and LinkedIn, as well as a "CITE" button and a "7" icon. The main content area is titled "Definition of ETHIC". The definition is presented in a numbered list:

- 1 **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
- 2 **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*
- 3 **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>

What do you know about ethics?

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



SINCE 1828

JOIN MWU | GAMES | BROWSE THESAURUS | 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, \dā- | '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

Art. 4 GDPR Definitions

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

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/>

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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

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What Happens to Data?

A Question of Time

To finish

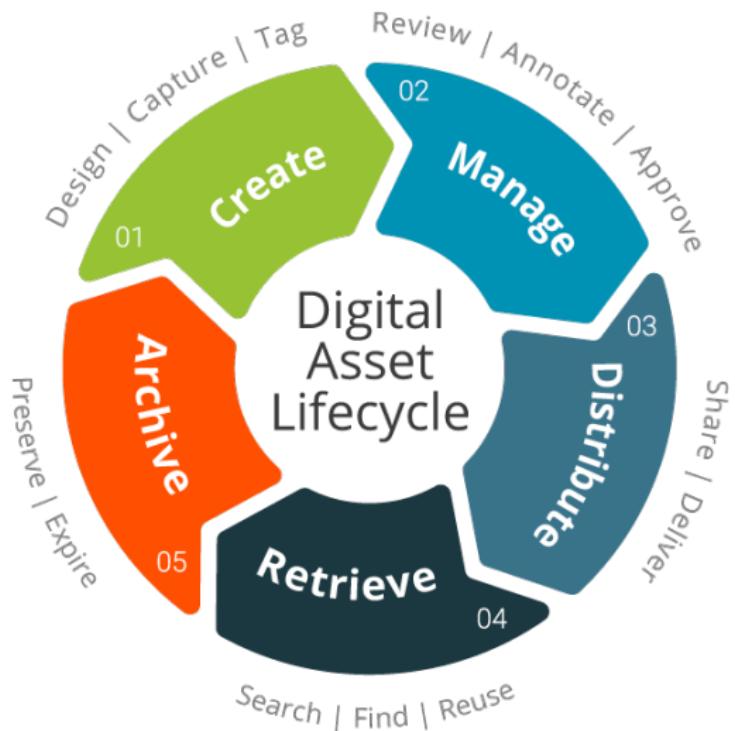
Your turn to think

Which ethical issues can you imagine? Which solutions?

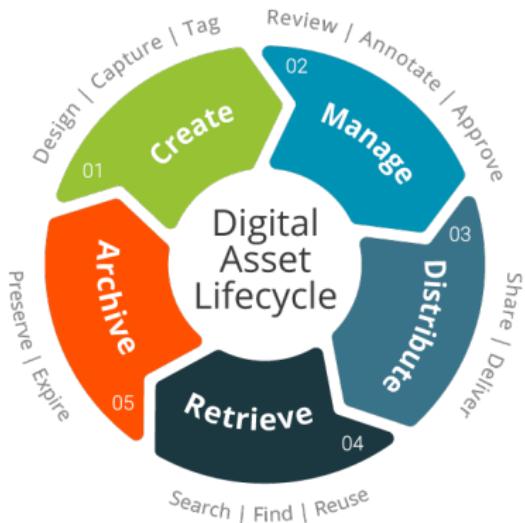
Automatically generated and assigned groups of 6 students, 20 minutes of preparation, then present to all of us (no slides, just you and the whiteboard):

- ▶ Chatbot Tay (EN)
- ▶ Mise en Open Data des décisions de justice (FR)
- ▶ Social credit in China (EN)
- ▶ Amazon Alexa and Google Home (EN)
- ▶ Reconnaissance faciale (FR)
- ▶ Data brokers (EN)
- ▶ Droit à l'oubli (FR)

Data Lifecycle



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)

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Who's dealing with it?

Is 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 ²⁷)	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"> • Expériences des médecins nazis sur des prisonniers en camp de concentration • Trois officiels nazis et vingt médecins impliqués, dont : <ul style="list-style-type: none"> – Heinrich Himmler : mécène et directeur de la médecine nazie, parfois surnommé « le meurtrier du Siècle ». Met en œuvre la solution finale – Josef Mengele : tortures, sévices corporels lors d'expériences médicales absurdes et inhumaines entraînant souvent la mort, à Auschwitz – Aribert Heim : vivisection humaine sur les détenus de Mauthausen 	<ul style="list-style-type: none"> • Fait suite aux atrocités de la Seconde Guerre mondiale • 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 	<ul style="list-style-type: none"> • Création le 12 juillet 1974 du National research act (Loi publique 93348 sur la recherche) • 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 Star²⁸ révèle l'affaire. N'a jamais donné de résultats concluants • 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.
Principes généraux	<ul style="list-style-type: none"> • Bienfaisance : rapport risque/bénéfice favorable • Respect du sujet de recherche : consentement volontaire, capacité de consentir, possibilité de quitter l'essai • Justice : utilité pour la société 	<ul style="list-style-type: none"> • Bienfaisance : rapport risque/bénéfice favorable • Respect du sujet de recherche : consentement informé • Justice : distinction entre recherche thérapeutique ou non • Responsabilité : pas uniquement au chercheur, avis extérieur nécessaire (comité d'éthique) 	<ul style="list-style-type: none"> • Bienfaisance : rapport risque/bénéfice favorable (distinction entre risques «minimes» et risques «plus que minimes») • Respect du sujet de recherche : consentement éclairé • Justice : sélection équitable des sujets
Forme	Dix principes fondamentaux	Loi consensuelle, nombreux paragraphes	Paragraphes agencés en trois catégories éthiques et applications

[Chenaud et al., 2008]

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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



(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.



Dittrich, D. and Kenneally, E. (2012).

The Menlo Report: Ethical Principles Guiding Information and Communication Technology Research.

Technical report, U.S. Department of Homeland Security.



Spiekermann, S. (2015).

Ethical IT Innovation: A Value-Based System Design

Approach.

CRC Press.