S6 – Data Ethics
D4 – Data and Ethics

Schedule

KW		Date	#	Topics	LernSetting WI	Lecturer
38 39	Self Study	First 2 weeks	0	Awareness - Entry Test with Moodle Test (20% counted to course grade)	Virtual	Selfstudy
38		KW38	0 + 7	Coaching Session (according to the information of the respective school)	on site	JRN= Juchler Norman Rerabek Martin Nyfeler Matthias
38	Fr, afternoon	23.09.2022	1	Personal Security	Virtual	Pascal Moriggl
39		KW39	1	Coaching Session	on site	FHNW: Pascal Moriggl ZHAW: JRN
39	Fr, afternoon	30.09.2022	2	Information Security & Cybersecurity I	Virtual	Petra M. Asprion
40		KW40	2	Coaching Session	on site	FHNW: Petra M. Asprion ZHAW: JRN
40	Fr, afternoon	07.10.2022	3	Information Security & Cybersecurity II	Virtual	Petra M. Asprion
41		KW41	3	Coaching Session	on site	FHNW: Pascal Moriggl ZHAW: JRN
41	Fr, afternoon	14.10.2022	4	Data Stewardship I	Virtual	Pascal Moriggl
42		KW42	4	Coaching Session	on site	FHNW: Pascal Moriggl ZHAW: JRN
42	Fr, afternoon	21.10.2022	5	Data Stewardship II	Virtual	Pascal Moriggl
43		KW43	5	Coaching Session	on site	FHNW: Pascal Moriggl ZHAW: JRN
43	Fr, afternoon	28.10.2022	6	Data Ethics	Virtual	Pascal Moriggl
44		KW44	6	Coaching Session	on site	FHNW: Pascal Moriggl ZHAW: JRN
44	Fr, afternoon	04.11.2022	7	Data Privacy	Virtual (Flipped Classroom)	Pascal Moriggl

Where are we at? Big Picture

1. Secure myself
2. Secure my Organisation
3. Keep my project clean through data management
4. Keep my project data clean through FAIR
5. Do the right* thing with the data (Ethics)
6. Do the correct thing with the data (Privacy)

Learning Objectives

- ✓ You have a general understanding of Ethics and its subcategories
- ✓ You are aware of the IRB and how it works regarding your projects
- ✓ You can apply the ethics canvas to one of your (research) projects from a data perspective
- ✓ You know where you can inform yourself about data ethics

Support via Videos

We use several videos from different sources to delve deeper into selected topics.

The most important ones are the WIRELESS PHILOSOPHY videos (http://www.wi-phi.com) which are produced by several universities.

Others are from the LITTLE GREEN BAGS series (University of St. Gallen).

Foundations of Ethics

Philosophy

Philosophy (from Greek «philosophia», «love of wisdom») is «the critical examination of the grounds for fundamental beliefs» (Encyclopædia Britannica) and the study of general and fundamental problems concerning existence, knowledge, values, reason, mind, and language.

Disciplines of philosophy are logic, philosophy of language, epistemology, ontology, philosophy of science, philosophy of law, philosophy of history, political philosophy, social philosophy, philosophy of technology, aesthetics and ethics.

The most important languages of philosophy are Greek, Latin, German and English.

Excercise: Famous Philosophers

- Platon (428/427 – 348/347)
- Aristotle (384 – 322)
- Immanuel Kant (1724 – 1804)
- Arthur Schopenhauer (1788 – 1860)
- Ludwig Wittgenstein (1889 – 1951)

Ethics

«Ethics, also called moral philosophy, the discipline concerned with what is morally good and bad, right and wrong.» (Encyclopædia Britannica, https://www.britannica.com/topic/ethics-philosophy)

Ethics deals with morality. To be more precise: It investigates forms and possibilities of morality. Ethics is the discipline, morality is the subject. We conduct ethics, and we own morality.

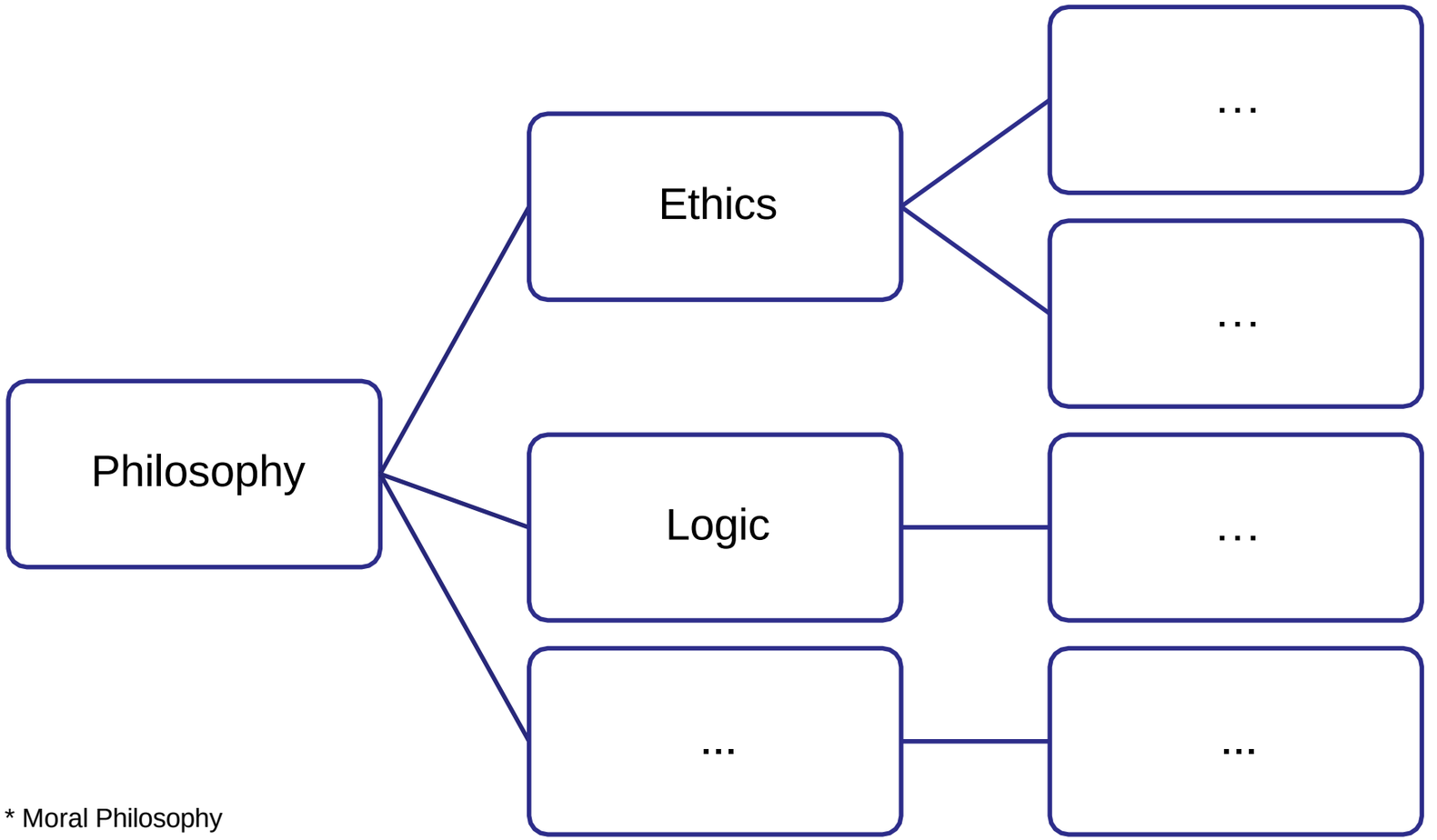
Ethics

Ethics as moral philosophy

- uses scientific methods (specific methods of ethics).
- does not consider political and religious authorities.
- does not use arguments which are related to habits or history.
- tries to make general statements about the good and bad acting.

Ethics as moral theology does not belong to ethics as a science.

Classification of Philosophy: Disciplines



* Moral Philosophy

Morality

Morality is a setting of rules, principles, values, beliefs and ideas of moral agents (in German: «Subjekte der Moral»). It is a kind of a normative framework for our behaviour (and perhaps for our thinking).

Morality refers to the fellow human beings, to the person him- or herself and to the environment (e.g., animal beings); these are moral patients (in German: «Objekte der Moral»).

Morality II

"Morality is a person or society's idea of what is right or wrong, especially in regard to a person's behavior"[1]

Morals have changed over time and based on location. For example, different countries can have different standards of morality. That said, researchers have determined that seven morals seem to transcend across the globe and across time:

Bravery: Bravery has historically helped people determine hierarchies. People who demonstrate the ability to be brave in tough situations have historically been seen as leaders.

Fairness: Think of terms like "meet in the middle" and the concept of taking turns.

Morality II

Defer to authority: Deferring to authority is important because it signifies that people will adhere to rules that attend to the greater good. This is necessary for a functioning society.

Helping the group: Traditions exist to help us feel closer to our group. This way, you feel more supported, and a general sense of altruism is promoted.

Loving your family: This is a more focused version of helping your group. It's the idea that loving and supporting your family allows you to raise people who will continue to uphold moral norms.

Returning favors: This goes for society as a whole and specifies that people may avoid behaviors that aren't generally altruistic.

Respecting others' property: This goes back to settling disputes based on prior possession, which also ties in the idea of fairness.

Ethics vs Morality

The big difference when it comes to ethics is that it refers to community values more than personal values. Dictionary.com defines the term as a system of values that are "moral" as determined by a **community**. 2

Morality is certainly relative since it is determined individually from person to person. In addition, morals can be heavily influenced by families and even religious beliefs, as well as past experiences.

Ethics are relative to different communities and cultures. For example, the ethical guidelines for the medical community don't really have an impact on the people outside of that community. That said, these ethics are still important as they promote caring for the community as a whole.

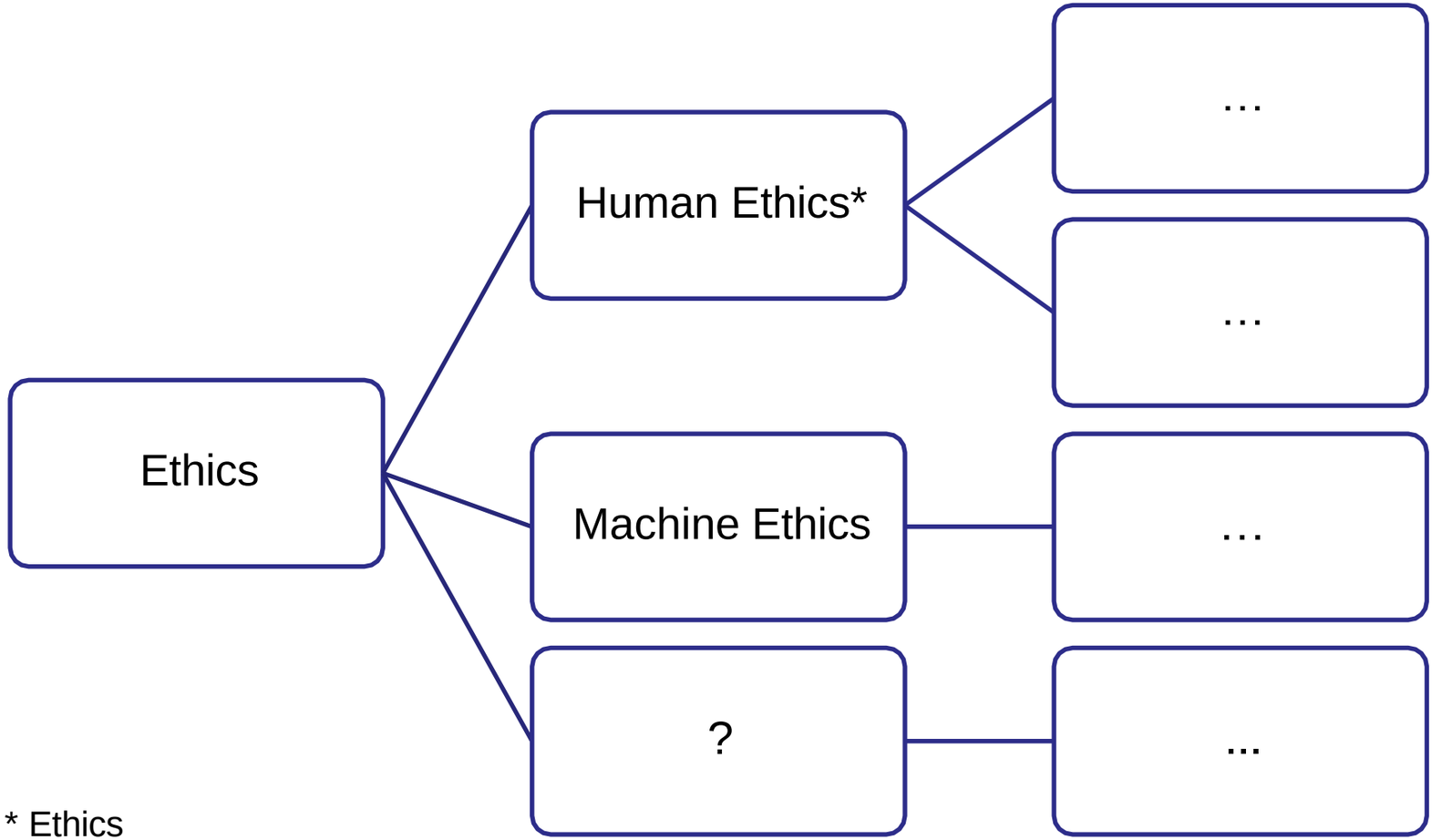
Back to Ethics

Classification of Ethics: Moral Agents

Ethics is usually human ethics (with humans as moral agents).

Perhaps also machines like robots and self-driving cars can be moral agents; according to the discipline of machine ethics, they are.

Classification of Ethics: Subject of Morality



* Ethics

Classification of Ethics: General Approach

Empirical ethics describes the phenomena of morality in different groups, institutions and cultures, explains the origin and function and tries to develop an empirical theory of human behaviour.

Normative ethics evaluates and criticizes the current ideas of morality and tries to develop a normative theory for human behaviour (like virtue ethics, deontological ethics/duty ethics or teleological ethics/consequentialism).

Wireless Philosophy: Consequentialism

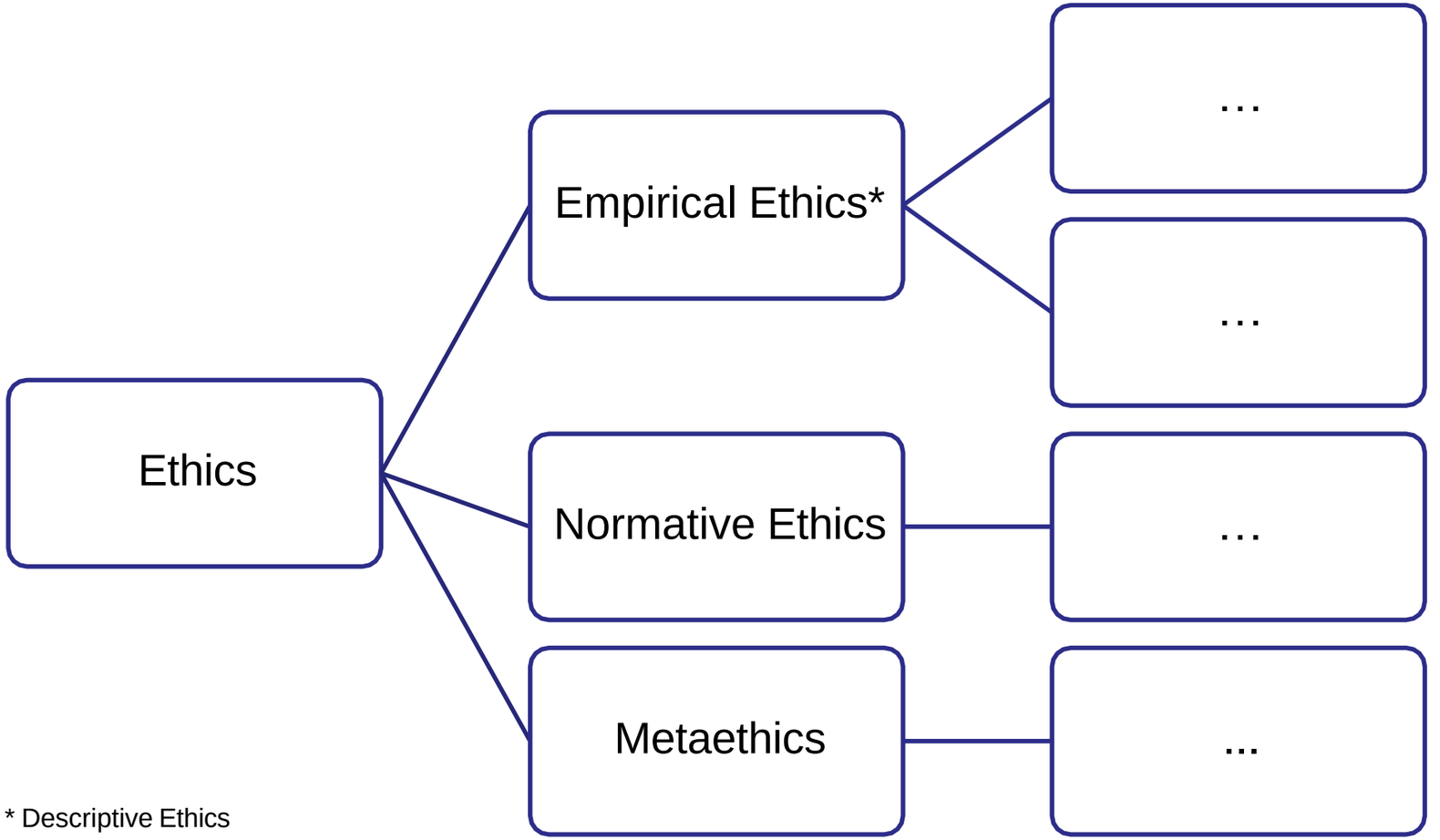
https://www.youtube.com/watch?v=hACdhD_kes8&list=PLtKNX4SfKpzWO2Yjvkp-_hMS0gTI948pIS

Classification of Ethics: General Approach

«Metaethics, the subdiscipline of ethics concerned with the nature of ethical the- ories ...» (Encyclopædia Britannica, https://www.britannica.com/topic/metaethics) It compares ethical theories and models of normative ethics and evaluates them.

A special approach of metaethics are language games in which the meaning of terms and concepts in the context of morality are explored.

Classification of Ethics: General Approach



* Descriptive Ethics

Excercise: The Good and the Bad

Not all statements with «good» or «bad» respectively «evil» are moral statements. Which of the following examples are, which are not?

«The weather is good.»

«The dog is evil.»

«She is a bad girl./He is a bad boy.»

Can you formulate some simple and short sentences with «good», «bad» or «evil»? Please write them down on a piece of paper!

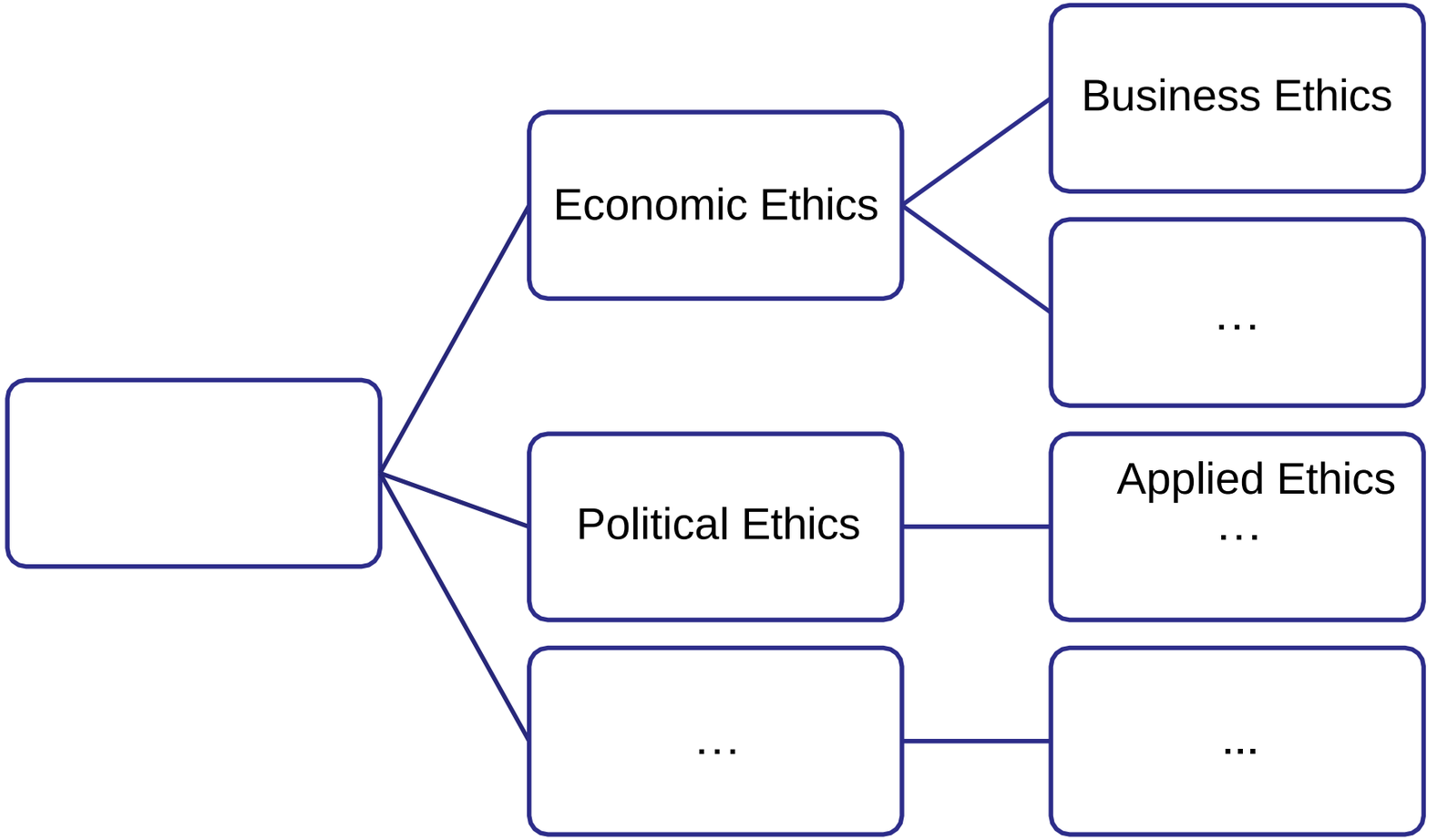
Classification of Ethics: Application Fields

We distinguish between theoretical and applied ethics.

«Applied ethics is a branch of ethics devoted to the treatment of moral problems, practices, and policies in personal life, professions, technology, and government.» (Oxford Bibliographies, https://www.oxfordbibliographies.com/view/document/obo-9780195396577/obo-9780195396577-0006.xml)

Fields of applied ethics are medical ethics, bioethics, environmental ethics, animal ethics, military ethics, peace ethics, technology ethics, Ethics, economic ethics (business ethics) and political ethics.

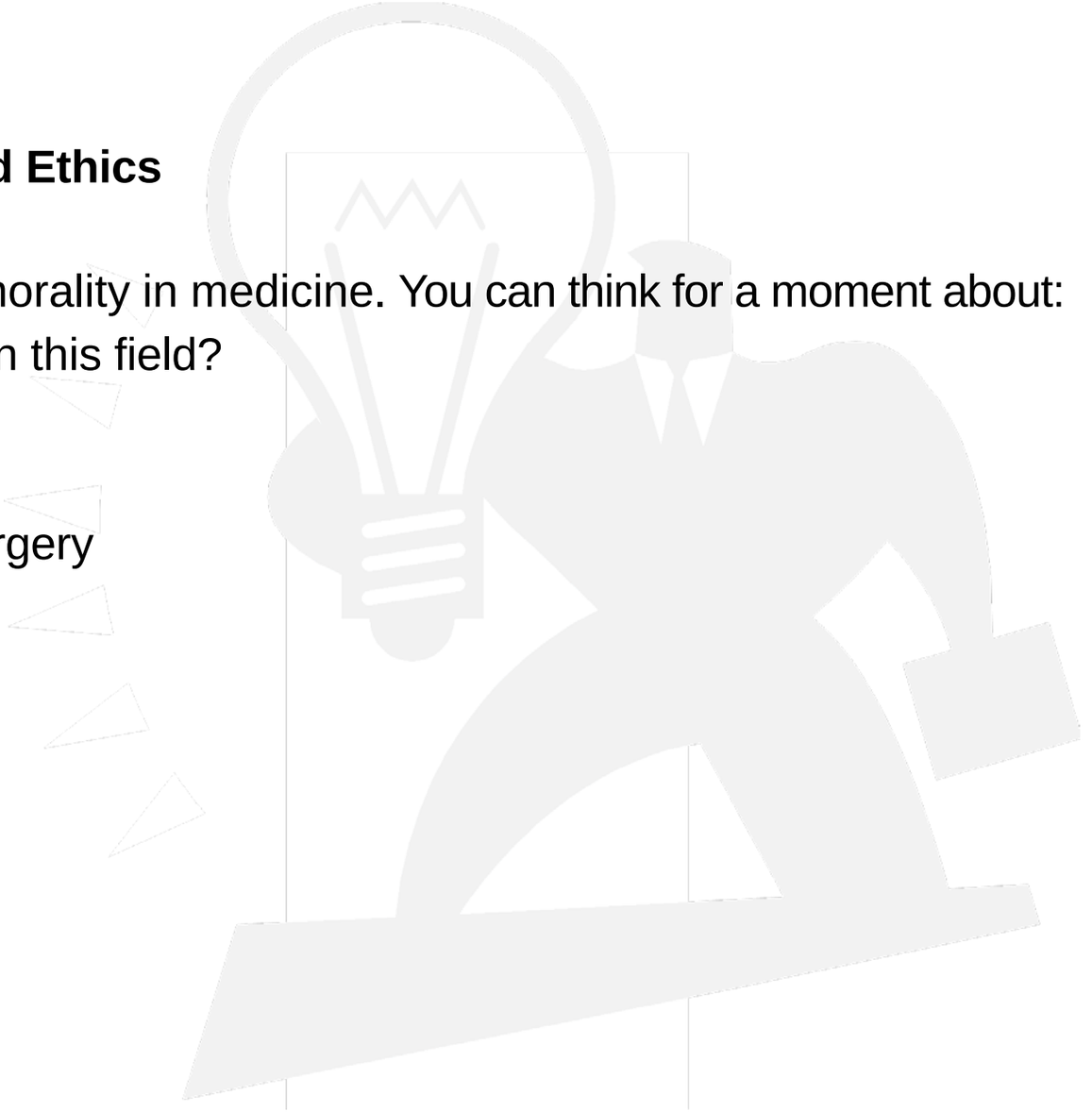
Classification of Applied Ethics: Application Fields



Discussion: Fields of Applied Ethics

Medical ethics deals with the morality in medicine. You can think for a moment about: What are important questions in this field?

- Assisted suicide
- Plastic surgery/cosmetic surgery
- …



Moral Justifications (According to Pieper)

There’s an old woman standing on the street.

You go to her and help her across the street.

When you come back, the other students ask you: Why did you do that?

Source: Der Postillon

Moral Justifications (According to Pieper)

Statement	Justification
«I helped her, because she suffered.»	With reference to a fact
«I helped her, because I like her.»	With reference to feelings
«I helped her to make her feel better.»	With reference to possible consequences
«I helped her, because helping is a virtue.»	With reference to a moral code
«I helped her, because the lecturer for ethics advocated that.»	With reference to a moral authority
«I helped her, because my conscience told me.»	With reference to the conscience

Ethical Methods (According to Pieper)

Important ethical methods of justification are:

- The logical method: I demonstrate that a statement is formally right or wrong.
- The discursive method: Two persons or parties try to reach a consensus; they declare their interests and exchange arguments.
- The dialectic method: I generate an idea of what is good (like equality) and look at each specific case.

There are further methods, not only for justification but also for description (e.g., the analytical or the hermeneutic method).

Foundations of Information Ethics

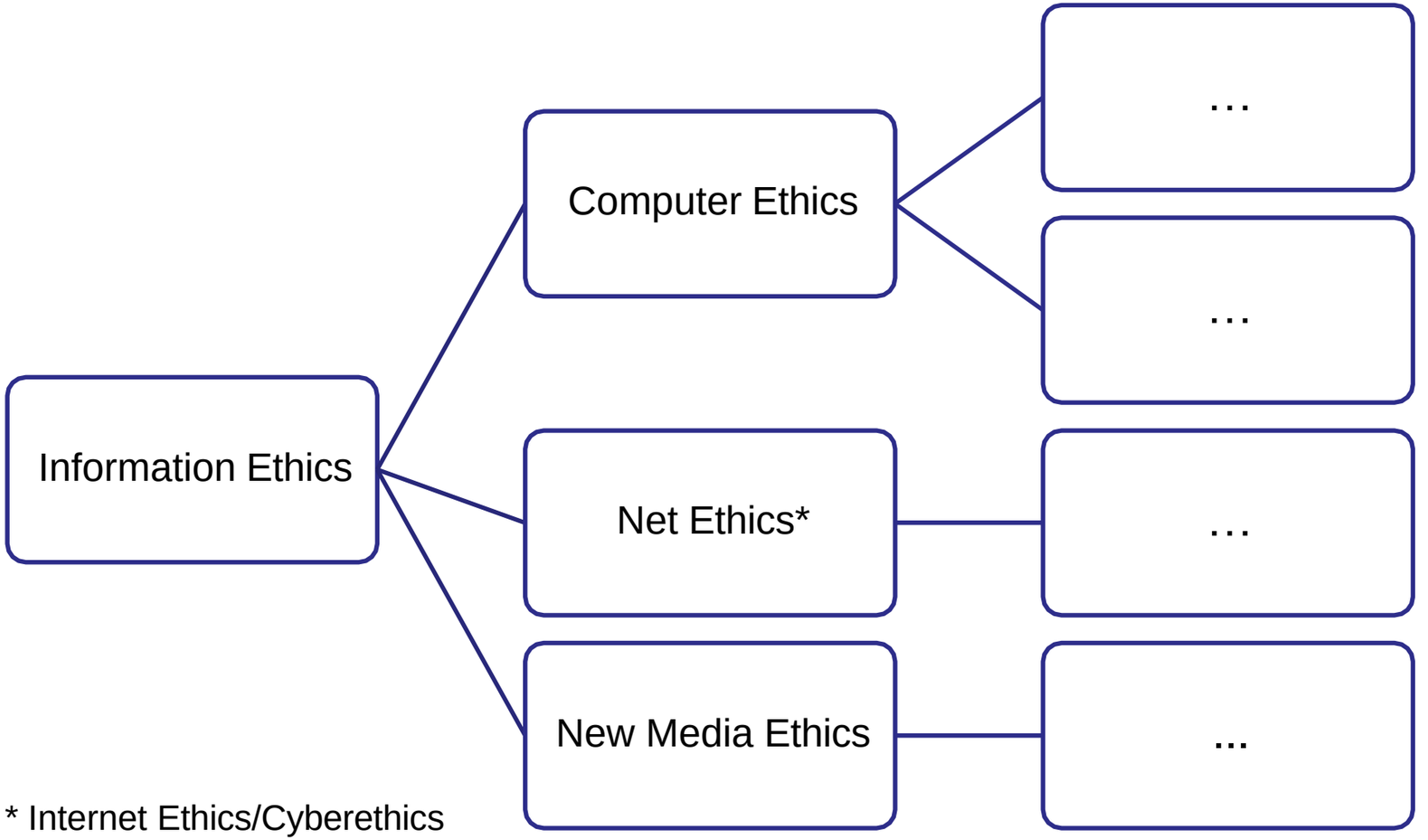
Information Ethics

The subject of information ethics is the morality of those who offer and use information and communication technology (ICT), application systems and new media.

It inquires how these persons, groups and organizations behave in aspects of morality and how they should behave.

According to Rafael Capurro, we can divide the discipline into computer ethics, net ethics and media ethics (the lecturer prefers the term of new media ethics).

Classification of Information Ethics: Fields of Application



* Internet Ethics/Cyberethics

Representatives of Information Ethics

Rainer Kuhlen: Influential representative of information science and ethics in the German-speaking area; former professor at the University of Konstanz

Rafael Capurro: Committed representative of media and information ethics; founder of the International Center for Information Ethics (ICIE)

Luciano Floridi: Influential representative of information ethics on the international stage; currently professor of philosophy and ethics of information at the University of Oxford

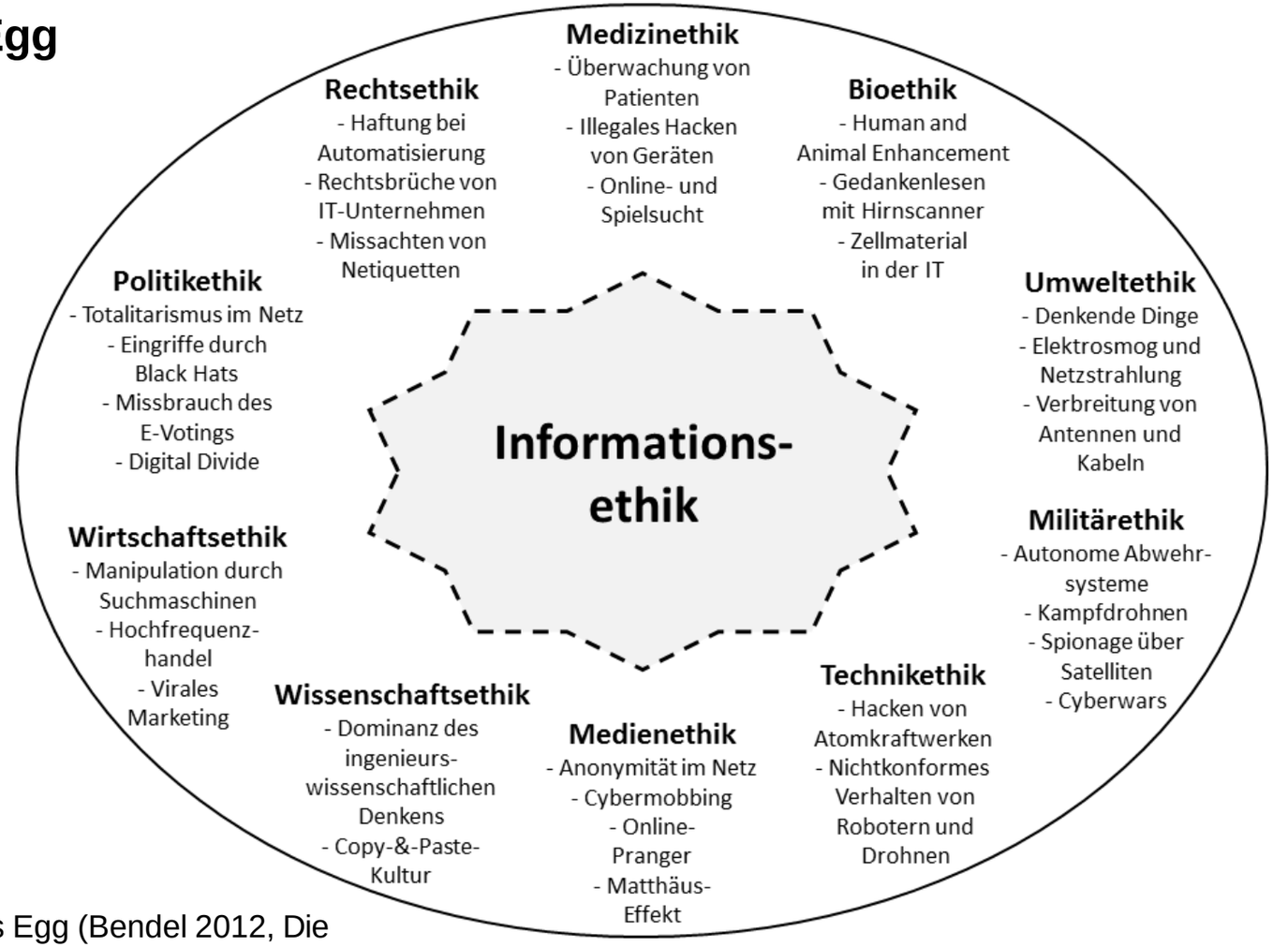
Images sources: http://www.kuhlen.name, http://www.capurro.de and http://blogs.oii.ox.ac.uk

Little Green Bags: «The Digital Good Life»

https://www.youtube.com/watch?annotation_id=annotation_1733772413&feature=iv&src_vid=ciZOwdJlNzo&v=_tUMnwkMSeg

The Fields of Applied Ethics and Machine Ethics

The Ethics Egg



The Ethics Egg (Bendel 2012, Die Medizinethik in der Informationsgesellschaft)

Technology Ethics

Technology ethics relates to moral issues of the use of technique and technology.

It can focus on the technology of vehicles or weapons as well as on nanotechnology. There are manifold relations to science ethics.

In the information society, technology ethics is also closely connected to information ethics.

Business Ethics

«Business ethics, branch of applied ethics that studies the moral dimensions of commercial activity, frequently but not exclusively with respect to corporations. It encompasses an extremely broad range of issues, including whether and how corporations – as distinct from their officers or shareholders – are moral agents» … (Encyclopædia Britannica, https://www.britannica.com/topic/business-ethics)

Animal Ethics

Animal ethics deals with the moral duties of humans towards animals and with the moral rights of animals.

The ability to suffer is an important moral and ethical argument. It can be used to justify species-appropriate animal farming or a ban of animal farming and animal use.

Wireless Philosophy: Animal Ethics

https://www.youtube.com/watch?v=3HAMk_ZYO7g

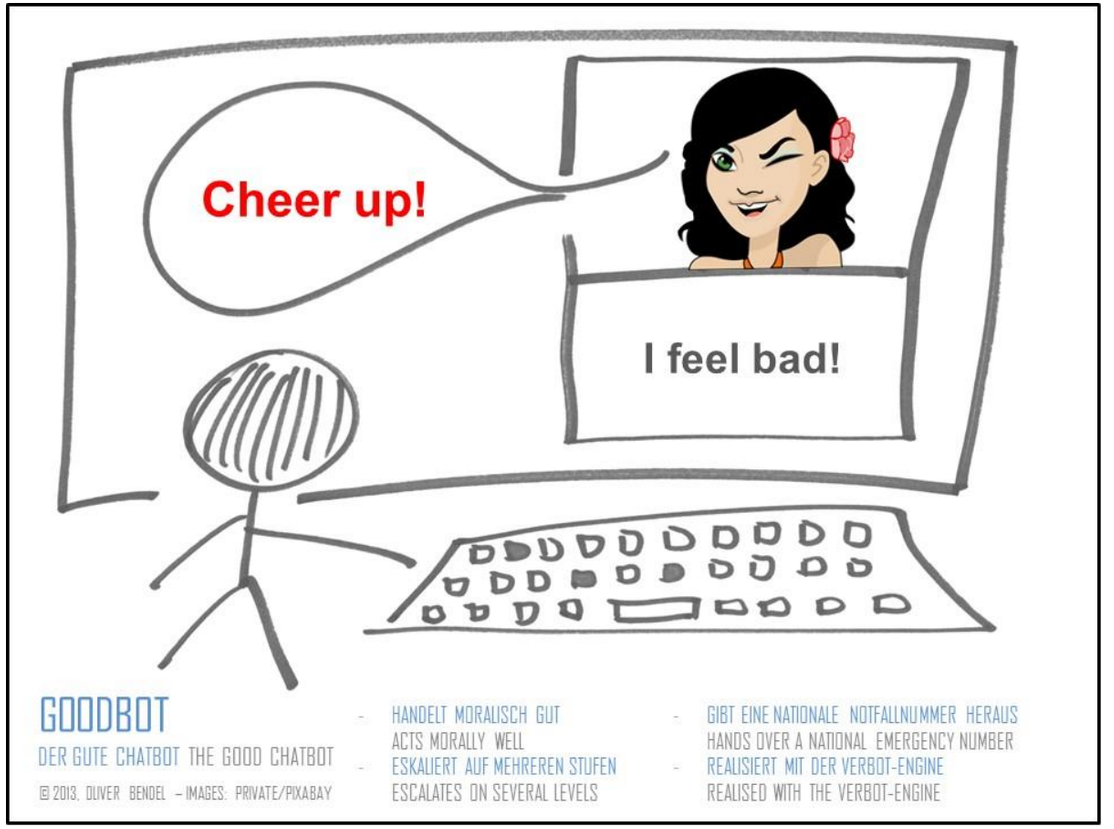
Machine Ethics

Machine ethics refers to the morality of semi-autonomous or autonomous machines, the morality of certain robots or bots is one example.

Hence these machines are moral agents. They decide and act in situations where they are left to their own devices, either by following pre-defined rules or by comparing the case to selected case models, or as machines capable of learning and deriving rules.

Moral machines have been known for some years, at least as prototypes.

Prototype: GOODBOT



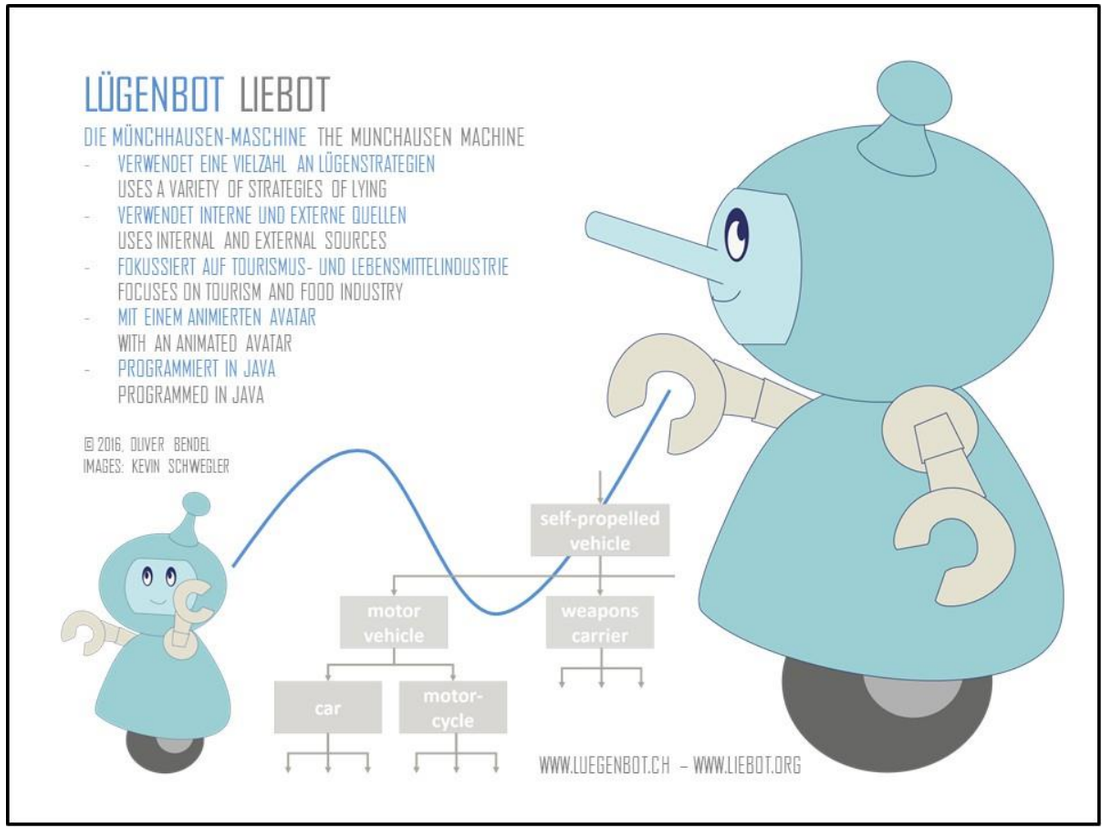
Chatbot identifies the problems of the user and evaluates them

Before handing over to a human it escalates on several levels

One of seven meta rules is that it should not lie

Can be described as a simple moral machine

Prototype: LÜGENBOT/LIEBOT

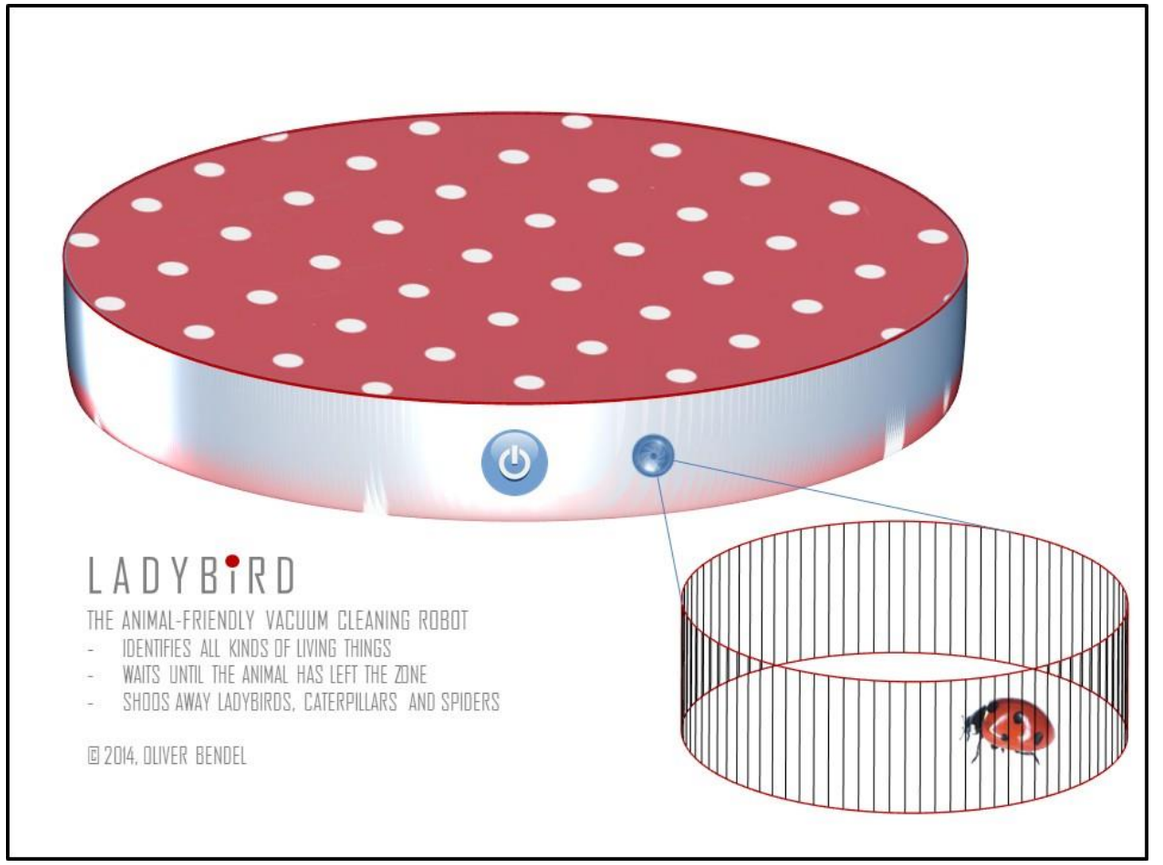


Chatbot tells systematically lies

Uses WordNet of Princeton University and different search engines; uses input of Cleverbot

According to the types of lies, the avatar changes its design

Prototype: LADYBIRD

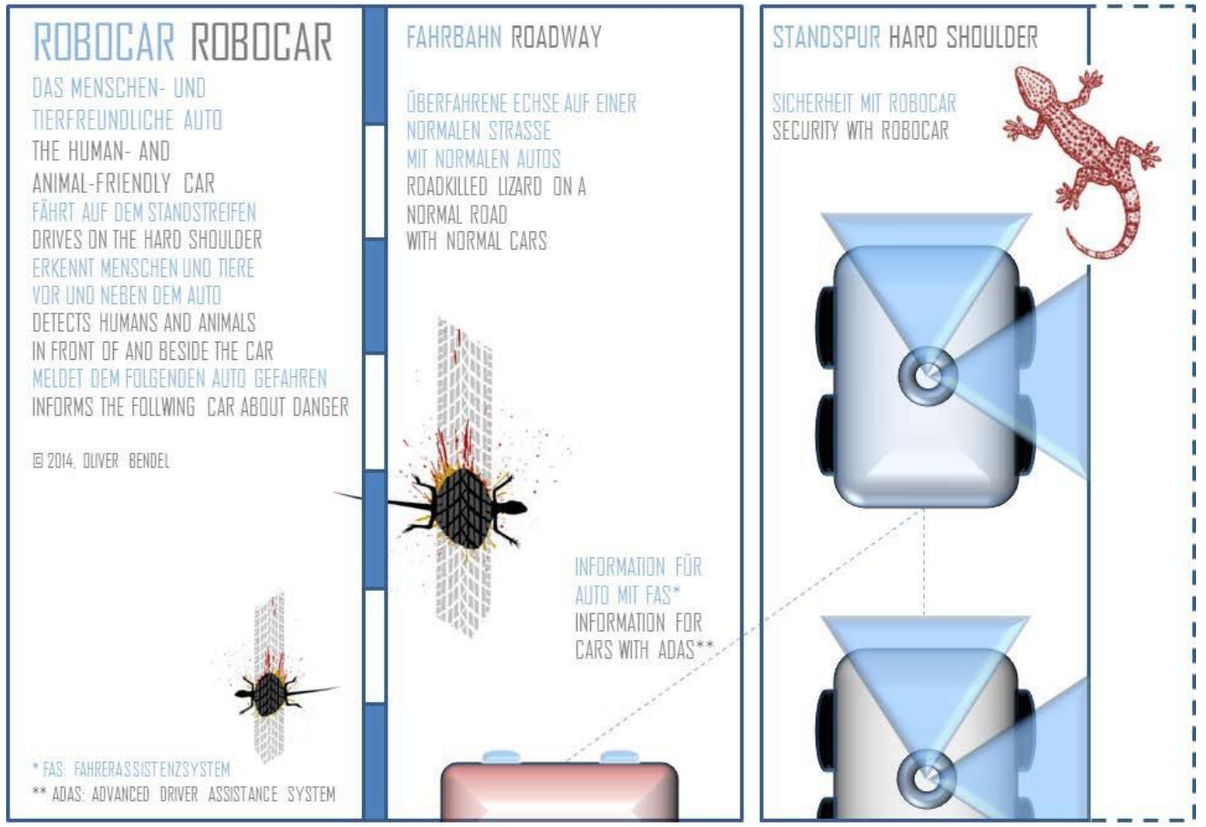


Detects a ladybird or another small animal.

Can stop its movement and work.

On request with kill button for spiders.

Concept: Animal Friendly Robot Cars



It evaluates animals of all kinds and stops for them or gets out of the way.

It does not stop for insects and if somebody is close behind it.

IRB – Institutional Review Board

What is an IRB, and how is it related to Life Science and Ethics?

What is an IRB?

The Institutional Review Board (IRB) is an administrative body established to protect the rights and welfare of human research subjects recruited to participate in research activities conducted under the auspices of the institution with which it is affiliated.

An IRB is committee set up by an institution to review, approve, and regulate research conducted under its jurisdiction. The National Research Act of 1974 directed all institutions receiving federal support research to establish IRBs (USA).

The IRB is charged with the responsibility of reviewing, prior to its initiation, all research (whether funded or not) involving human participants. The IRB is concerned with protecting the welfare, rights, and privacy of human subjects. The IRB has the authority to approve, exempt, disapprove, monitor, and require modifications in all research activities that fall within its jurisdiction as specified by both the federal regulations and institutional policy. The IRB shall have at least five members of varying backgrounds in order to provide complete and adequate review of human research and its institutional, legal, scientific, and social implications. The Board will also include at least one member who is not affiliated with the institution and one member who is not a scientist. The IRB has several consultants who advise the Board and are periodically involved in protocol review.

Purpose of the IRB

- ❑ To protect the rights of human subjects in research
- ❑ To ensure human subjects are informed of their rights as participants and understand the consequences of the research

The IRB is **not** charged with evaluating or modifying the science of a research project beyond protecting the rights of human subjects ensure human subjects are informed of their rights as participants and understand the consequences of the research.

The IRB is not charged with evaluating or modifying the science of a research project beyond protecting the rights of human subjects

Purpose of the IRB II

In the not-so-distant past, the burden of research lay heavily on vulnerable populations such as children, prisoners, the economically disadvantaged, the elderly, those with cognitive impairments, and minority groups. History is filled with examples of individuals and groups targeted for cruel and unethical research and experimentation. **Unethical** human experimentation such as that conducted during World War II (link is external)and the Tuskegee Syphilis Study resulted in the creation of regulatory and ethical safeguards designed to protect the rights and dignity of participants in clinical trials and research studies.

IRBs were the ultimate result and are in place to ensure research is conducted **ethically** and in accordance with federal regulations. IRBs serve as an objective third party, an oversight committee, governed by federal regulations to protect participants and manage risk to those involved in research.

Types of IRB Review

Exempt	Expedited	Full Board	Does not need IRB Review
Research on two different teaching strategies	Research where disclosure of the participant's identity might result in negative legal, financial, economic or social consequences	Research that might put participants at risk, such as research on domestic violence or illegal drug use	Activities with no hypothesis-driven methodologies and no research protocol
Analyzing census data about aging or housing	Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture from healthy, nonpregnant adults who weigh at least 110 pounds.	Research using sensitive information (e.g., information that reasonable persons would not want disclosed)	Course-related activities designed specifically for educational or teaching purposes,
Data that comes from sources that are publicly available	Research that involves combining de identified data sets in a way that may make some data individually identifiable.	Research studies on human subjects that involve greater than minimal risk	Literature review addresses previous research in a field and supports the researcher's purpose or research question
Observing adult and child interactions at a sports game	Interviews or surveys on sensitive topics where the subject can be identified		Surveys issued or completed by University personnel for the intent and purposes of improving services and programs
Surveys or interviews of non-vulnerable adults about non-sensitive topics	Linguistic and ethnographic studies, or studies involving focus groups		
	Almost all research involving minors		
	Studies of existing data or pathological specimens that include identifying information		
	Analyses of data collected via recordings		

Data relevant….

Criteria for IRB Approval

(1) Risks to subjects are minimized

(2) Risks to subjects are reasonable in relation to anticipated benefits

(3) Selection of subjects is equitable.

(4) Informed consent will be sought from each prospective subject or the subject's legally authorized representative, in accordance with, and to the extent required by §46.116.

(5) Informed consent will be appropriately documented, in accordance with, and to the extent required by §46.117.

(6) When appropriate, the research plan makes adequate provision for monitoring the data collected to ensure the safety of subjects.

(7) When appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data.

Information Security…?

Consequences of IRB failures

Universities and Hospitals shut down by FDA and/or OHRP (Office for Human Research Protections)

Mar 1999 West Los Angeles Veterans Administration Medical Center
May 1999 Duke University Medical Center
Aug 1999 University of Illinois
Sep 1999 University of Colorado
Sep 1999 University of Pennsylvania
Jan 2000 Virginia Commonwealth University
Jan 2000 University of Alabama at Birmingham
Jun 2000 University of Oklahoma – Tulsa
Jun 2001 Johns Hopkins Medical University
August 2008 – Indiana University voluntarily moves IRB reviews to Indianapolis campus

Consequences of IRB failures

Duke

- Routine site visit in December, 1998 uncovered 22 administrative deficiencies (including inadequate documentation)
- All NIH-funded activities were suspended until the deficiencies were addressed

Texas Applied Biomedical Services

- FDA audit in 2012 identified 5 significant violations resulting in the suspension of all ongoing trials

Consequences of IRB failures

University of Colorado – Denver

- –FDA and OHRP ordered the suspension of thousands of human research studies
- –According to the school, the cost to revamp research guidelines, strengthen its internal review board and hire consultants was $3 million.

What is an Ethical Review (as conducted by an IRB)

The IRB's authority is founded in and guided by many sources, including regulatory statutes, institutional policies, ethical canons, and members' own perceptions of community and professional standards.

Standards suit the discipline and the institutions:

1. Protect institution from bad research
2. Protect the public (from time wasting to danger)
3. Protect against errors that could lead to falsification or fabrication
4. Protect values such as trust, accountability, mutual respect and fairness

What is an Ethical Review (as conducted by an IRB)

An institute active in research normally follows a scholarly code of conduct defined by the institution itself. Such codes can include certain universal values:

1. The treatment of human subjects
2. Honesty
3. Maintaining integrity of all experiments and research
4. Publishing the research and results
5. Granting access to others to allow reproduction of testing
6. Personal responsibility for the research
7. Acknowledging others contributions (not just citations)

Data Stewardship…?

https://doctoralnet.com/

Ethical Review – How does this translate to you?

1. Not to have a biased point of view
2. Not to ask questions that dont relate to your problem or question directly
3. Dont manipulate questions or later data to reflect what you want them to reflect
4. Informed consent
5. No harm for participating or not
6. No undo influence from researcher to participant
7. Neutrality is key

Ethical Review – Why is it tricky?

Cultural understanding of life and science change over time

1950‘s

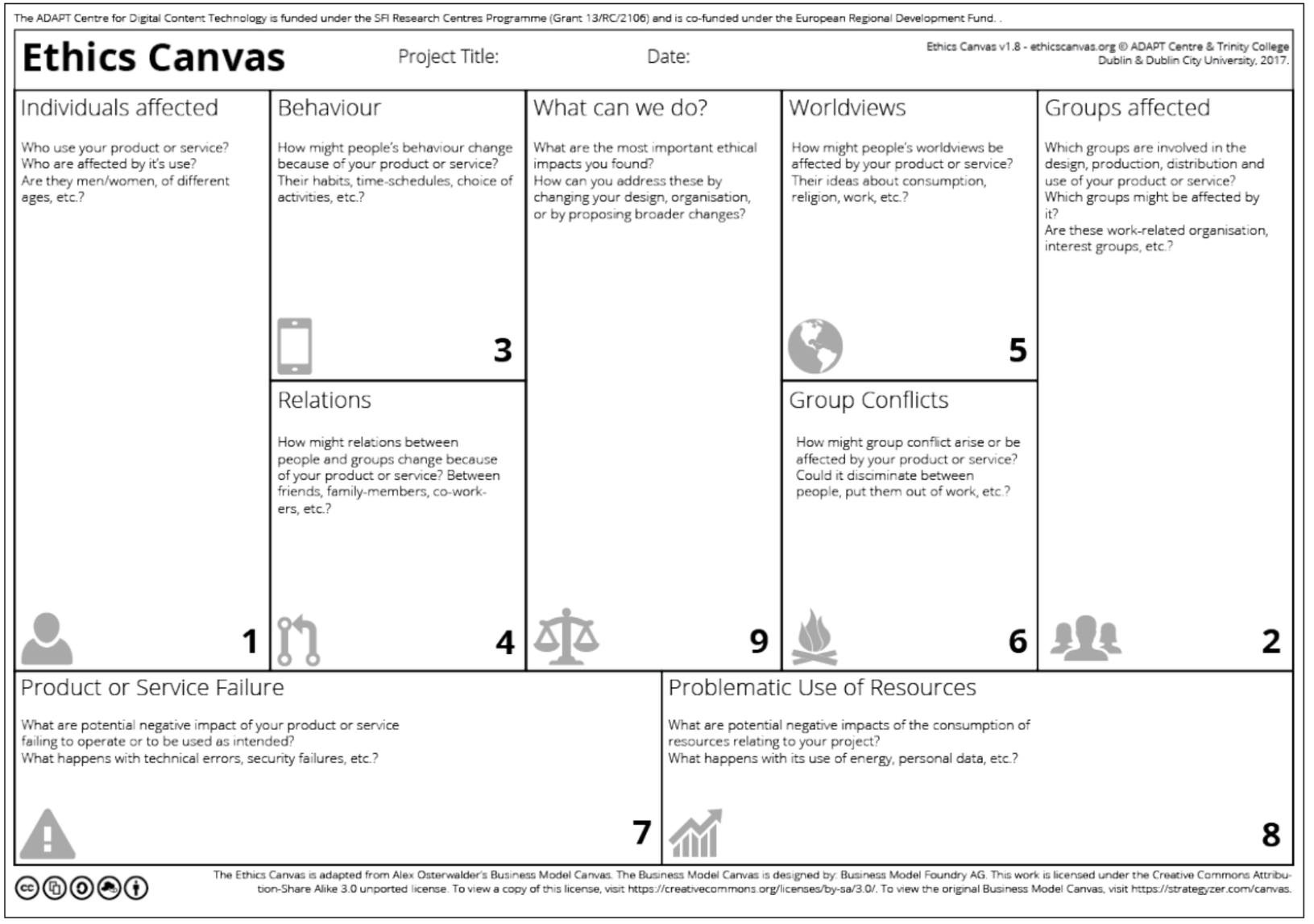
- Animals are not considered in ethics
- Experiments on people in care were conducted
- Anything goes if the person agrees to sign off on it
- Conflict of interest between research / business

2050‘s

- Animals have rights as subjects too
- Protected status for children/prisoners – who next?
- Should any experiments mess with DNA? Allow for cross breeding species?
- Embryo mapping? Brain cell manipulation? Chipping people or other forms of life?

Ethic Canvas

We could need the help of a „tool“ to assess ethical implications that our projects bring with them. Let us dive right into Data Ethics and the Ethic Canvas.



The ADAPT Centre for Digital Content Technology is funded under the SFI Research Centres Programme (Grant 13/RC/2106) and is co-funded under the European Regional Development Fund. .

Ethics Canvas

Project Title: Date:

Individuals affected

Who use your product or service?
Who are affected by it's use?
Are they men/women, of different ages, etc.?

1

Behaviour

How might people's behaviour change because of your product or service?
Their habits, time-schedules, choice of activities, etc.?

3

Relations

How might relations between people and groups change because of your product or service? Between friends, family-members, co-workers, etc.?

4

What can we do?

What are the most important ethical impacts you found?
How can you address these by changing your design, organisation, or by proposing broader changes?

9

Worldviews

How might people's worldviews be affected by your product or service?
Their ideas about consumption, religion, work, etc.?

5

Group Conflicts

How might group conflict arise or be affected by your product or service?
Could it discriminate between people, put them out of work, etc.?

6

Groups affected

Which groups are involved in the design, production, distribution and use of your product or service?
Which groups might be affected by it?
Are these work-related organisation, interest groups, etc.?

2

Product or Service Failure

What are potential negative impact of your product or service failing to operate or to be used as intended?
What happens with technical errors, security failures, etc.?

7

Problematic Use of Resources

What are potential negative impacts of the consumption of resources relating to your project?
What happens with its use of energy, personal data, etc.?

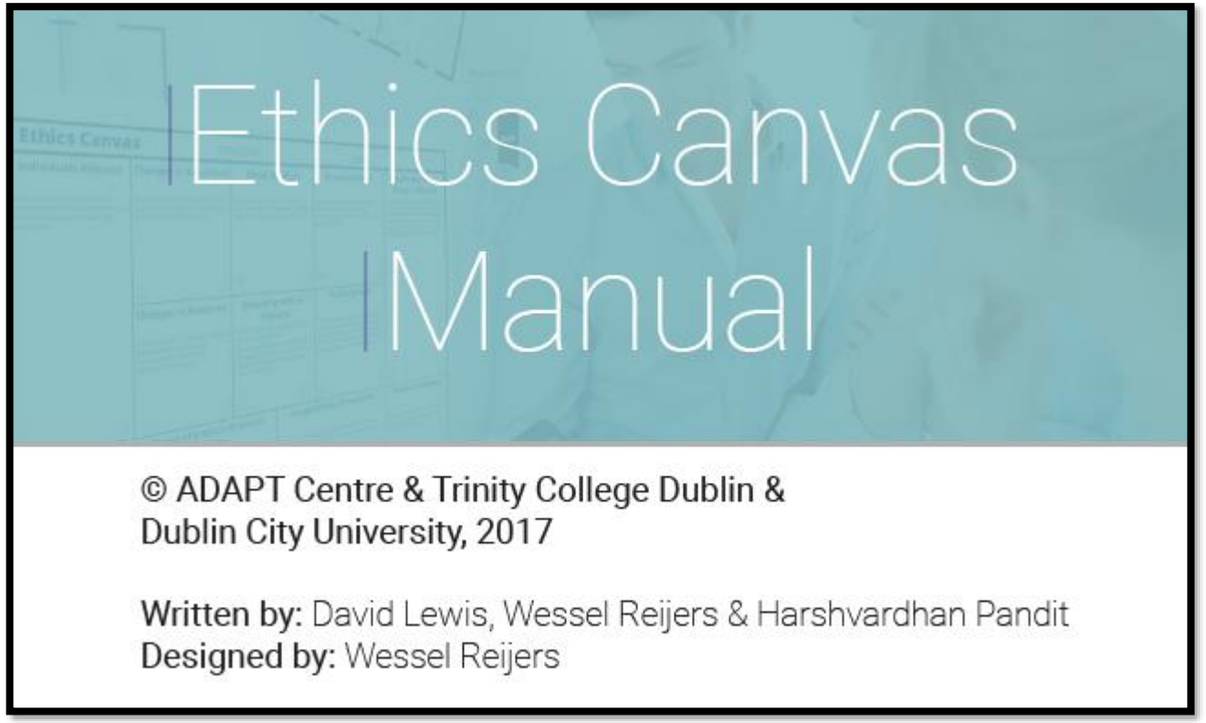
8

"We developed Ethics Canvas as a novel method to address these challenges using a tool that encourages discussions pertaining to practicing ethics in research and innovation."

Harshvardhan J. Pandit and Dave Lewis. 2018. Ease and Ethics of User Profiling in Black Mirror. In Companion Proceedings of the The Web Conference 2018 (WWW '18). International World Wide Web Conferences Steering Committee, Republic and Canton of Geneva, CHE, 1577–1583. https://doi.org/10.1145/3184558.3191614

Ethics Canvas

At this point, you are **advised** to read the followig documents:



This manual guides you through each of the sections that are pertinent to the Ethics Canvas.

They come as a PDF slideshow, and are uploaded on moodle. Please have an overview.

Ethics Canvas

At this point, you are **advised** to read the followig documents:

This template will be the base for the coaching session. The idea is to fill in this template covering your project that was defined earlier, bot in the DMP and at the FAIR data-level.

You find the high-resolution document on Moodle!

Ethics Canvas

At this point, you are **advised** to read the followig documents:

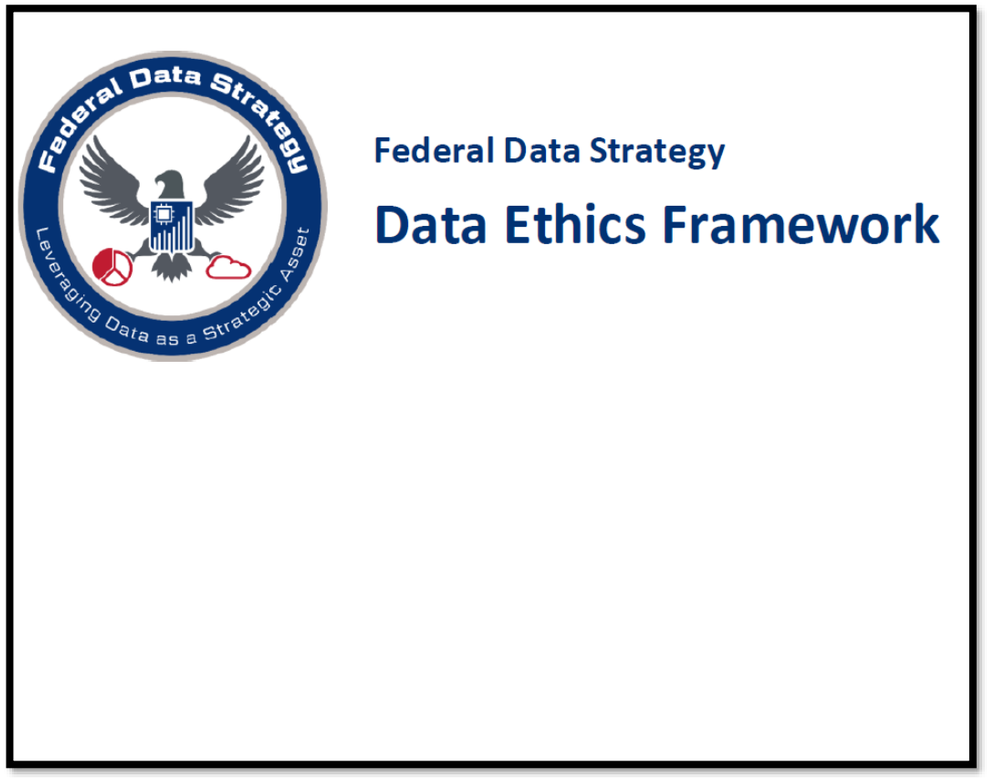
This explanation follows the ODI Data Ethics Canvas. It is a very good overview of all aspects related to ethical implications in (research) projects.

This document serves as guideline of how to fill in the Canvas template for the coaching session. The main idea is to consult this document if you want to sharpen your answers. You will not have to study ist content, simply use it as material to read up missing information.

You find the PDF on moodle.

Data Ethics Material

At this point, you are pointed to further reading materials that **you can consult, but you don‘t have to**.



This document shows a full-blown collection of definitions, structure, use cases and examples regarding Data Ethics.

You find it here
https://resources.data.gov/assets/documents/fds-data-ethics-framework.pdf

Or also uploaded on Moodle.

Questions?

The idea for today was to give you an introduction overview about

- ❑ Foundation of Ethics
- ❑ Information- and other sub-areas of ethics
- ❑ The Internal Review Board
- ❑ The Ethics Canvas

The material shall enable you to identify, discuss and decide upon ethical aspects in your data, your work, and in your community.