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# **UNIFR OPEN SCIENCE WEEK** Open Data and Management of Sensitive Research Data



- 1. Data management involves many legal fields.
- 2. In the academic world, everybody has to manage **different data**.
- 3. These data, depending on the **field of research** and the **partners involved**, are often covered by confidentiality clauses, professional secrecy, functional privacy, data protection, patent law...
- 4. To understand the **general legal context** and to apply the **organizational and technical measures** key skills are needed.
- 5. The question is... what is **your role** and where to **start**?

### **COURSE OBJECTIVES** IDENTIFY THE MOST RELEVANT LEGAL QUESTION



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### **1. MANY LEGAL FIELDS** LEGAL JUNGLE

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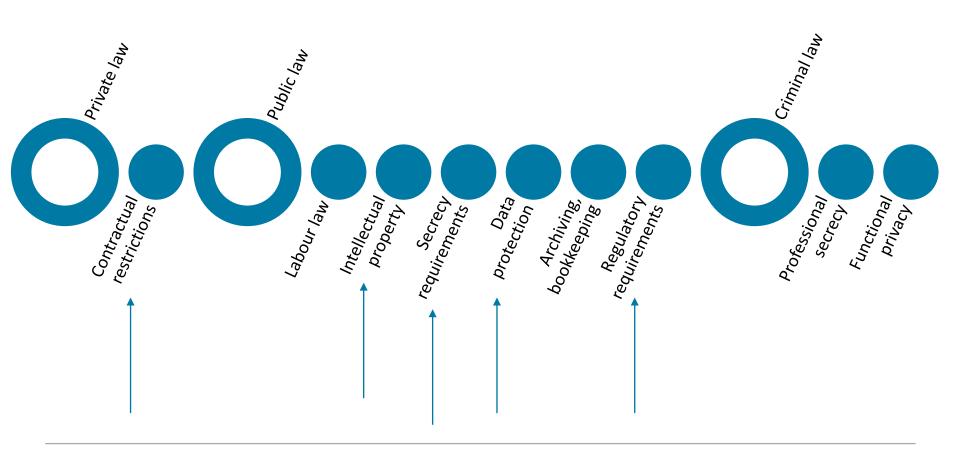
"Until now, data archiving platforms in the fields of humanities and social sciences in Switzerland mainly focused on technical issues of research data archiving. However, the introduction of the European General Data Protection Regulation (GDPR), the need to have complete Data Management Plans (DMPs) for projects of the Swiss National Science Foundation (SNF), and the upcoming revisions of the Swiss Federal Act on Data Protection (FADP) and the Swiss Federal Act on Copyrights and Related Rights (CopA), **a good understanding of the legal background of data management becomes more and more important in order to reduce legal risks and avoid high penalties**. However, often it is not easy for researchers to orient themselves within the **legal jungle**. It is therefore necessary to identify the most relevant legal questions and provide specific solution approaches that are easily understandable also to legal laymen."

Source: www.swissuniversities.ch/fileadmin/swissuniversities/Dokumente/Organisation/SUK-P/SUK\_P-2/192-009\_DMLawTool\_Abstract\_26.08.2019.pdf

### **1. MANY LEGAL FIELDS**



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### **1. MANY LEGAL FIELDS** CONTRACTUAL RESTRICTIONS

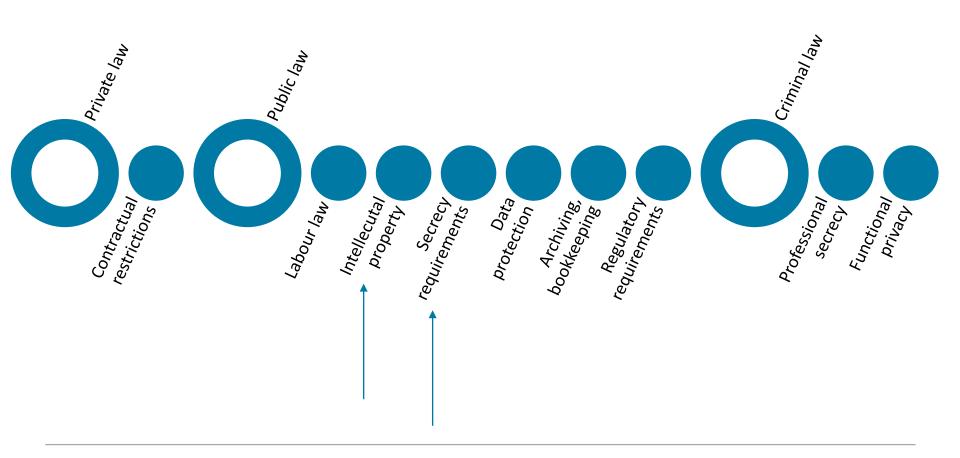


- Contracts
  - Research (with SME, industry)
  - Cloud (Open Science)
- Clauses
  - Confidential clauses
    - Protection of secrets (personal or material data are concerned, business secrets)
    - Intellectual property rights, know-how
    - Data collection (customer base)
    - Professional secrets (Medical, Bank clients)
  - Exclusivity clauses
  - Exclusions or limitation of liability clauses

### **1. MANY LEGAL FIELDS**



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- Copyright
  - Co-author, authentification, conflict management
  - Fraud <u>https://www-francetvinfo-fr.cdn.ampproject.org/c/s/www.francetvinfo.fr/sante/maladie/coronavirus/enquete-les-etudes-scientifiques-elles-aussi-victimes-des-fraudeurs</u> 4833107.amp
- Trademark
- Patent
  - Protection of secrets (technological innovation, condition of novelty)
  - Research and cookies
  - Communication and security

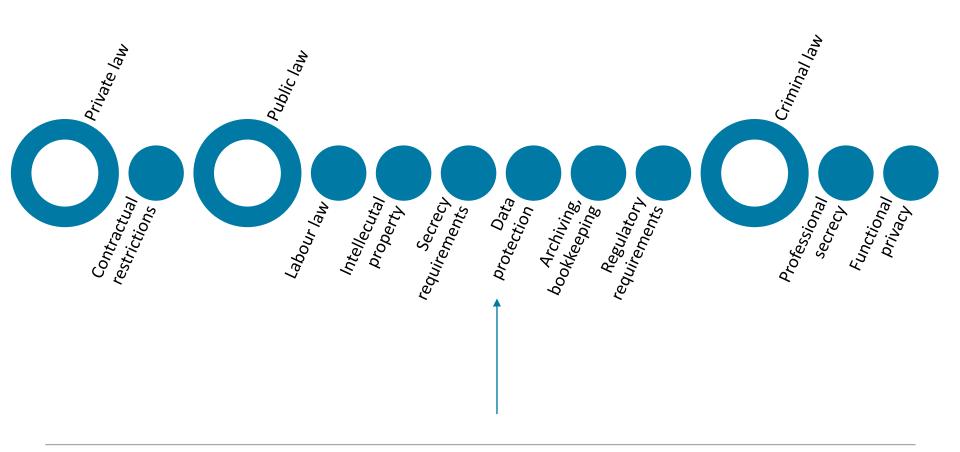
"One of the rationales for patents is that they stimulate economic and technological development and promote competition by creating a financial motivation for invention in return for the disclosure of the invention to the public. Although the potential of the patent system has been widely recognized in the context of dynamic innovation activities, some critics have claimed that the **current patent system stymies R&D and technological advances**."

Source: https://www.wipo.int/patent-law/en/developments/research.html

### **1. MANY LEGAL FIELDS**



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### **1. MANY LEGAL FIELDS** DATA PROTECTION



- General principles applicable to the processing of personal data
- These principles should be considered as an introductive guideline and basic framework for the particular requirements for processing personal data
  - Lawfulness, fairness and transparency
  - Purpose limitation
  - Data minimization
  - Accuracy
  - Storage limitation
  - Integrity & confidentiality



- Processing data in a transparent manner to the data subject means not only providing the relevant information of the processing activity itself, but also informing the data subject in regards to their data subject rights
- "Emphasise that transparency is a fundamental condition for enabling individuals to exercise control over their own data and to ensure effective protection of their personal data, which could serve as a basis for improved information requirements." (European Commission, Commission staff working paper, Impact Assessment, 25.01.2012)
- Fundamental right
- Difficult but possible: AI & Transparency

### **1. MANY LEGAL FIELDS** LIMITATION

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First component:

- Collect for specified (sufficiently defined, depending on the particular context and prior to the collection)
- explicit (sufficiently unambiguous and clearly expressed and should leave no doubt or difficulty in understanding)
- and legitimate purposes (in accordance with the law in the broadest sense, legitimacy of a given purpose can also change over time)

Second component:

Not further processed in a manner that is incompatible with those purposes

• Requires a compatibility test (double negation prohibiting incompatibility - means, any further processing is still authorised as long as it is not incompatible)

### **1. MANY LEGAL FIELDS** MINIMALISATION

- Personal data shall be "adequate, relevant and limited to what is necessary"
- No universal approach of determining the necessity of the data processing activity
- Has to be assessed in relation to the specified, explicit and legitimate purpose for which the data have been collected on a case-by-case basis
- Think about the option: Anonymisation! Closely linked to the principle of purpose limitation

### **1. MANY LEGAL FIELDS** NECESSITY

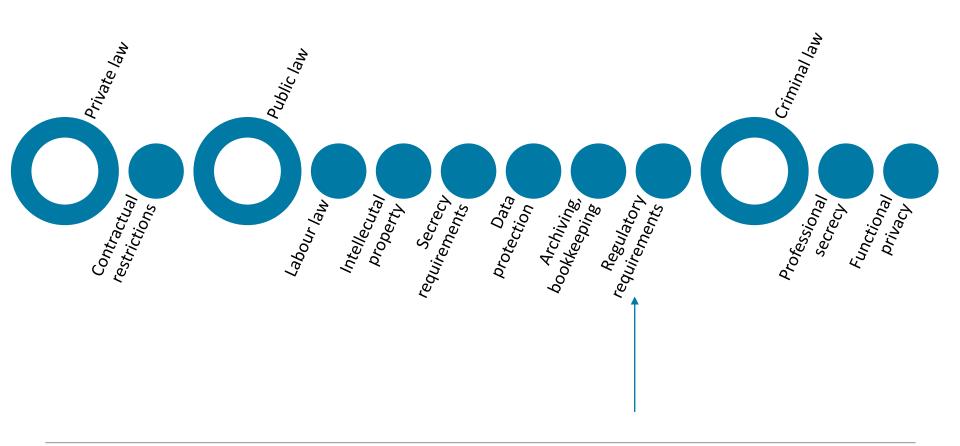


- Factual Element: Personal related data shall only be processed if and to the extent that such processing actually casually supports the fulfilment of the relevant purpose
- Judgmental Element: Personal related data shall only be processed if and to the extent that the relevant purpose cannot be reasonably achieved by other means avoiding such processing

### **1. MANY LEGAL FIELDS**



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### **1. MANY LEGAL FIELDS** REGULATORY REQUIREMENTS



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- Dual-use items can be used for both civilian and military applications. Switzerland controls the export, transit and brokering of dual-use items to contribute to international peace and security and prevent the proliferation of Weapons of Mass Destruction (WMD).
- Export Controls are rules and restrictions imposed by governments (based on international agreements as mentioned earlier) on businesses on the movements and transfers of activities related to certain listed
  - ✓ goods,
  - ✓ software and
  - ✓ Technology
- In scope of the Dual use regulation is: <u>the export, the import, the transit and the brokerage</u> of above mentioned items

### **1. MANY LEGAL FIELDS** REGULATORY REQUIREMENTS

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- Technology & Dual Use
  - Means information for the development, manufacture or use of goods that is neither generally accessible nor serves for purposes of pure scientific research (e.g. software, access to software and technology – such clouds computing etc.). This information takes the form of Technical data or technical assistance.

# Basic Principles of Export Controls

Principles in Academia

- Sensitive subject matters:
  - Biology, including Biotechnology and Medicine
  - Chemistry, Biochemistry
  - Physics
  - Nuclear Technology
  - Energy and environmental technology
  - Information and communication technology
  - Electrical Engineering
  - Aerospace and transport technology
  - Mechanical Engineering
  - Materials Engineering- Process Engineering

### **2. DIFFERENT DATA GENERAL – PERSONAL - SENSITIVE**

# **General Data Protection Regulation (GDPR)**

#### Personal Data

Requirements:

- 1. notice of privacy
- explanation for use of Personal Data 2.
- consent to use/transfer the data outside of EEA 3.

Examples:

- name and surname
- home address
- email address
- ID card number
- IP address

doctor that could be used to

#### **Special Categories of Data**

#### Requirements:

- explanation of the need for this sensitive data
- explanation that the US may not offer the same protection of personal data 2.

genetic data

- explicit consent to use and/or transfer that type of data з.
- racial/ethnic origin
  - political opinions
- biometric data for identifying a person
- religious or philosophical beliefs · health-related data
- trade union membership

- https://research.ucr.edu/ori/faq/faq-gdpr
- sex life or sexual orientation

#### cookie ID . phone identifier .

 data held by a hospital or identify a person





All Data

### **2. DIFFERENT DATA** SENSITIVE DATA

- Personal data revealing racial or ethnic origin, political opinions, religious and philosophical beliefs [...] health or data concerning a naturals person's sex life or sexual orientation
- Processing data must be justified by the data subject's explicit consent

### **2. DIFFERENT DATA** CLOUD ISSUES

- Data security
- Data process in by third parties
- Cross-border transfer



### **3. FIELD OF RESEARCH** PARTIES INVOLVED



- COMPLEX CASE: Research with big Pharma exclusivity to be published where?
- COMPLEX CASE: Research with a watchmaking company check the novelty check the plagiarism – when – to publish?
- COMPLEX CASE: Arbitrage court ou big pharma requires personal data in the companies?



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Data breach due to:

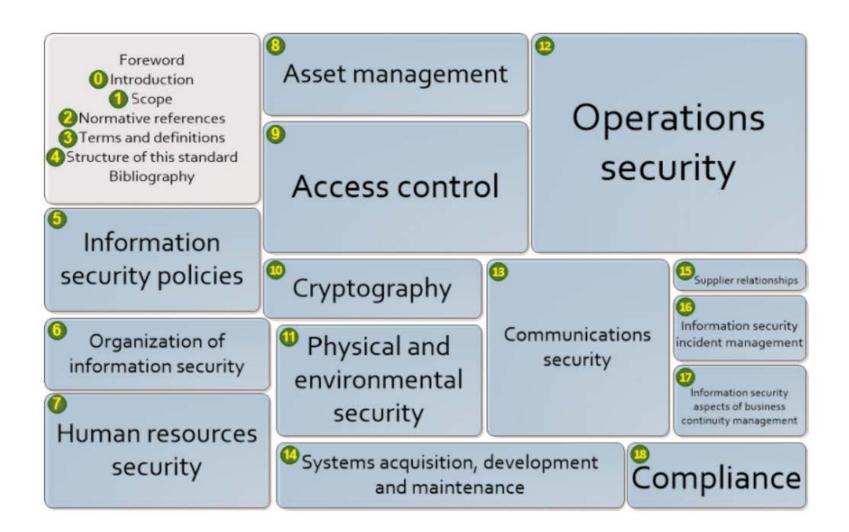
- Lack of confidentiality
- Availability
- Integrity



- Security regulations (appropriate technical and organizational measures TOMs)
- Sanctions EU EUR 20 million / 4% annual turnover Sanctions Suisse CHF 250'000

### **4. TOMS** EX. ISO





### **4. TOMS** ORGANISATION (UNIBAS)



#### Klasse 0

Öffentliche Informationen

Diese Informationen sind für die Öffentlichkeit bestimmt und können uneingeschränkt veröffentlicht und geteilt werden.

#### Klasse I Interne Informationen

Diese Informationen sind für den universitätsinternen Gebrauch und nicht für die Öffentlichkeit bestimmt. Das Veröffentlichen oder die Weitergabe dieser Informationen hätte aber keine oder nur geringe negative Auswirkungen für die Universität oder einzelne Personen.

#### Klasse II

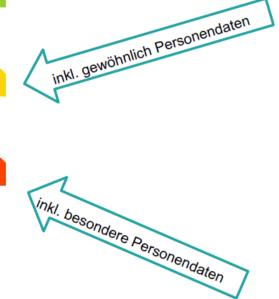
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#### Klasse III

#### Geheime Informationen

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### **5. YOUR ROLE** YOU HAVE TO ASSUME



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### **5. YOUR ROLE** STOP THINKING

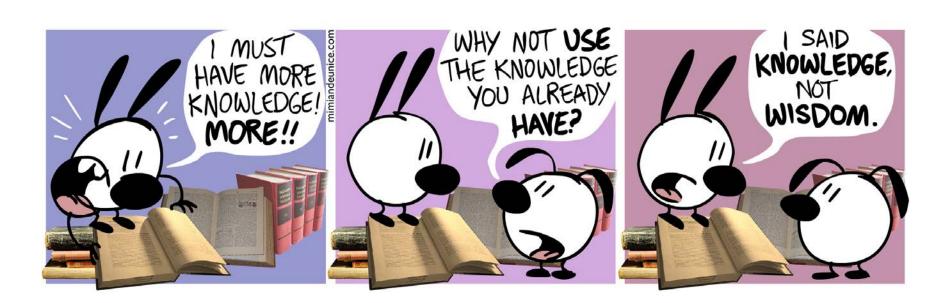


- We see the security as overvalued
- We are not an attractive subject for attack
- We have never been affected
- We have our systems under control
- We regulate ad hoc
- We have our techies
- We delegate the security
- We cannot afford it
- We are insured
- We are powerless

### **MORE ABOUT LEGAL STANDARDS**



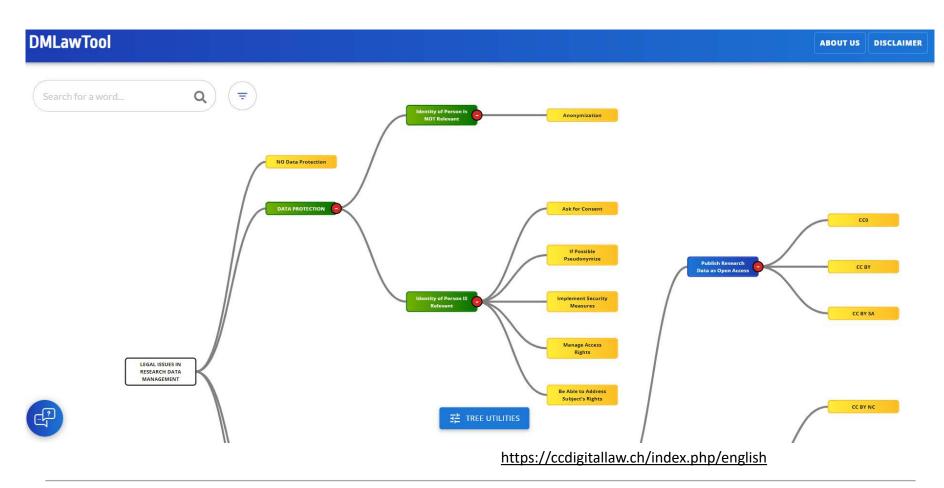
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### **DMLAWTOOL** HTTPS://DMLAWTOOL.CCDIGITALLAW.CH/



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### MORE ABOUT LEGAL STANDARDS LINK



"How can I meet ethical and legal standards while respecting the epistemological and methodological codes of my discipline? How to respond to the growing demand for data openness without violating the new data protection rules? How do I store my data securely? Can I share everything? What will happen to my data after I retire?"

https://forscenter.ch/data-services/data-management/?lang=fr

https://www.path2integrity.eu/ri-materials

https://www.college-de-france.fr/media/catalogues-et-ressources-enligne/UPL5745041992875344860 relier les ids.pdf

https://www.ouvrirlascience.fr/wp-content/uploads/2021/10/Guide-formation\_science\_ouverte\_ED\_web\_DP.pdf

https://www.pwc.ch/de/insights/regulierung/veraenderung-revidiertes-dsg.html



La fin de la publication scientifique ? Une analyse entre légitimité, prédation et automatisation

https://hal.archives-ouvertes.fr/hal-03435153



## **EXCURSUS** (SOURCE: ZÜRCHER VERWALTUNGSRATSKONFERENZ 2021)



