

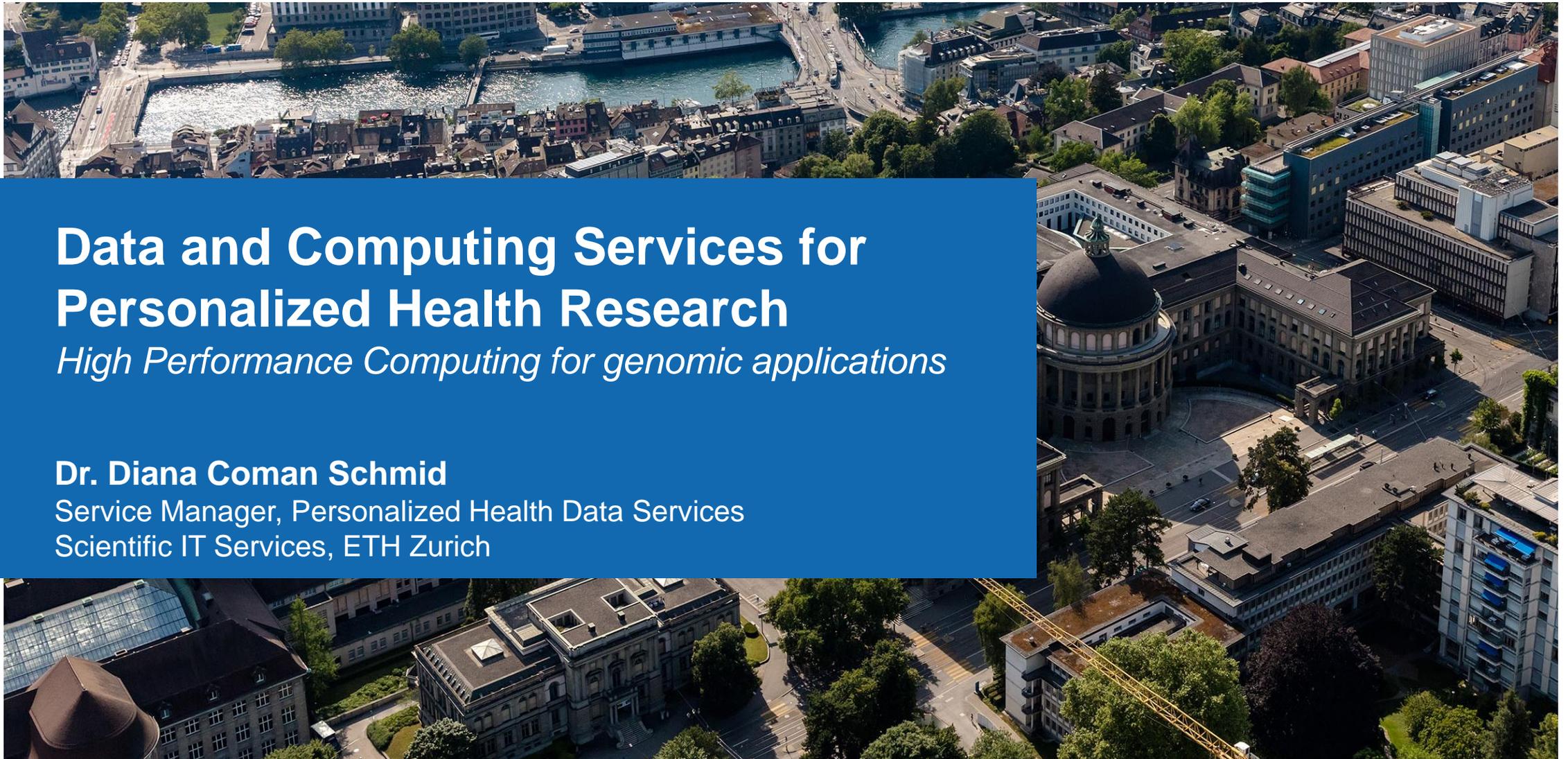


Data and Computing Services for Personalized Health Research

High Performance Computing for genomic applications

Dr. Diana Coman Schmid

Service Manager, Personalized Health Data Services
Scientific IT Services, ETH Zurich



Outline

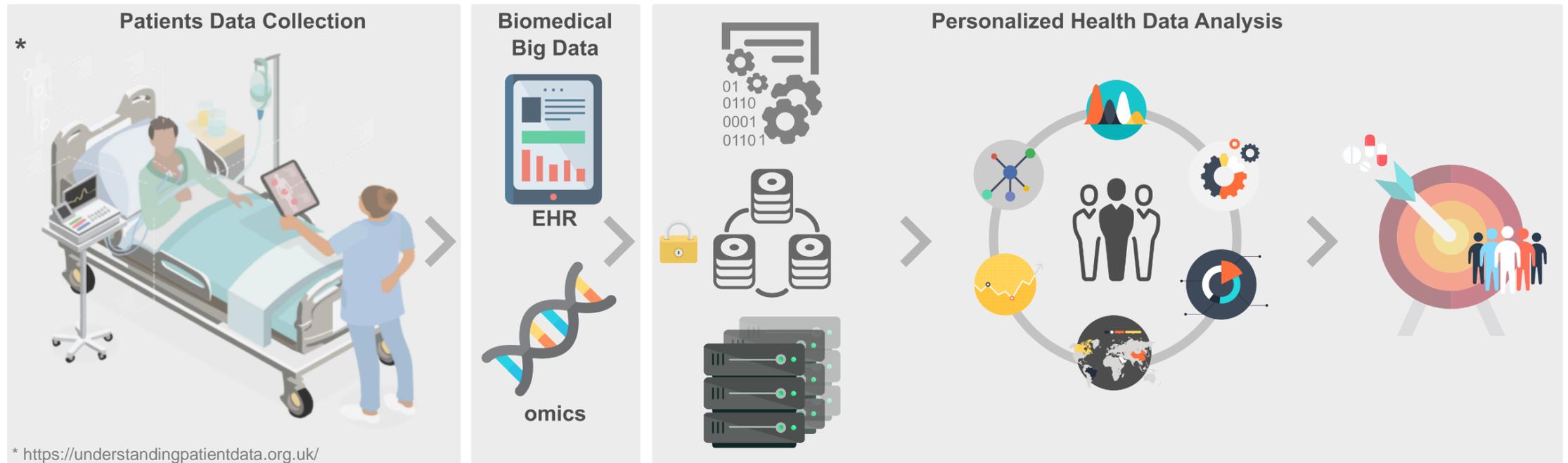
- ▶ personalized health (PH) research: [data driven, sensitive personal data \(confidential data\)](#)
- ▶ data confidentiality and individuals privacy in PH Research: [data protection and IT security awareness](#)
- ▶ secure data and computing services for PH research: [Leonhard Med and BioMedIT](#)

Personalized health (PH) research

Data driven, sensitive personal data (confidential data)

Personalized Health Research

Goal: provide the **right treatment**, at the **right moment** to the **right patients** (precision medicine) and ensure that as many people as possible **stay healthy** (prevention; personalized health).



○ Research on human data: **sensitive personal data**
Hereafter, per convention: **confidential research data**

Personalized Health Research

Trends

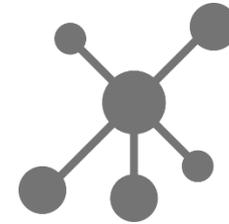
Confidential research data

Individual Studies



Classical Biomedical Research

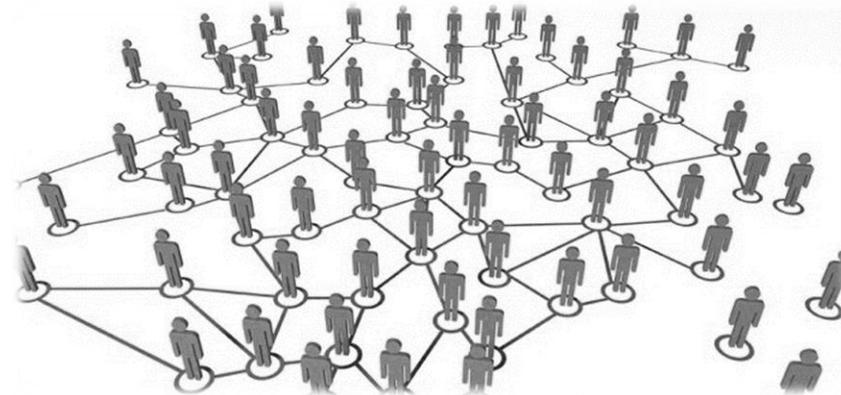
Data Driven Biomedical Research



Now

Networks of Studies

Citizens



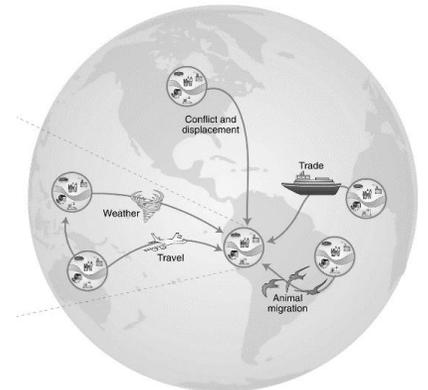
<https://www.laboursolutions.com.au>

One Health



<http://www.oie.int/en/for-the-media/onehealth/>

Global Health



Hernando-Amado *et al.*, 2019, Collignon *et al.*, 2018

Datasets are combined

Priv.
Conf.
Risk

Data FAIRness

Swiss Programs for Personalized Health Research



- SPHN key achievements of first funding period 2017-2020**
- ▶ 24 health-related personal data projects
 - ▶ building up secure data and IT infrastructures: BioMedIT
 - ▶ setting up Hospital Data Warehouses
 - ▶ developing a semantic strategy for health-related personal data

Handling confidential data in research > a _____ Paradigm Shift

○ From
Standard Research Infrastructure and Services
Towards
Secure & Versatile & User-friendly Scientific Data and IT Services

PROTECT CONFIDENTIAL DATA & INDIVIDUALS PRIVACY WHILE DOING RESEARCH

Legal & Ethics	Infrastructure & Services	Usage
<ul style="list-style-type: none">▪ Sensitive personal data▪ Data types & legal specification, ethics▪ Strictly controlled data access, use and sharing	<ul style="list-style-type: none">▪ Distributed data providers and large data lakes▪ Dataset combination: central vs. federation▪ FAIRness of sensitive personal data▪ Storage and compute power	<ul style="list-style-type: none">▪ Researchers: security & usability▪ Clinicians: UX, web services▪ Citizens: https://www.midata.coop MIDATA.coop https://swissdatacustodian.ch Swiss Data Custodian

NEW ecosystem

Data confidentiality and individuals privacy in PH Research

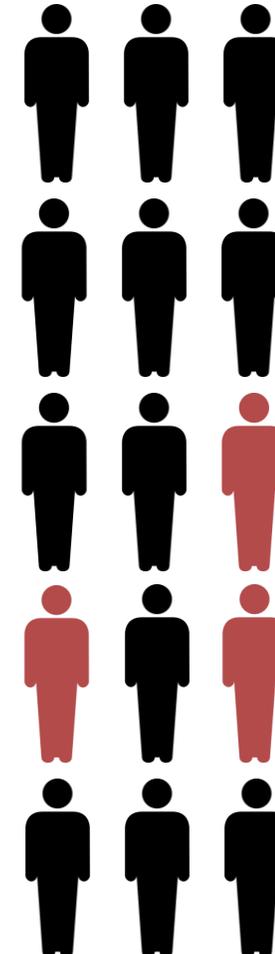
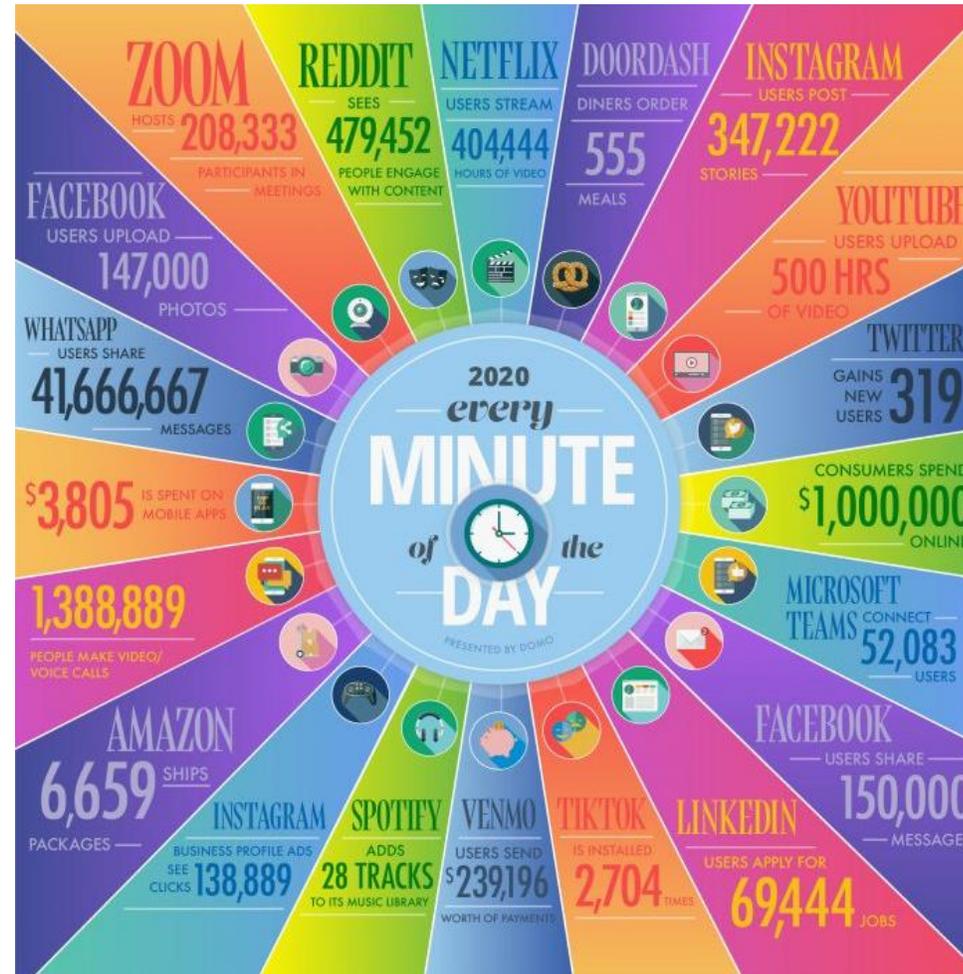
Data protection and IT security awareness

Data > Personal and Confidential Data (Sensitive Personal Data)

~ **2.5** quintillion bytes of data are created every day

90 % of all data was produced in the last few years

50 TB of data could easily be generated by a person every year



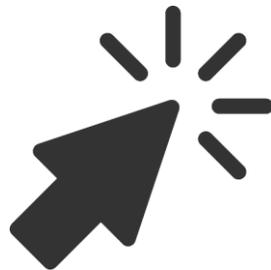
<https://www.domo.com/learn/data-never-sleeps-8>

Digital life > do you have control?

Terms of Service



reading



click & agree



<https://www.dimayarovinsky.com/#/i-agree/>

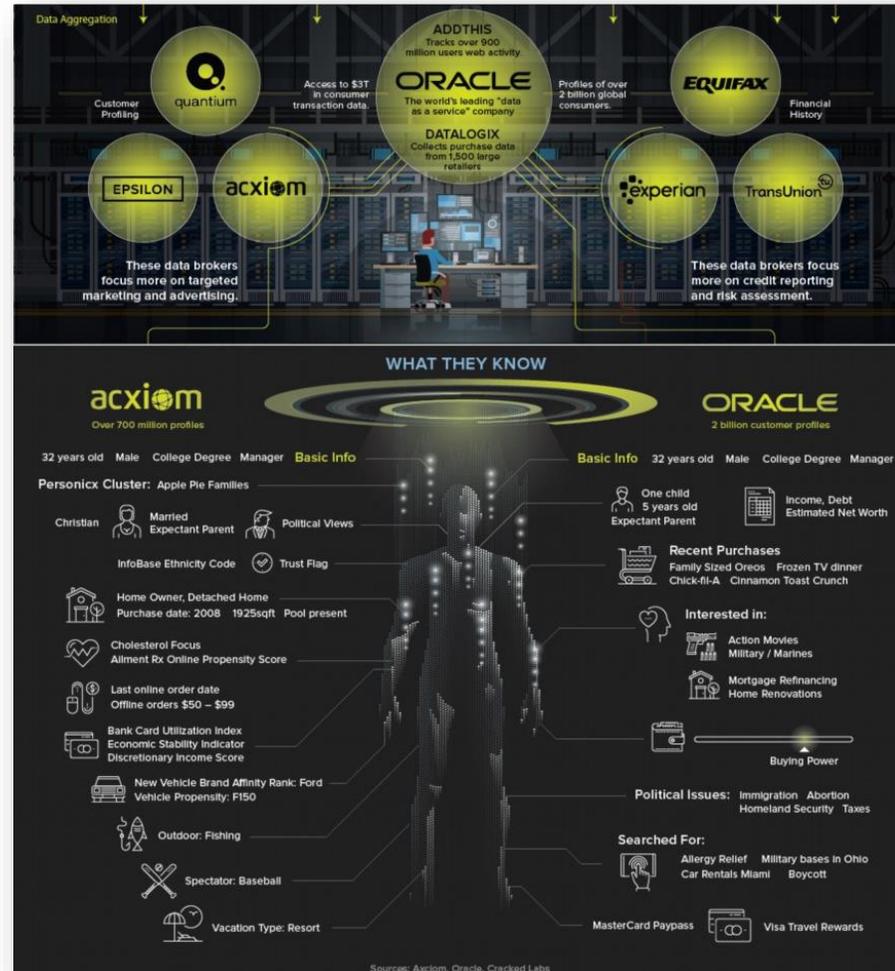
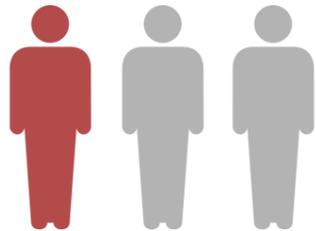
Where is my data

Who uses it

For what

Digital life > do you have control?

2.7 billion personal profiles stored



<http://www.visualcapitalist.com/personal-data-ecosystem/>

2-4 breaches involving **medical data** every week (US)

October 27, 2020
Helsinki, Finland (CNN Business)
confidential records of thousands of psychotherapy patients in Finland have been hacked and some are now facing the **threat of blackmail**.
Attackers were able to steal records related to **therapy sessions, as well as patients' personal information**

<https://edition.cnn.com/2020/10/27/tech/finland-therapy-patients-blackmailed-data-breach-intl/index.html>

Personal Data for Research > examples

In what area of your life would you like to increase your feelings of happiness? Select all that apply.

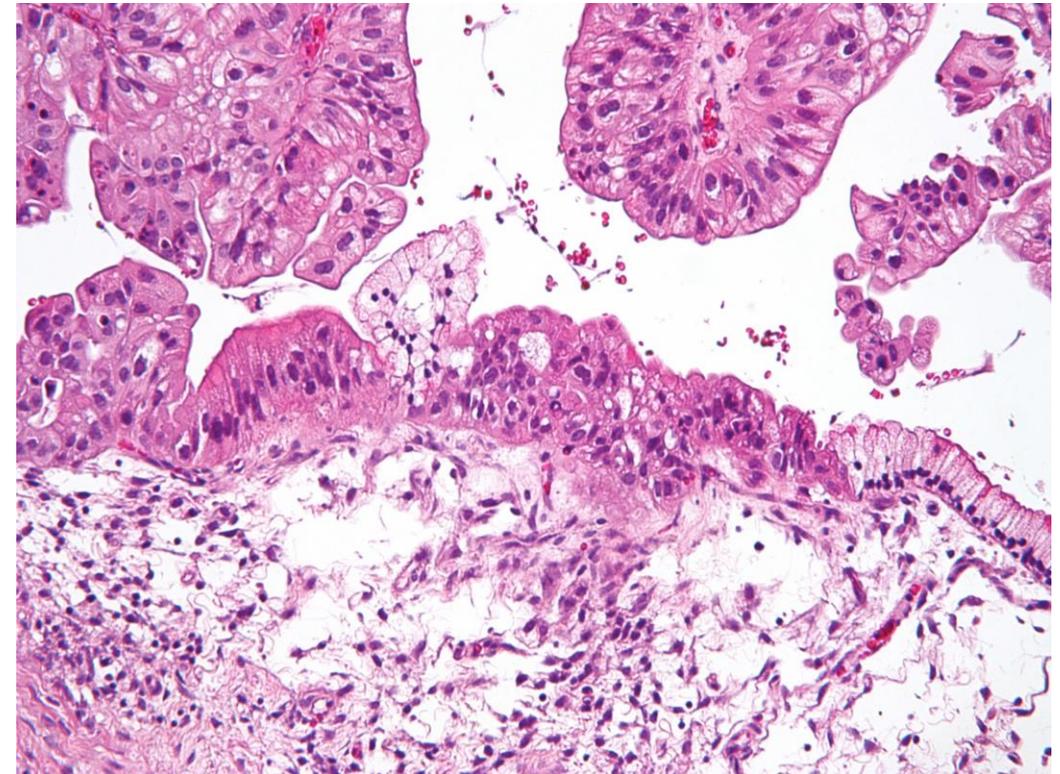
- Family
- Friends
- Relationship
- Workplace
- Career
- Health
- Wealth
- Surroundings
- Leisure time

Please state your agreement with the below statements:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I am pleased with the way I am	<input type="radio"/>				
I am pleased with the way I approach life	<input type="radio"/>				
I am pleased with the way I approach problems	<input type="radio"/>				
I am rarely interested in other people	<input type="radio"/>				
I feel that life is rewarding	<input type="radio"/>				
I am committed and involved	<input type="radio"/>				
I always see the bad in people	<input type="radio"/>				

<https://www.questionpro.com/survey-templates/happiness-survey-template/>

Happiness survey



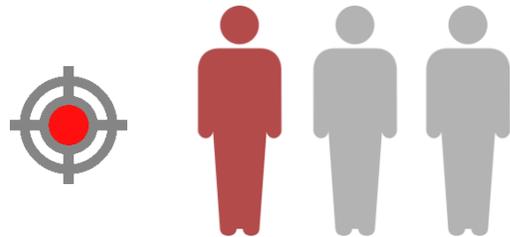
https://upload.wikimedia.org/wikipedia/commons/thumb/b/b8/Mucinous_imp_ovarian_tumour_intermed_mag.jpg/350px-Mucinous_imp_ovarian_tumour_intermed_mag.jpg

Pathology image

Personal Data for Research > examples

In what area of your life would you like to increase your feelings of happiness? Select all that apply.

- Family
- Friends
- Relationship
- Workplace
- Career
- Health
- Wealth
- Surroundings
- Leisure time



- Personal data
- Sensitive (health-related); «happiness» data too?
- De-identified from Research perspective:
 - Whose pathology image this is ? **No info**
 - Who answered «Career» ? **No info**
- Qualitative, Quantitative Research:
 - ✓ What diagnosis based on pathology image
 - ✓ How many answered «Career»
- Data protection:
 - Sensitive personal data (health-related)
 - **What is the risk** for data confidentiality and individuals privacy ?

Happiness s

Personal Data for Research > examples



<https://edu.sib.swiss/course/view.php?id=424>



Privacy Notice

How ESS collects your Information

When you register to access the ESS data we will collect data to allow us to record user details.

What Information ESS collects

ESS may collect the following types of personal data about you:

- Your name (title, first and surname) and contact information such as address, email address and institutional address. Your country of domicile and user category (eg Faculty member, PhD Student, Government official or other) as well as the academic discipline are recorded.
- The personal data are stored in a safe environment in accordance with GDPR requirements at NSD – Norwegian Centre for Research Data, Bergen, Norway. Backup systems are provided by the University of Bergen, Norway.

https://www.europeansocialsurvey.org/about/web_privacy.html

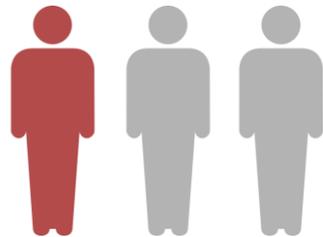
Social survey

The screenshot displays a patient record for 'Correctional Health' with patient ID ABCD-1234. The patient is 39 years old, female, with a DOB of 19710211. The current provider is Jennifer Watson RN. The record includes a navigation sidebar, a 'Specialty Template Set' (CHM), 'Reason(s) for visit', 'Chronic Problem List', 'Medical' history, 'Allergies', 'Vitals' table, 'Medications' table, and 'Patient Service info' table. A 'Health Monitor' section shows due dates for various tests like TST, Lipid Panel, Colonoscopy, Sigmoidoscopy, FOBT x3, Breast Exam, Mammogram, PAP Test, GYN Exam, and DEXA Scan.

Electronic Health Record

<https://medrecordsinfo.com/healthfusion-stands-out-among-emr-software-solutions/>

Personal Data for Research > examples



- Personal data
- Sensitive (health-related)
- Identifying information at Data Controller:
 - directly: name, address, etc.
 - indirectly: gender, age, medical history etc.
- Data protection:
 - Sensitive personal data (health-related) with **identifying information**
 - **What is the risk** for data confidentiality and individuals privacy ?

How ESS collects

When you register to access user details.

What Information

ESS may collect the following

- Your name (title, first and last), email address and institution (eg Faculty member, PhD student, academic discipline are
- The personal data are stored

requirements at NSD – Norwegian Centre for Research Data, Bergen, Norway. Backup systems are provided by the University of Bergen, Norway.

https://www.europeansocialsurvey.org/about/web_privacy.html

Provider visit	07/15/2010	Due:	Colonoscopy	08/23/2010
Consult Request			Sigmoidoscopy	07/15/2011
Other Templates			FOBT x3	
TST	08/23/2010		PAP Test	
			GYN Exam	
			DEXA Scan	

Electronic Health Record

<https://medrecordsinfo.com/healthfusion-stands-out-among-emr-software-solutions/>

Social survey

Research on confidential data > basic awareness



<https://edu.sib.swiss/course/view.php?id=424>

DMP

- Who “owns” persons/patients data, who and how “controls” these data
- Did the persons/patients give consent?
- Are the data de-identified, anonymized?

Data governance

ARDM ANALISYS

- Can my colleague send me briefly per encrypted e-mail a small dataset with data for only 5 patients for “quick” preliminary analyses?
- Can I use my laptop for “quick” look at this small dataset for the 5 patients?
- Can I send back to my research colleague preliminary findings about each of the 5 patients (patient level)?
- Do I need to keep track of who accessed/modified/deleted persons/patients data?

Data transfer, use

PUB.

- Am I allowed to publish persons/patients data in scientific journals?
- What happens if I publish patient data on open access research repos?
- What is the impact of data breach for myself, university, patients?

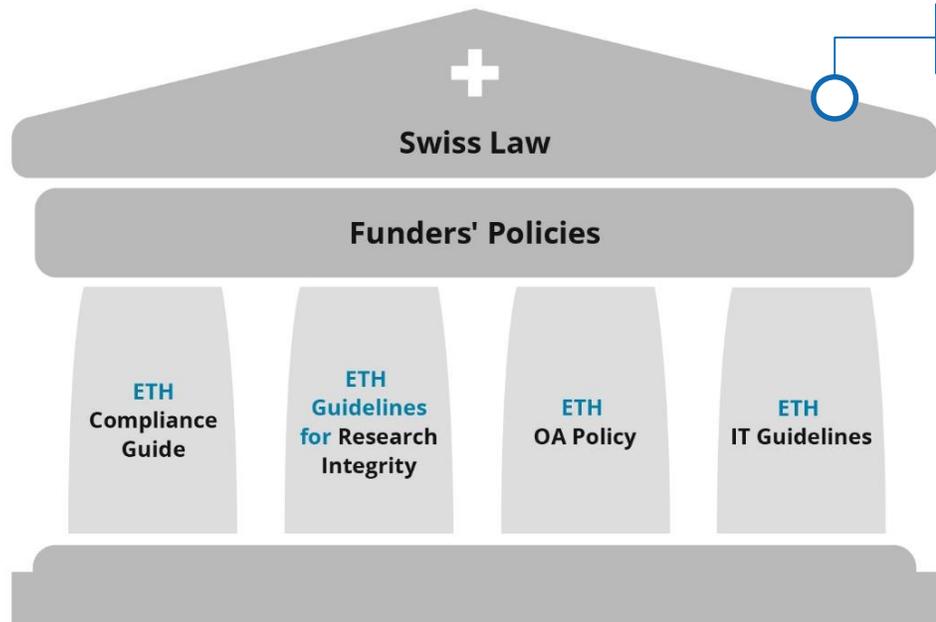
Responsibility, accountability

Research on confidential data requires special security measures: protect individuals privacy and ensure confidentiality of data OVER THE FULL DATA LIFECYCLE



Confidential Research Data

 Sensitive Personal Data,



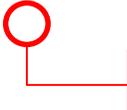
Swiss Criminal Code
Art. 321 Breach of Professional
Confidentiality (rel. HRA)

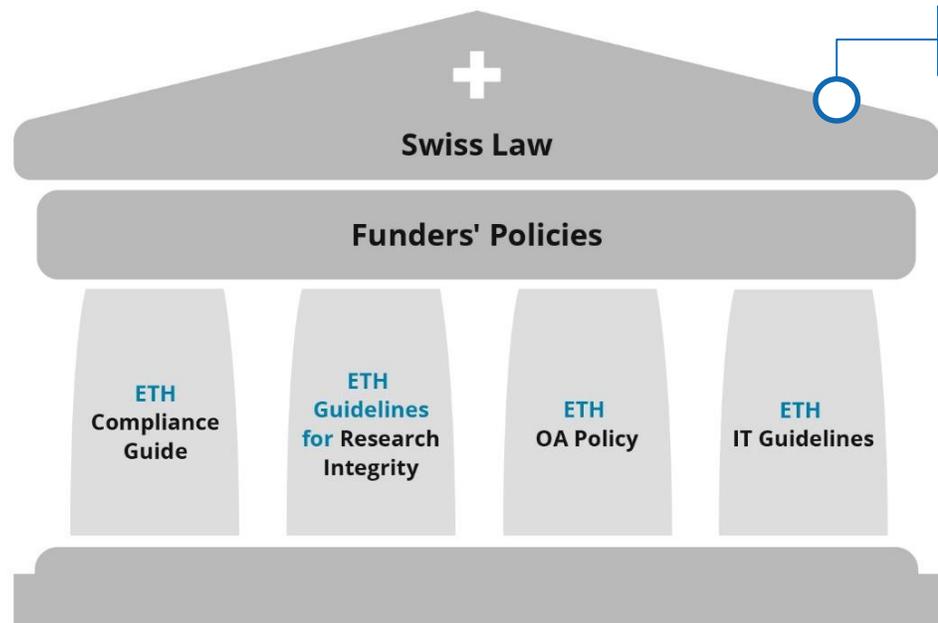
Adapted based on: Matthias Töwe
<http://www.library.ethz.ch/en/Services/Courses-and-guided-tours/Workshops>





Confidential Research Data

 Sensitive Personal Data, *FADP Art. 3c*



Federal Act on Data Protection
Art. 3c Sensitive Personal Data

Human Research Act
Art. 32-35 Further Use of Biol. Material
and Health-Related Pers. Data for Research

Human Research Ordinance
Art. 25-27 Anonymization, Coding
Art. 28-31 Informed Consent

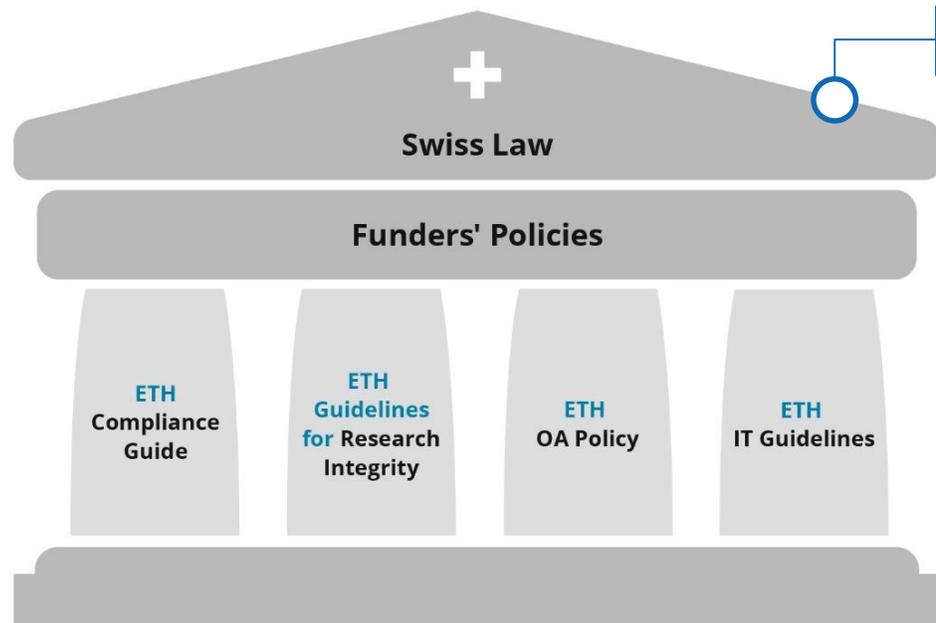
Swiss Criminal Code
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Confidentiality (rel. HRA)

Adapted based on: Matthias Töwe
<http://www.library.ethz.ch/en/Services/Courses-and-guided-tours/Workshops>



Confidential Research Data

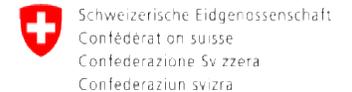
○ Sensitive Personal Data, *FADP Art. 3c*



Adapted based on: Matthias Töwe
<http://www.library.ethz.ch/en/Services/Courses-and-guided-tours/Workshops>



Federal Act on Data Protection Art. 3c Sensitive Personal Data



The following definitions apply:

- a. *personal data (data)*: all information relating to an identified or identifiable person;
- b. *data subjects*: natural or legal persons whose data is processed;
- c. **sensitive personal data**: data on:
 1. religious, ideological, political or trade union-related views or activities,
 2. **health**, the intimate sphere or the racial origin,
- e. **processing**: any operation with personal data, irrespective of the

Examples of personal data



<https://edu.sib.swiss/course/view.php?id=424>



Directly identifying information

- Full name & home address
- ID number
- Driver licence
- Social security number
- Biometric information (incl. finger prints)
- Genetic information

Indirectly identifying information

- Gender
- Birth date
- Job position
- IP address
- Blood sugar levels
- Daily movements

Examples of personal data



Directly identifying information

- ▶ Full name & home address
- ▶ ID number
- ▶ Driver licence
- ▶ Social security number
- ▶ Biometric information (incl. finger prints)
- ▶ Genetic information

 Sensitive Personal Data

Indirectly identifying information

- ▶ Gender
- ▶ Birth date
- ▶ Job position
- ▶ IP address
- ▶ Blood sugar levels
- ▶ Daily movements

 Personal Data

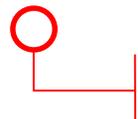


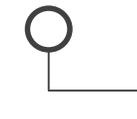
Directly identifying information

- ▶ Full name & home address
- ▶ ID number
- ▶ Driver licence
- ▶ Social security number
- ▶ Biometric information (incl. finger prints)
- ▶ Genetic information

Indirectly identifying information

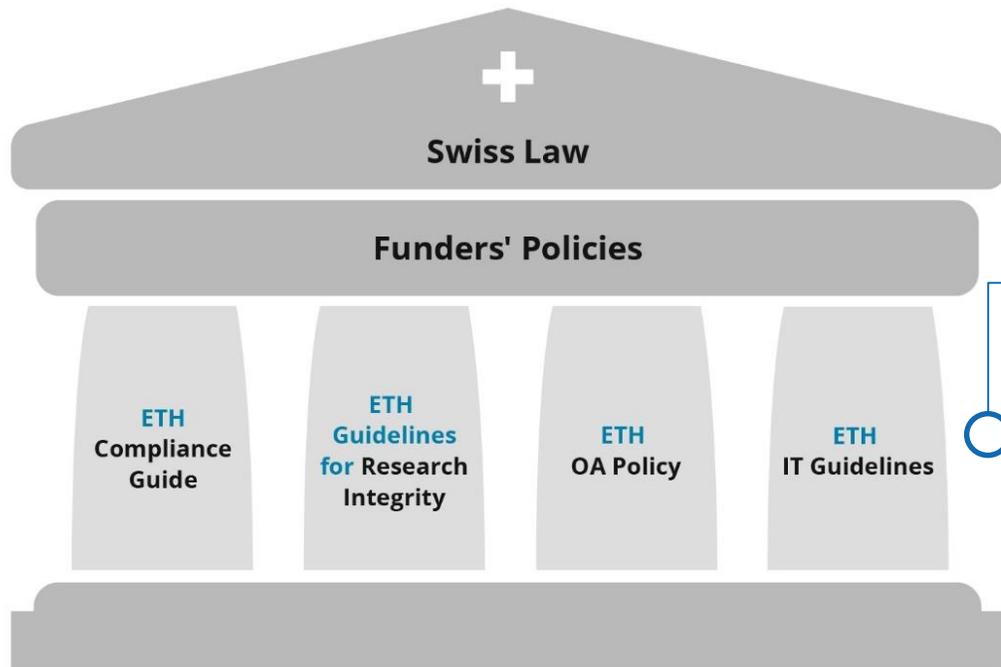
- ▶ Gender
- ▶ Birth date
- ▶ Job position
- ▶ IP address
- ▶ Blood sugar levels
- ▶ Daily movements

 Sensitive Personal Data

 Personal Data



Research Regulations > Research, Human Data



ETH

[see RDM S1, 2, 6]

Compliance Guide

Guidelines for Research Integrity

Open Access Policy

ETH IT Policies

Directive on Information Security

Acceptable Use Policy for Telem. Res. (BOT)

Leonhard Med Acceptable Use Policy

Leonhard Med Endpoints

National level, EU

SPHN Information Security Policy

SPHN ELSI Framework

Good Clinical Practice, GCP ICH E6(R2) <https://www.ema.europa.eu>

See *GDPR*

IT Security Guidelines ETH > Research



ETH zürich

Services & resources

News & events | Organisation | Employment & work | Teaching | Finance & controlling | IT Services

ETH Zurich > Services & resources

The following information describes IT-security related documents and guidelines, which apply to the employees of ETH Zurich.

	Open all +
Acceptable Use Policy for Telematics Resources	Open +
Information Security	Open +
Standards System Care	Open +
Best Practice Rules	Open +
Web Policy	Open +
Software Licenses Guidelines	Open +
Leonhard Med	Open +
Internal information	Open +

General

Specific to Confidential Data

IT Security Guidelines ETH > Research, Human Data



The following information describes IT-security related documents and guidelines, which apply to the employees of ETH Zurich.

Open all +

Leonhard Med Open +

Specific to Confidential Data

Effective May 2019

Acceptable Use Policy

<https://rechtssammlung.sp.ethz.ch/Dokumente/438.1.pdf>

Scope:

prevent breach of confidentiality, integrity, or availability of [...] Data entrusted to the "Leonhard Med IT" system.

Roles & Definitions:

Project Leader, User, Confidential Data

PL: *accountable* whole project data life cycle in LeoMed

Compliance: must be signed by every User

Guidelines for ETH Zurich LeoMed Endpoints

<https://rechtssammlung.sp.ethz.ch/Dokumente/438.2.pdf>

Scope:

requirements for the secure setup, maintenance and use of computer systems [...] "Endpoint" to Leonhard Med

Roles & Definitions:

Project Leader, User, Endpoint

PL: *accountable*, User: *responsible* for Endpoint security

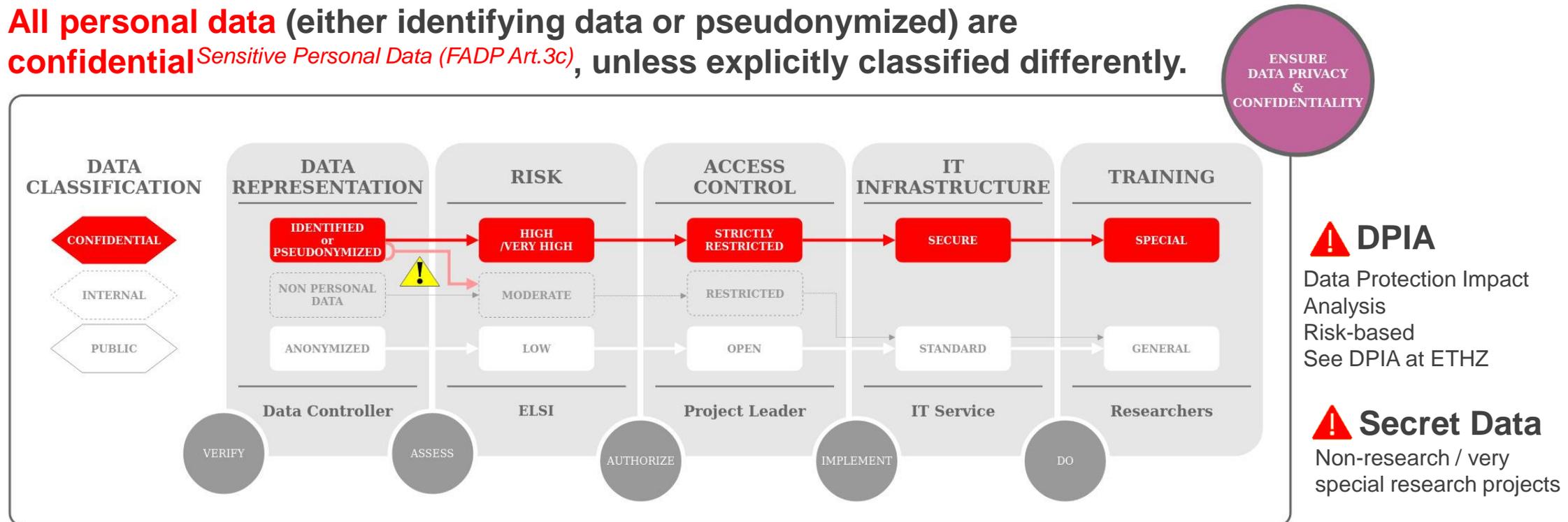
Compliance: mandatory [...] for members of ETH Zurich

Data classification

YES or NO: **Confidential Research Data** compliant with Swiss legislation and policies

Data classification policy: Leonhard Med, ETH and SPHN *Swiss Personalized Health Network*

All personal data (either identifying data or pseudonymized) are **confidential** *Sensitive Personal Data (FADP Art.3c)*, unless explicitly classified differently.



Data classification scenarios <-> Technical & Organizational Measures

Confidential Research Data

Genotyping data (DNA sequencing)

- WGS (Whole Genome Sequencing) data
- WES (Whole Exome Sequencing) data
- Specialized genomic panels (e.g. cancer panels)
- Single cell sequencing, ChIP-seq, ATAC-seq
- Information in some types of QC files

Examples: the content of

- Raw sequence reads in **FASTA** or similar formats
- **VCF** (Variant Calling Format)
- **SAM** (Sequence Alignment/Map) and **BAM** (binary version of SAM)

Confidential Research Data

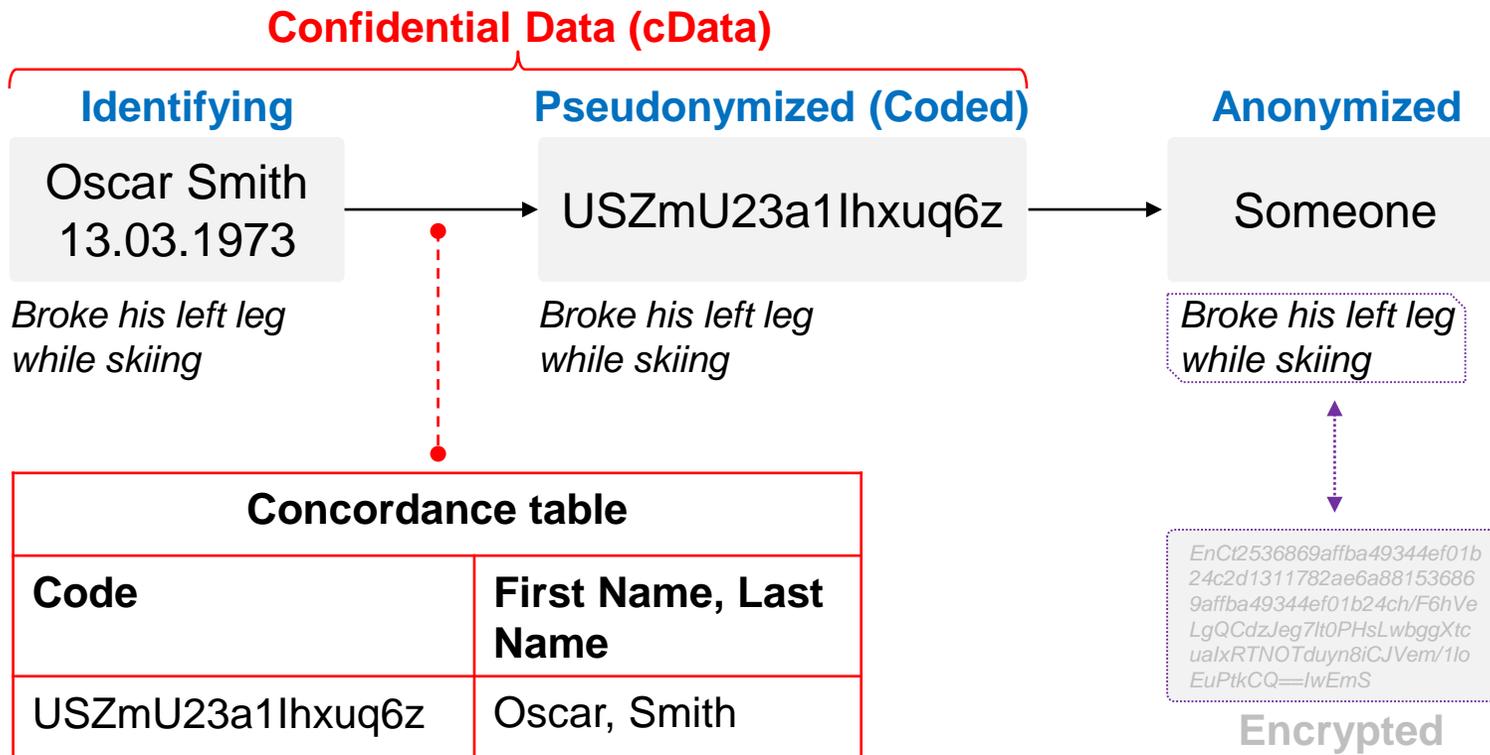
- **Raw data** in genomics, transcriptomics, proteomics
- Patient derived human cell lines
- Biobanks and cohorts
- Imaging data
- Immunological screening
- Controlled access data in TCGA, dbGAP

- *Note: data in combined datasets (aggregation) are often confidential*

○ For now, these are **strictly guidelines** (i.e. defined per policy and not defined in laws to this level of detail)

Confidential Data > a Representation Example

A Guide for technical and organizational measures The Federal Data Protection and Information Commissioner (FDPIC) 2015



- **IF concordance table exists, data are NOT anonymous**
- **Pseudonymization: identifying information is replaced by a code (e.g. concordance table) only accessible with a “key” under strict security regulations**
- **⚠ Pseudonymized data are confidential data**

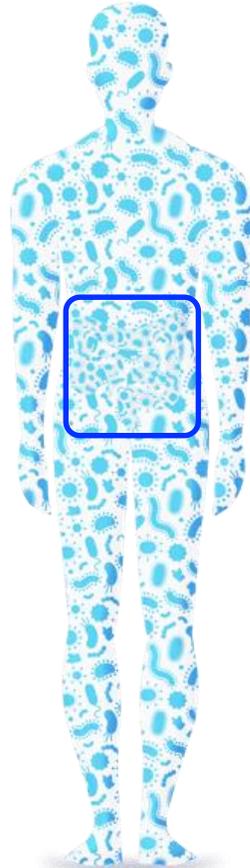
Research Data Classification *per policy* > Confidential ; Public ; Internal

Genome
Health records
Some social surveys
Psychiatry video sessions
Mobility profiles

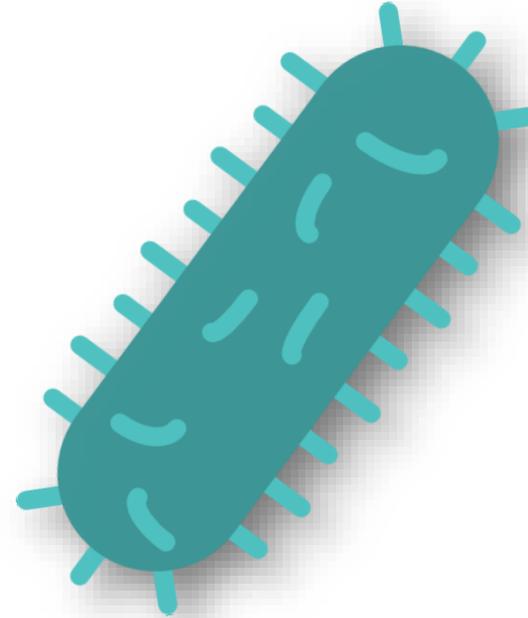
...

⚠ Microbiome

- sampled from human
- may identify people*



<https://www.viome.com/our-science>



Bacteria

- sampled from hospital
- non-human data
- near real-time surveillance

* Franzosa et al., 2015, Wagner et al., 2016

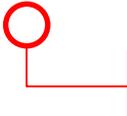
Confidential + Public = Confidential

HRO Definitions > Anonymization

Anonymisation, HRO (art. 25)

For the anonymisation of biological material and health-related personal data, **all items which, when combined, would enable the data subject to be identified without disproportionate effort, must be irreversibly masked or deleted.**

In particular, the name, address, date of birth and unique identification numbers must be masked or deleted.

 **Anonymized data are out of HRA scope**

Confidential Data terminology



<https://edu.sib.swiss/course/view.php?id=424>

- **de-identification:** process used to prevent a person's identity from being connected with information, i.e., the identity of a person can't be obtained anymore
 - **Pseudonymization = coding:** substitutes the identity of a data subject in such a way that additional information is required to *re-identify* the data subject. For example, name, age and home address are substituted by a unique code.
 - **anonymization:** irreversibly destroys any way of identifying a data subject. *Note: anonymization must not be confused with pseudonymization!*
- **re-identification:** process of matching de-identified data with publicly available information, or auxiliary data, in order to discover the individual to which the data belongs to.

Encryption: processes of encoding a message (cf. SPHN Glossary)

SPHN Glossary: <https://www.sphn.ch/en/news-events-publications/publications.html>

Summary > Data Privacy and Protection, Laws and Regulations

- Follow Swiss laws and regulations for using **confidential data** (i.e., sensitive personal data) in research
- Follow local, national , international applicable IT Security Policies and Guidelines
- Be aware of Roles (Project Leader, User, Data Processor etc.) and their Responsibilities and Accountabilities (e.g. data classification, data management etc.)
- Note the diff.: anonymized vs. coded/pseudonymized data
- Know that research with **confidential** requires TOMs (technical and organizational measures) **e.g. Secure Data and IT infrastructures**

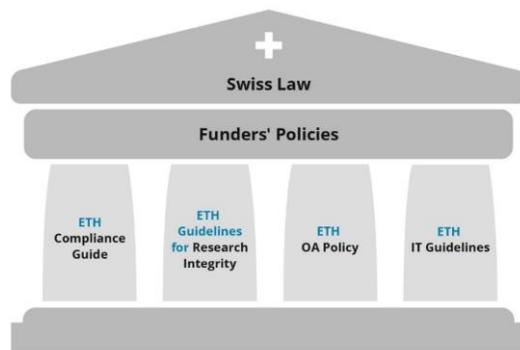
Secure data and computing services for PH research

Leonhard Med and BioMedIT

Laws and Regulations in Switzerland > Research, Human Data

Do researchers need to use special secure IT infrastructures?

Yes, if handling **CONFIDENTIAL DATA** *SENSITIVE PERSONAL DATA (FADP)* for research



Adapted based on: Matthias Töwe
<http://www.library.ethz.ch/en/Services/Courses-and-guided-tours/Workshops>



Secure scientific data & IT infrastructure



Technical & Organizational Measures



Leonhard Med

OR / AND

**infrastructures
with similar level
of security***

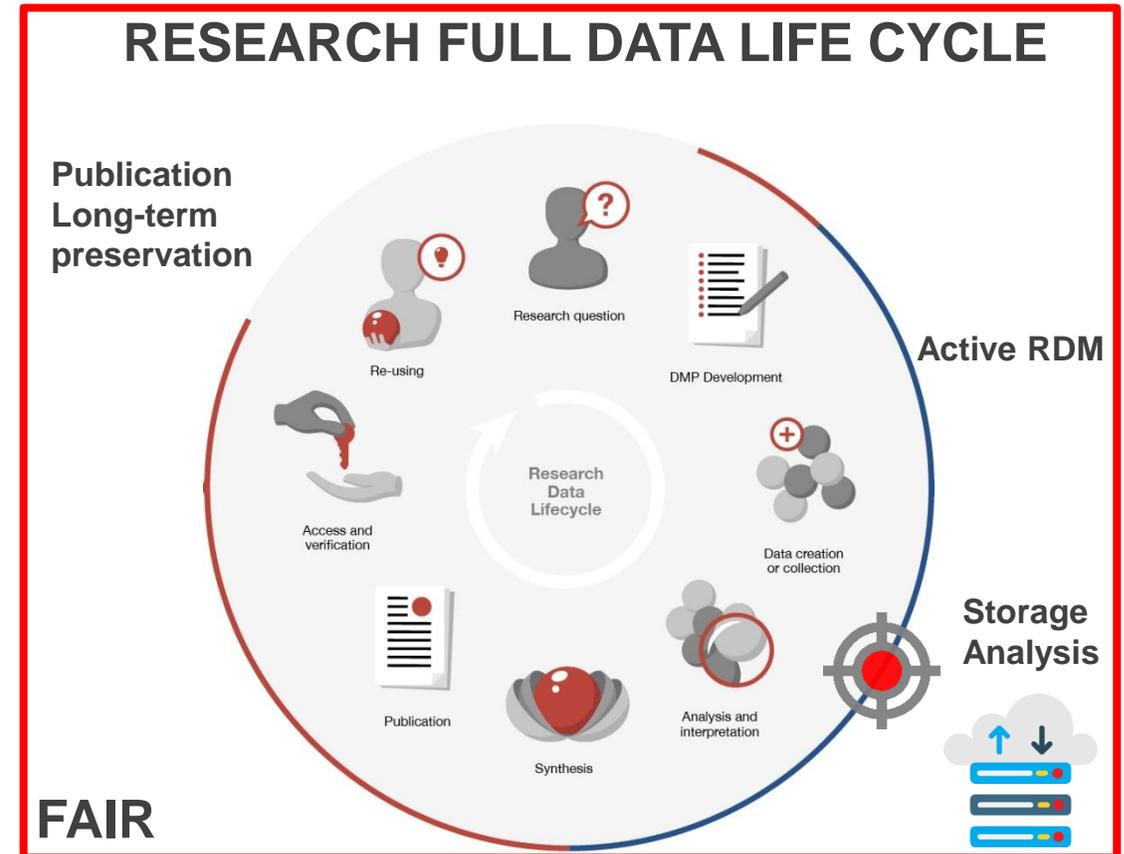
**consult your local IT support*

Secure handling of **confidential research data** - Technical & Organizational Measures (TOM)

Regulations for confidential research data

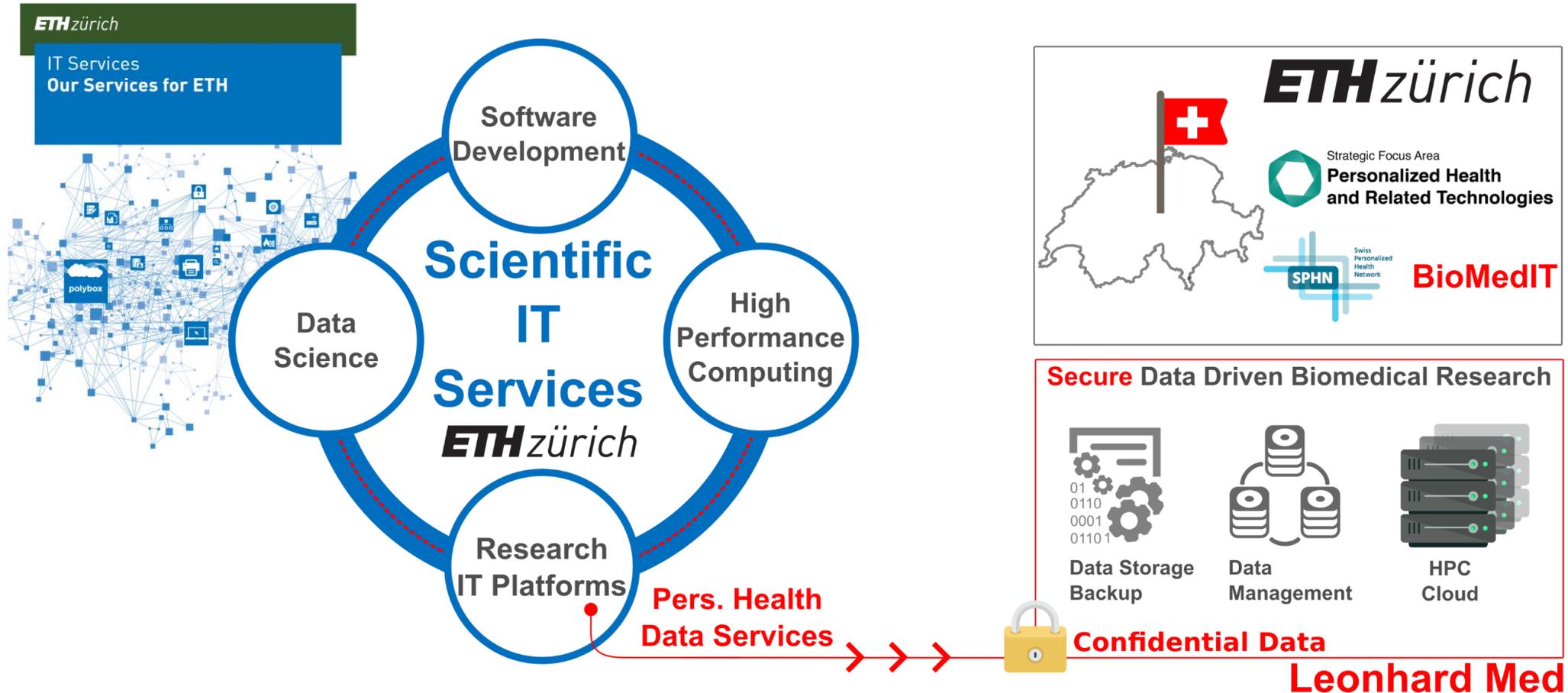
- Study participant **informed consent**
- **Ethical approval** to make data available for reuse in research
- **Contract** for data transfer from controllers (e.g. Hospitals) to secure Data & IT infrastructures (processors) where Researchers analyze data
- **Users** (e.g. researchers) are *Responsible* to comply with applicable regulations
- **Project Leaders** (e.g. PIs) are *Accountable* for the research Data Management over the full data life cycle
- **Secure Data and IT infrastructures** (data processor)

Secure scientific data & IT infrastructure



Technical & Organizational Measures

Leonhard Med: secure scientific data & IT platform, Scientific IT Services at ETH Zurich



Leonhard Med: secure scientific data & IT platform for **bioinformatics** applications in data driven **biomedical research** and in general, for **confidential research data**.

Leonhard Med for ETH and Swiss Research with Confidential Data

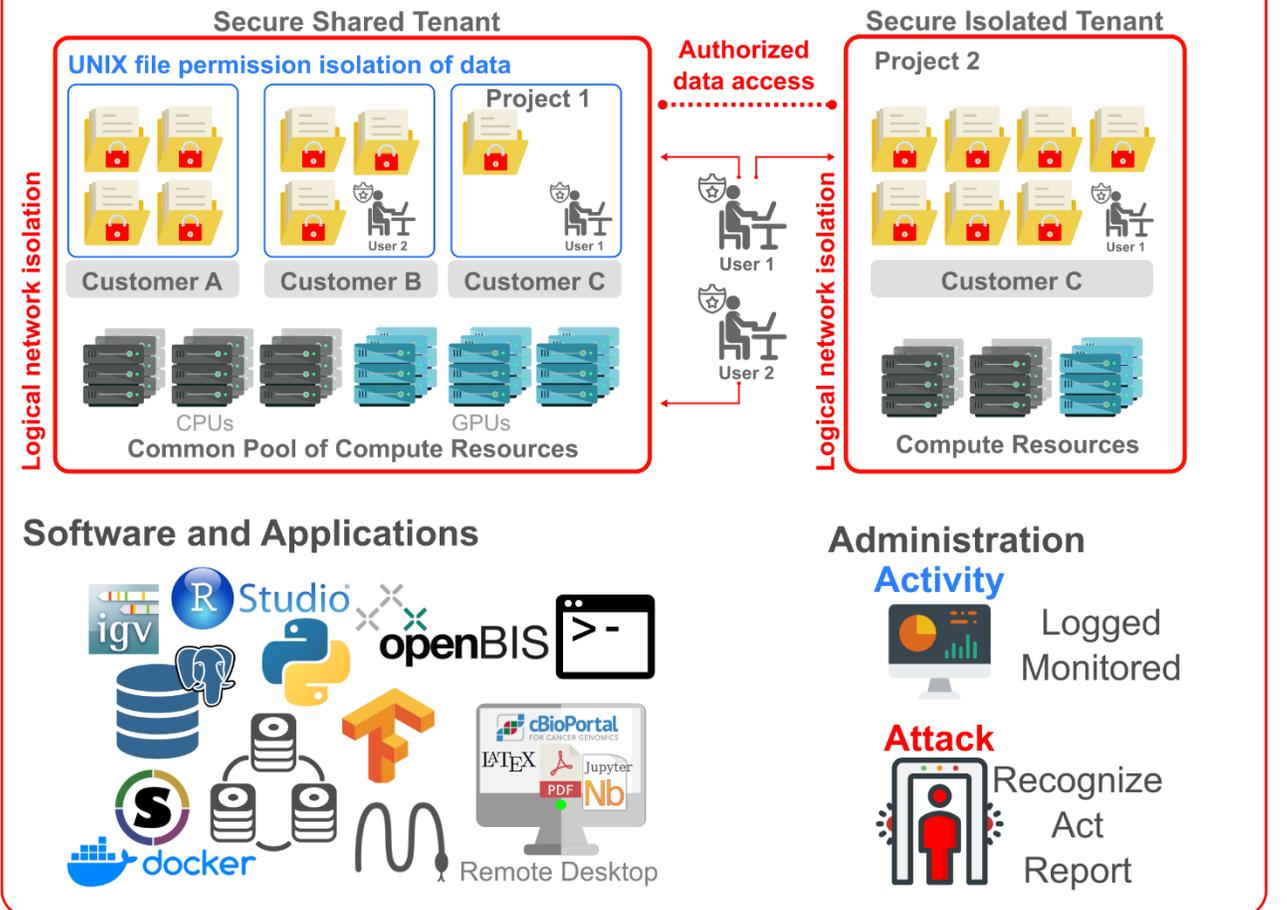
Leonhard Med

- is a powerful research IT platform to securely store, manage and process (e.g. bioinformatics, data science) **confidential research data**
- enables collaborative, large-scale and very diverse **biomedical research** (including academies and hospitals) at ETH Zurich
- is part of the national **BioMedIT network** of secure data centers supporting projects in the SPHN and PHRT national programs

SPHN: Swiss Personalized Health Network
PHRT: Personalized Health and Related Technologies

Leonhard Med: secure scientific data & IT platform

Multi-tenant High Performance Storage and Compute Resources



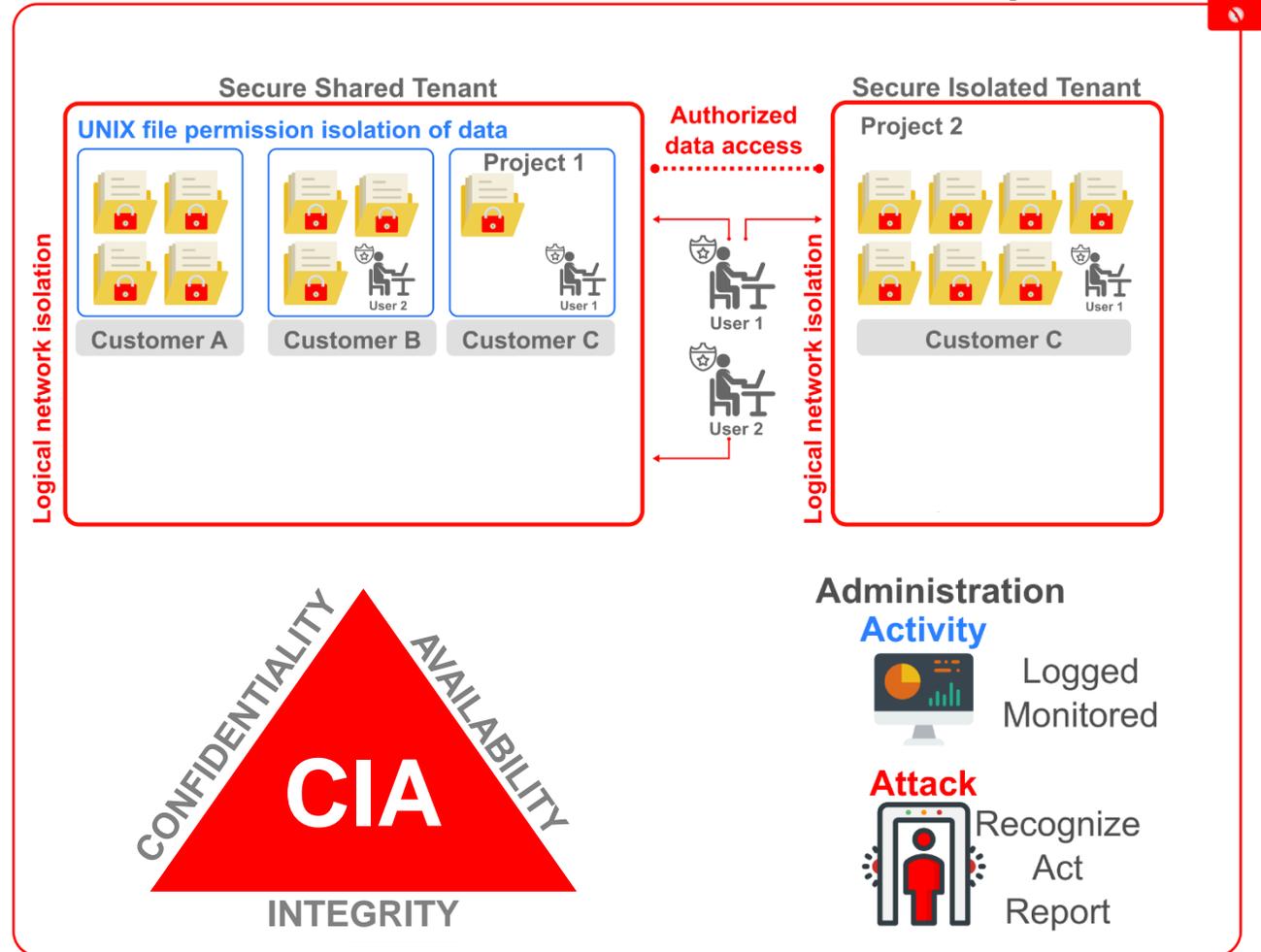
Technical & Organizational Measures

Leonhard Med security controls

CIA measures, confidential data

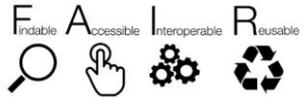
- physical security of the data center
- data strictly isolated between customers
- user access strictly restricted
- internet access strictly controlled
- data encryption during transfer & in backup
- logging & monitoring
- Leonhard Med Acceptable Use Policy

Leonhard Med: secure scientific data & IT platform



Technical & Organizational Measures

Leonhard Med as Bioinformatics Platform



Research Requirements Leonhard Med

Usage & Users

Interinstitutional



Universities
Hospitals
Research Facilities
National Registries
*Citizens

Interdisciplinary



Researchers, Clinicians
IT, Ethics, Law experts
Computer scientists
Molecular biologists
Data scientists

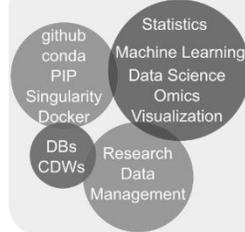
Sustainable



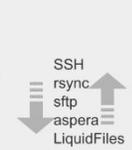
Interoperability of data
Portability of code
Reproducibility
Data mgmt. & sharing
Long term data storage

Data, Tools & Resources

Analytical Software



Data Transfer



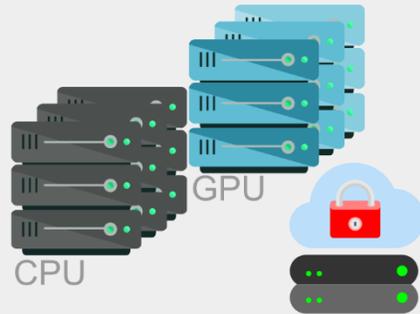
Data Sources



Confidential Data



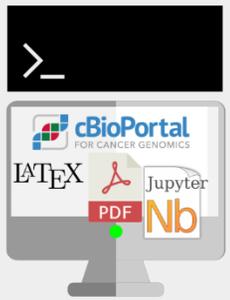
Multi-tenant High Performance Storage



High Performance Computing



Data Analytics and Management Tools



Usability



Administration

Leonhard Med: secure scientific data & IT platform

 in production
since **2018**

 **25** project
spaces

 **> 200**
users

 **> 2 PB**
data

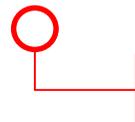
 **+** cloud, GCP,
web services

Leonhard Med data & IT platform: how can it be used for research?

- ✓ secure project space for data storage, management and analysis
- ✓ secure and collaborative compute environment for data analysis (bioinformatics, ML, etc.)
- ✓ secure data transfer from distributed sources
- ▶ customizable e.g., hosting specialized web-based applications, DBs, clinical data warehouses etc.

Leonhard Med: secure scientific data & IT platform

What are the rules and regulations of Leonhard Med?

 Leonhard Med Acceptable Use Policy

Leonhard Med AUP

- ✓ Project Leader (e.g. one of the PIs of a consortium)
- ✓ PL is accountable for the full data life cycle, including data classification*
- ✓ Users are authorized to access and process project's data by PL
- ✓ PL and Every User must comply with the AUP

* *PL + Affiliated Legal Office* ▶ *DPIA* ▶ *Data Classification*
Data Protection Impact Analysis

Leonhard Med: secure scientific data & IT platform

How do I get to use Leonhard Med?



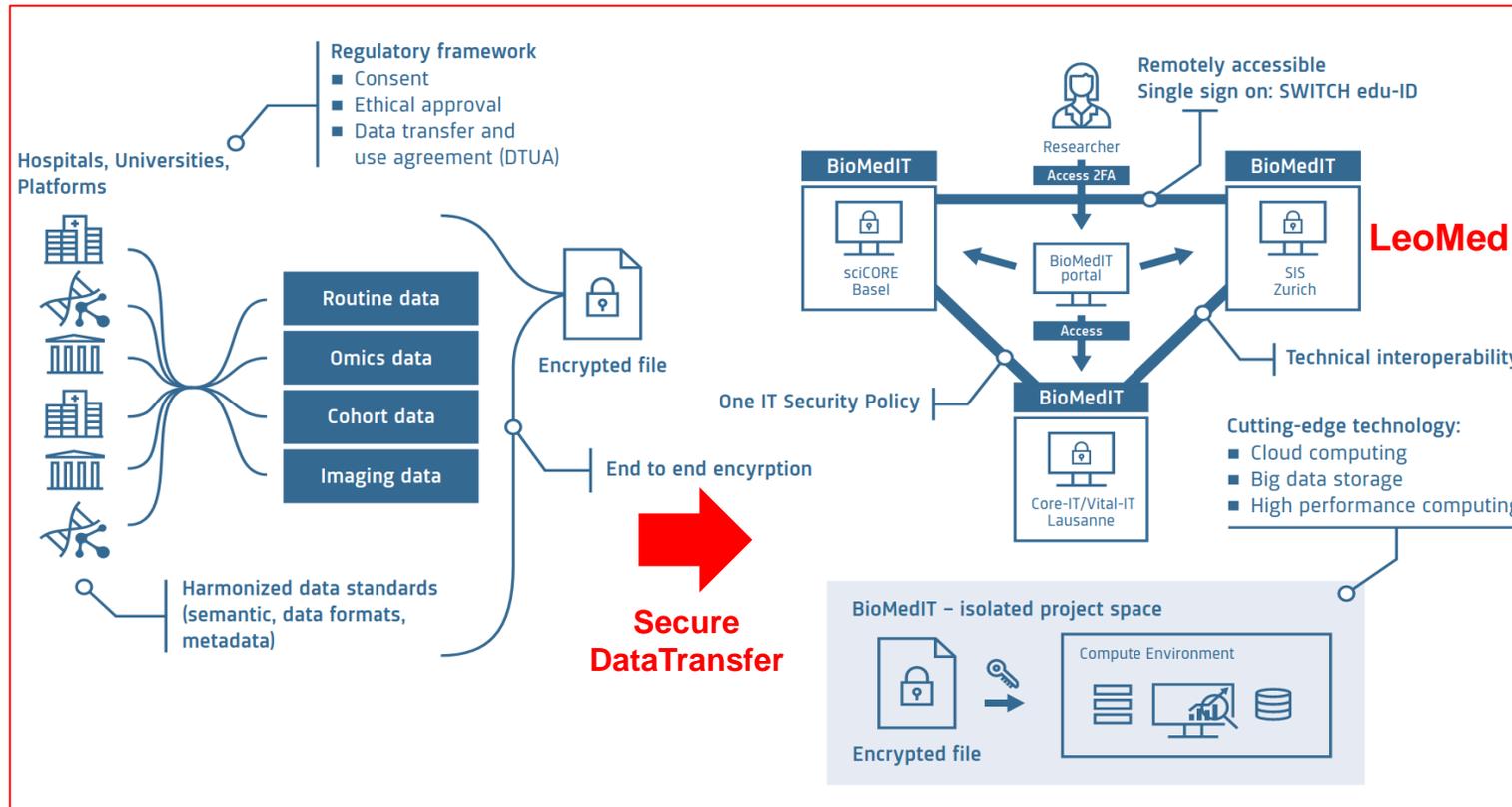
Leonhard Med information on service, regulations and expert consulting

Leonhard Med get in touch

- ✓ **Scientific IT Services, ETH Zurich and services for confidential data**
<https://sis.id.ethz.ch/services/index.html#confidential-research-data>
- ✓ **Leonhard Med Service Level Agreement**
<https://ethz.ch/services/en/it-services/catalogue/server-cluster/hpc.html>
- ✓ **Leonhard Med Acceptable Use Policy**
<https://rechtssammlung.sp.ethz.ch/Dokumente/438.1.pdf>
- ▶ **Leonhard Med, support letter, budget, DMP etc.: contact diana.coman@id.ethz.ch**

Leonhard Med: the Zurich regional node of **BioMedIT**

Lowering computational boundaries for research with confidential data



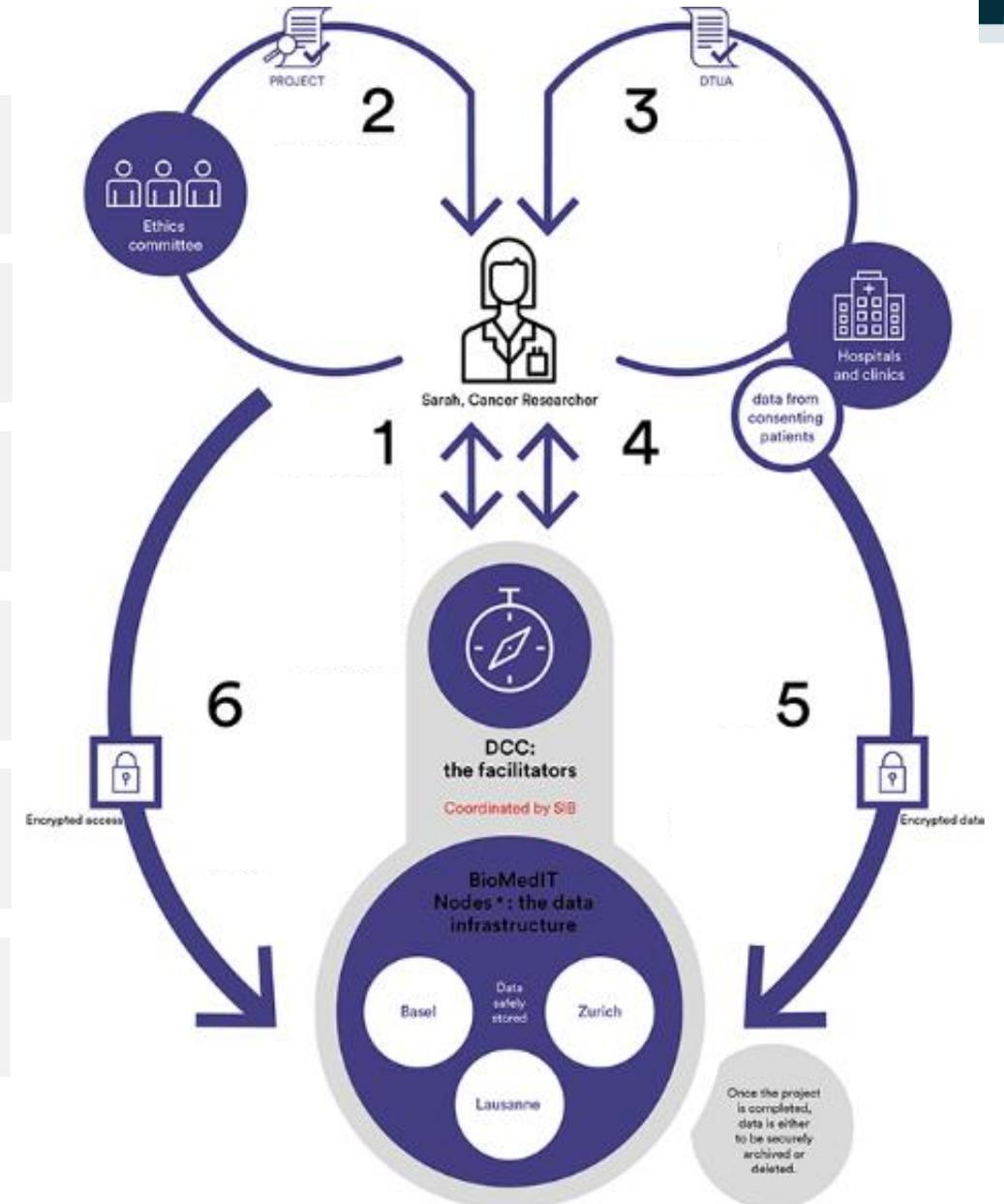
- Data governance
- Secure data transfer process
- Data mgmt., data FAIRness
- Restricted data sharing (secondary use)
- Interoperability of data and bioinformatics workflows
- Data Privacy & IT Security Training

Adapted from: <https://www.sphn.ch/>

Sarah, Cancer Researcher using BioMedIT network



- 1** The **data query**: in order to build her research project, Sarah channels a data query via a Data Coordination Centre (DCC). She learns that three Swiss hospitals have patient data relevant to her project.
- 2** Obtaining **ethical clearance**: Sarah submits her project proposal, detailing the type and proposed usage of patient data, to an ethics committee, and obtains ethical approval.
- 3** Signing a **Data Transfer and Use Agreement (DTUA)**: Sarah requests data from the hospitals and signs a DTUA with the hospitals to formalize the data use rights and possible Intellectual Property derived from the research.
- 4** **Access rights** (and project registering) : Sarah registers the project and members of the research team at appropriate organization and obtains access rights.
- 5** **Secure data: handling**: The hospitals **encrypt** the **de-identified and consented patient data** and copy them to a secure research IT infrastructure for storage and processing (e.g. **Leonhard Med BioMedIT** node Zurich)
- 6** **Secure access and processing**: Sarah can now access the protected data at **Leonhard Med BioMedIT** node Zurich, do ARDM run her data analysis to proceed with her research project.



Best practices

Guidelines for secure handling of confidential research data over the full data life cycle

Best practices for secure handling of confidential research data

Do

- Know which data are **confidential** and which access restriction rules apply (i.e., as per DTUA)
- Aim for FAIRness of **confidential research data** (*note: FAIR data may be under restricted access; code & analytic methods under open access*)
- Be “security aware” (i.e., secure your computer) and follow relevant trainings (e.g. SPHN/BioMedIT, <https://edu.sib.swiss/course/view.php?id=424>)
- Follow data privacy rules (laws, policies, guidelines) and only handle **confidential research data** for which you have explicit authorization (i.e., by a Project Leader)
- Use TOMs over the full data life cycle, e.g., secure Data and IT infrastructures, data mgmt. plan, long term preservation etc.)
- Report promptly security incidents to responsible persons at your institution

Best practices for secure handling of confidential research data

Don't

- Don't work with data if you don't have explicit authorization, in doubt ask your research supervisor
- Don't share your login account used to access secure systems
- Don't copy **confidential research data** on your computer without authorization (i.e., by PL)
- Don't send **confidential research data** per regular e-mail or tools like regular Dropbox
- Don't share **confidential research data** for which you have use authorization without PL's permission
- Don't consider without formal confirmation (i.e., at Data Provider) that coded/pseudonymized data are anonymized and thus non-confidential
- Don't publish **confidential research data** in public repositories (e.g. GitHub)

Best practices for secure handling of confidential research data

○ Incompliance with relevant policies >> consequences

- Revocation of access right to **confidential research data**
- Revocation of access right to respective secure Data and IT infrastructures (e.g. Leonhard Med)
- Sanctions at home institute, Project Leader is accountable
- Depending on impact (i.e., minor vs. major data breach, unintentional vs. criminal misuse) individual researcher is accountable
- Swiss penal code might be applied
- Research impact (institution reputation, restrict data access etc.)
- *Note: moral obligation towards the individuals who had consented to share their sensitive personal data for research*

Further links general data and IT security at ETH

Information & IT Security in Everyday Life

Online training

Our compliance training provides comprehensive information on current topics of information and IT security. [Take a look at the trailer!](#)



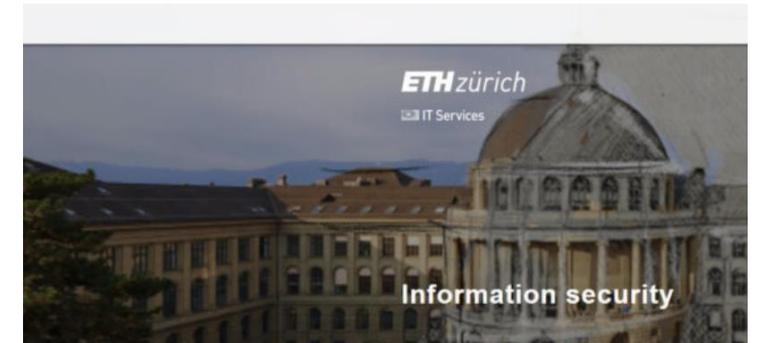
Everyday life topics

- [Reporting Cyber Attacks & Incidents →](#)
- [Passwords, PINs, & Co. →](#)
- [Protecting Devices →](#)
- [Secure Handling of Email →](#)
- [Secure on the Internet →](#)
- [Social Engineering →](#)
- [Data Security →](#)
- [Information security house rules →](#)

<https://ethz.ch/services/en/it-services/it-security/awareness.html>

<https://blogs.ethz.ch/its/2019/12/18/compliance-training-information-security/#more-1902>

“Information Security” training module



Find resources by type or search for topics like **architectu**

[All](#) [Case studies](#) [Codes and Guidelines](#) [Digital Media](#) [ETH](#) [Laws & Legislation](#) [Organisations](#)

ETH zürich
ETHics
Resource
Platform

A grid of six resource cards from the ETHics Resource Platform. The cards are: 1. Podcast: #CRISPR (with laptop icon); 2. Case Study: 'Designer Babies' you say that like it's a bad thing? (with baby icon); 3. Case Study: A case of moral deafness? (with person icon); 4. Code & Guidelines: ACM Code of Ethics and Professional Conduct (with person and screen icon); 5. Code of Conduct: Algo.Rules (with person and screen icon); 6. Code & Guidelines: AMA Code of Medical Ethics (with person icon).

<https://www.ethicsrp.ethz.ch/explore-resources/>

Closing remarks

The 3 top things to think about your research & confidential data

Secure handling of confidential research data

○ | The 3 top things to think about your research & confidential data

Data Confidentiality and Individuals Privacy Protection

- ▶ Data **classification**: e.g. public, internal OR confidential
confidential research data requires strict protection
- ▶ Use TOMs for **confidential research data** in your research, e.g. Leonhard Med BioMedIT Node Zurich
which laws and regulations, cybersecurity and data protection measures do you need to follow, what to do in case of data breach
- ▶ .. over **the full data life cycle** (FAIR). ⚠ Note: data analysis is «just» one of the steps in the process.

Thank you

for joining **Data and Computing Services for
Personalized Health Research**

High Performance Computing for genomic applications



Acknowledgements

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@SPHN_ch
@PHRT_CH

- ▶ Michal Okoniewski, SIS ETHZ
- ▶ Leonhard Med Team and openBIS team, SIS ETHZ
- ▶ BioMedIT Team, SIB
- ▶ SPHN, PHRT partner projects