Modul 2

Datafication, data privacy and digital health records

Imprint

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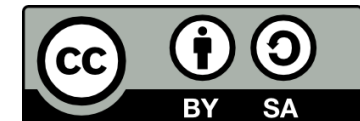Stiftung Digitale Chancen: Dörte Stahl, Nenja Wolbers
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Learning Outcomes

After this training you will be able (literacy) to:

1. Relate datafication and data privacy to GDPR and the socioeconomic context of eHealth data (Module 1)
2. Understand how citizens (trainees) interact with data and organize health practices (Module 2)
3. Evaluate health data storage solutions and platforms (Module 3)
4. Track or block the data trackers in their personal online environment (optional)

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Lecture No. 1 Introduction to Datafication, Data Privacy and GDPR

- Socioeconomic figures related to eHealth and the datafication of health

- Introduction to Data Privacy and GDPR

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Lecture No. 1 Introduction to Datafication, Data Privacy a nd GDPR

- Datafication is the process of recording people's everyday life in quantified data.

- In the context of health, **datafication is the process where individuals' activity, behavior and experiences are recorded in quantified data and made analyzable by an array of actors in and beyond clinical settings, as reference points for health.**

Source : Mayer-Schönberger, V, Cukier, K. (2013) Big data: A revolution that will transform how we live, work, and think. Houghton Mifflin Harcourt.

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Lecture No. 1 Introduction to Datafication, Data Privacy and GDPR

- The datafication of health has two defining features :

a) the ability to *infer* individuals' health status from data and

b) the ability to *repurpose data* about health for other uses.

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Activity 1:

Create your own health profile based on the personna described on the next slide

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Activity 1:

Name me
☺

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Activity 1:

Name : Moschoula

- Female, around 70 years old, retired with an active fulfilling career *(personal info)*

- Family of four to take care of, all living nearby, shops and cooks often *(family info)*

- Follows weekly yoga class, mostly online and loves painting *(main activities)*

- Uses skype, (smart)phone, web browsing and has a social media account to look for info and contact friends and relatives *(digital practices)*

- Diabetic (type B), insulin treatment, daily measurements, slightly overweight *(personal health data)*

- Consults doctors monthly, does exams often for various issues, spends an important part of her retirement on health *(personal health related data)*

- She is curious about learning and open to using new tools such health apps or wearables *(personal attitude)*

- Health is a source of stress both personal and economic (personal statement)

"She wants to live a healthy life and become more autonomous of her health situation"

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- What are her needs?

- What apps would you suggest she uses?

- What data is she sharing when she uses that data?

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Activity 1:

- Describe and discuss the different profiles created

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Lecture No. 1 Introduction to Datafication, Data Privacy a nd GDPR

- The datafication of health has two defining features (infer, repurpose) that create two areas of impact:

a) the ability to infer health status from personal data has accelerated the shifting of knowledge about health beyond traditional clinical / doctors' boundaries

   a) Realizing more self-health, empowerment, autonomy

   b) Creating new type of care communities and services

b) the ability to repurpose data is increasingly used for purposes not directly relating to healthcare

   a) Monetization and advertisement

   b) Life affecting decisions (loans, insurance, work productivity)

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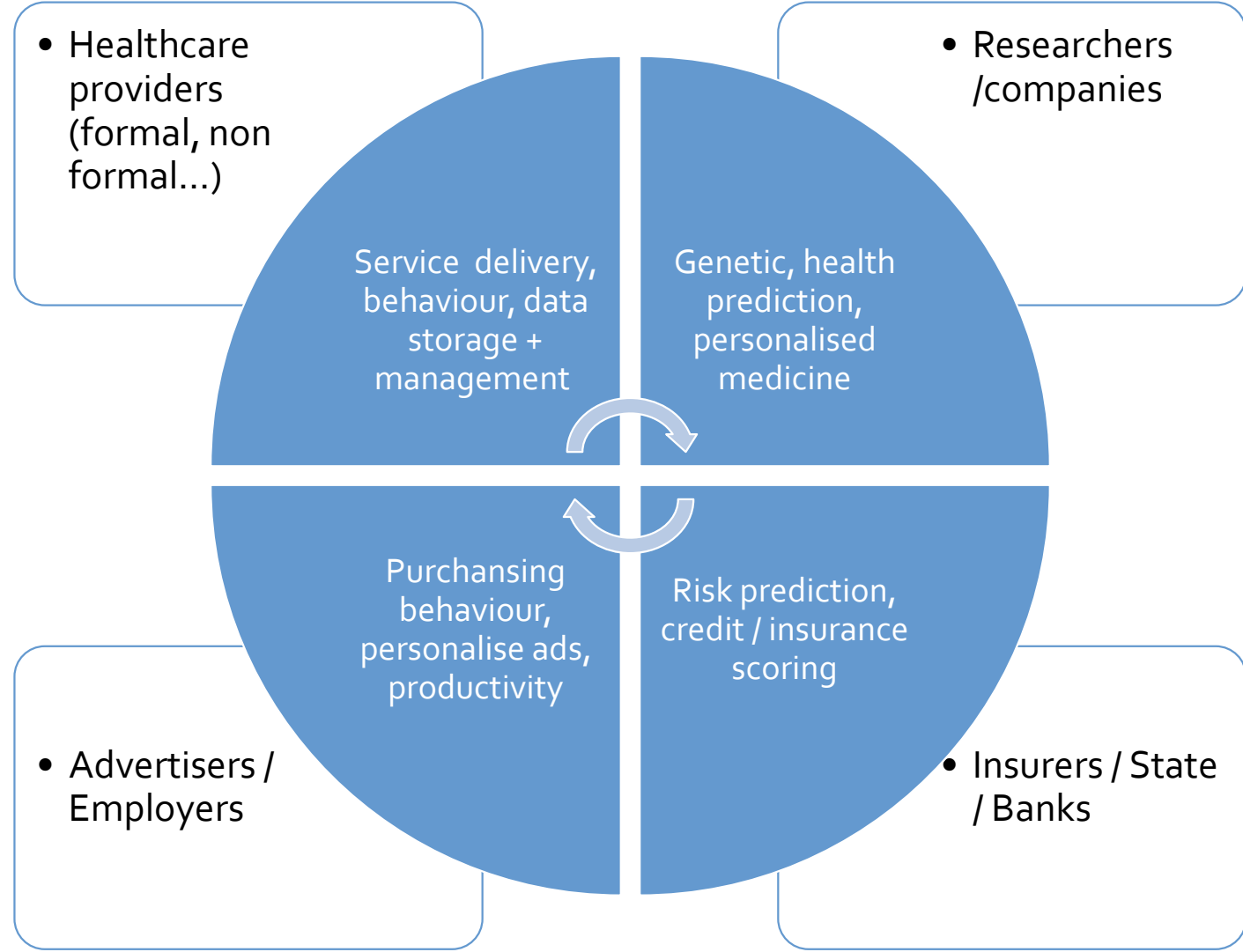
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Transition to socioeconomic trends

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Lecture No. 1 Introduction to Datafication, Data Privacy and GDPR

- A Swedish study predicted depression with approximately 60% accuracy and delivered interventions to people displaying depressive symptoms.

- Various proof-of-concept studies have highlighted how apps can link dynamic mental health status changes to fluctuations in smartphone usage in adult patients with major depressive disorder.

Source: Wahle, F. et al. (2016) 'Mobile Sensing and Support for People With Depression: A Pilot Trial in the Wild', JMIR mHealth and uHealth, 4(3), p. e111. doi: 10.2196/mhealth.5960.

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- The potential for native advertising in mobile health (m-health) technologies, like wearables and smartphones, provides examples of how technology companies can use data to merge health and commercial content in ways that are hard to detect.

Source: Sharethrough. Native Advertising - The Official Definition. Available at: https://www.sharethrough.com/nativeadvertising/ (Accessed: 28.11.2022).

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- Across the EU: health spending is equivalent to approximately 10% of EU countries' GDP.

Source: Eurostat (2019), Healthcare expenditure statistics. Available at: https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Healthcare_expenditure_statistics (Accessed: 28.11.2022).

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Some initial thoughts / trends:

- Reinforced algorithmic decision making

- Individualized health monitoring and non-health-related predictions

- Individualized judgements on a large scale

- Blurring distinctions between health and non-health data

- Increased predictive power based on smartphones, wearables, electronic eHealth records, genetic data, online activity, smart sensors, IoT...

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Lecture No. 1 Introduction to Datafication, Privacy and GDPR

Transition from datafication to GDPR

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Lecture No. 1 Introduction to Datafication, Data Privacy and GDPR

- A narrow practical interpretation of health data is data collected within the running of a healthcare system, for example in the delivery of healthcare services or the conducting of medical research.

- Broader definitions consider any **data relating to health, such as any data relating to the physical or mental health of an individual.**

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Lecture No. 1 Introduction to Datafication, Data Privacy and GDPR

- Under the General Data Protection Regulation (GDPR) in the EU, the specification of 'special category' concerns data that is sensitive because its exposure could significantly impact the rights and freedoms of the data subject.

- Due to that sensitivity, special category data is data that should be given specified and unique protection under law.

Source : What personal data is considered sensitive? Available at: https://ec.europa.eu/info/law/law-topic/data-protection/reform/rules-business-and-organisations/legal-grounds-processing-data/sensitive-data/what-personal-data-considered-sensitive_en

(Accessed: 28.11 2022).

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Lecture No. 1 Introduction to Datafication, Data Privacy and GDPR

- The General Data Protection Regulation (EU) (GDPR) is a regulation in EU law on data protection and privacy in the European Union (EU) and the European Economic Area (EEA) implemented in 2018.

- It addresses the transfer of personal data outside the EU and EEA areas.

- The GDPR's primary aim is to enhance individuals' control and rights over their personal data and to simplify the regulatory environment for international business.

Source: Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation)

Available at: http://data.europa.eu/eli/reg/2016/679/oj

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Lecture No. 1 Introduction to Datafication, Data Privacy and GDPR

Personal data	Personal and sensible data
Name	Health
Age	Genetic
(IP) address	Biometric
Salary	Religion
Identity number	Ethinicity
Social security number	Justice
Photo	Political opinions

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Lecture No. 1 Introduction to Datafication, Data Privacy and GDPR

- Laws like the GDPR are designed as principles-based, so that they incorporate a broad range of data under the definition of health data.

- The GDPR offers non-exhaustive guidance as to what the 'special categories of data' might be, such as 'genetic data', 'biological samples', or 'medical history' and refers to traditional clinical actors and settings such as physicians or other health professionals, hospitals and medical devices.

Source : Recital 35 - Health Data', General Data Protection Regulation (GDPR). Available at: https://gdpr-info.eu/recitals/no-35/

(Accessed: 28.11.2022).

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Lecture No. 1 Introduction to Datafication, Data Privacy and GDPR

Transition to the citizen approach

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Lecture No. 1 Introduction to Datafication, Data Privacy and GDPR

- **Right of access** - Access your data!
- **Right to withdraw consent** - Withdraw your consent!
- **Right to object** - Object to the processing of your data!
- **Right to rectification** - Correct your data!
- **Right to erasure** - Have your data deleted!
- **Right to data portability** - Transfer your data!
- **Right to restriction of processing** - Restrict processing!
- **Automated individual decision-making** - Be protected from Automated Decision Making!
- **Right to lodge a complaint** - Complain to your DPA!

Source : NOYB, My Privacy is None of Your Business. Available at: https://noyb.eu/en/exercise-your-rights

(Accessed: 28.11.2022).

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Activity 2

Demand for my personal data

- Select a platform / service

- Document your choice

- Ask for your data

• Document your porcess

- What do you expect to find ?

- Follow up !

Via : https://www.mydatadoneright.eu/

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Lecture No. 2

Understand how participants interact with data and how they organize health practices

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Lecture No. 2 Understand how participants interact with data and how they organize health practices

- What is health data, a citizen-based approach:

1. Data about health can exist and be generated across any aspect of life that can be made digital.

2. Data about health is increasingly diverse, facilitating a shift in focus from understanding and treating disease to maintaining wellbeing and assisting disease prevention.

3. Data about health increasingly relates to an individual's health rather than aggregate population level figures.

4. Quantifiable data about health can be measured, compared, aggregated and used to make profiles, predictions and scores.

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Lecture No. 2 Understand how participants interact with data and how they organize health practices

| Activity	Device	Health inference	Use
Web browsing	Web intefaces	Blood levels	Intervention
Phone use	Smartphones	Heart rate	Precision
Working	Smart sensing	Concentration	Personalised diagnosis
Sleeping	Wearables	Nutrition	Insurance plans
Social media	Smart home	Sleep	Nutrition plans
		Stress	Wellbeing
		Fitness	Population Monitoring
		Emotions	Productivity analysis
		Mobility	
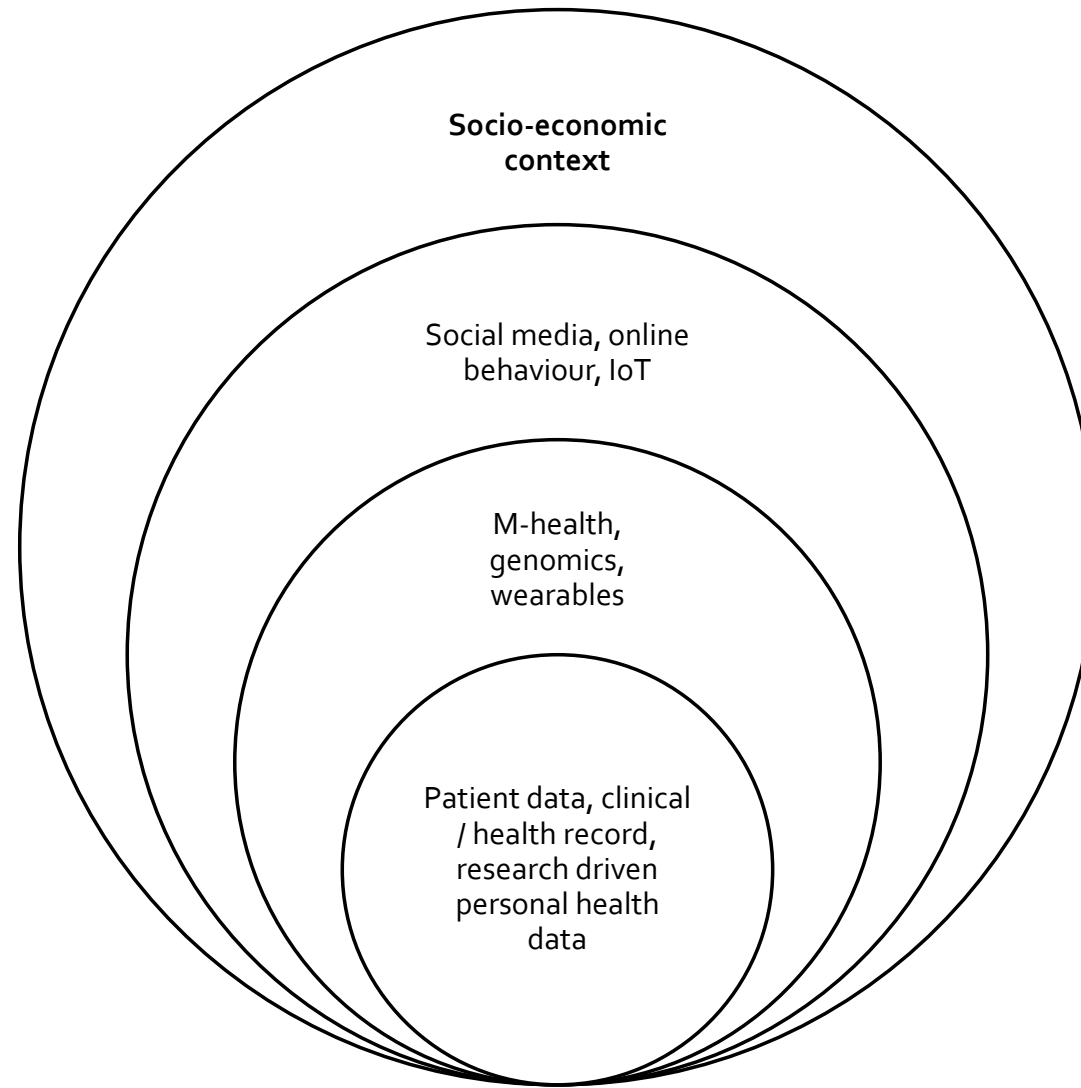
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Activity 3

- Based on a design thinking methodology: Mapping eHealth related, personal data

- Give a concrete scenario: Describe your actions (i.e., for 24 hours) the last time you were ill and wanted to collect information:
  - What is and where is your (health) data?
  - The entities involved: doctor (health professionals), Social care (informal or formal), Hospitals, Friends, Google, Apps, Other?
  - What type of data have you shared ?
  - Describe how you perceive the activity of others : illness, related habits, online usage habits and concrete user patterns.

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Lecture No. 3

- eHealth records and my health data platforms

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Lecture No. 3 eHealth records and my health data platforms

- Introduction
  - When creating a personal health data record:

- What are my option to do this at a national level?

- Who has access to my data?

- How can they be used?

- What are the alternatives?

- Is privacy by design respected?

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Lecture No. 3
eHealth records and my health data platforms

- **National Strategy**

Santé 2030

Stratégie Cybersanté Suisse 2.0

- **Legal Framework**

Loi fédérale sur le dossier électronique du patient

Ordonnance sur le dossier électronique du patient

Ordonnance du DFI sur le dossier électronique du patient

Ordonnance sur les aides financières pour le dossier électronique du patient

- **Important documents (governance)**

Stratégie CARA 2030 (PDF, 1.2 Mo)

Statuts de l'association CARA (PDF, 111 Ko)

Rapport d'activité 2020 (PDF, 19.7 Mo)

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Lecture No. 3 eHealth records and my health data platforms

- Case study : The Electronic Patient Record (EPR) in Geneva & Switzerland (CARA)

Source:https://www.biopole.ch/story/the-electronic-patient-file-story-of-a-collaboration-between-cara-and-swiss-post/

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Lecture No. 3
eHealth records and my health data platforms

The federal government is actively involved in the implementation of the eHealth Switzerland strategy, especially through the Federal Law on the Electronic Patient Record (LDEP). The EPR Act describes and defines the electronic patient record (EPR) as a tool for patients to:

- improve the quality of medical treatment;
- improve patient treatment processes
- increase patient safety;
- increase the efficiency of the health care system;
- promote patient competence in health care.

To this end, it regulates the organizational, technical and safety aspects:

- opening of an EPR
- access rights for health professionals
- access to medical documents in medical emergency situations
- identification of patients and health professionals in the EPR
- establishment of "communities of reference" and "communities"
- financial support from the Confederation.

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Lecture No. 3 eHealth records and my health data platforms

- CARA (EPR platform) is financed by the public health services of the cantons of Fribourg, Geneva, Jura, Valais and Vaud, as well as by the Confederation.

- All hospitals and private clinics in Switzerland, including rehabilitation and psychiatric clinics, are already participating in the CARA electronic patient record.

- Many other care providers are participating or will participate soon (home care services, medico-social institutions (EMS), birthing centers, doctors' offices, pharmacies, independent nurses, physiotherapists, laboratories, midwives).

Source: CARA, https://www.cara.ch/fr/Public/Localisation-des-professionnels-affilies.html

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Lecture No. 3
eHealth records and my health data platforms

- The Electronic Patient Record (EPR) is your online health record, available through the Internet, which belongs to you and contains health documents useful in case of treatment. They are filed by healthcare professionals (e.g. prescriptions for the pharmacy, hospital discharge report, vaccination record, X-rays) or by you (e.g. advance directives).

- You are and will always remain the owner of this file and the data it contains. You decide which health professionals can access your data. For children or for people who do not wish to manage their file themselves, it is possible to appoint a representative who will manage the file in the patient's place.

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Lecture No. 3 eHealth records and my health data platforms

- You must have a certified electronic means of identification to guarantee your identity when using the EPR. CARA does not issue these credentials, but you can obtain them free of charge from other organizations:
  - TrustID
  - GenevaID
  - VaudID Health
  - SwissID

- It is possible to obtain your means of identification from the services of CARA's member cantons.

- You can then use the platform with your Internet browser on the CARA portal.

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Lecture No. 3 eHealth records and my health data platforms

The evolution of the platform

Values	2022	2023	2024	2025	2026	2027	2028	2029	2030
Number of EPRs opened (in thousands)	20	70	120	170	220	300	450	700	1 100
CARA related expenditures (in MCHF)	9,46	11,43	12,06	12,78	16,52	17,47	19,09	20,69	21,30
Employees	12	15	18	22	26	32	39	47	50
Cost par EPR open (in CHF)	473	163	101	75	75	58	42	30	19

Lecture No. 3 eHealth records and my health data platforms

- Patientrecord.ch is the official information platform on the electronic patient record (EPR) by eHealth Suisse, the Confederation and the cantons.

- The provision of healthcare is the responsibility of the cantons. However, e-Health projects must be effective across cantonal borders because people are very mobile nowadays: they move, change doctors or travel to other regions. National digital networking is the best way to tackle this.

- The national EPR project therefore envisages a national framework (the Federal Act on the Electronic Patient Record) with regional or national implementation which is carried out by EPR providers (EPR communities).

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Lecture No. 3 eHealth records and my health data platforms

- Developing inclusive and participatory health data practices (open questions)

1. How should data-driven systems be designed to ensure the experiences of those who fall outside of the category of a technology's 'typical user' are not excluded?

2. How does the datafication of health minimize or create opportunities for individual expressions and experiences of health identity?

3. What opportunities are there to increase the ability for people to participate in and influence the structures that govern health and data?

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Activity 4

Install an extension tracking cookies and ads for my web browser or cell phone

- Install the extension (Ublock) or such as apps (TC Slim : https://trackercontrol.org/ and Exodus)
  - What is my closest hospital - clinic doing with my web navigation data?
  - Who follows my mobile apps?
- Track, report and discuss

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Indirect Assessment

- For Indirect Assessment use open debriefing/reflective questions to the learners like:

a) What did you learn from the trainings?

b) Did you improve any of your skills? Why?

c) What was the most interesting part for you?

d) What would you have changed?

- Delete this slide

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Further Reading

- Add interesting educational resources
- Follow APA 6th Edition for citing

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Bibliography

- Follow APA 6th edition
  - https://www.scribbr.com/apa-style/format/