



Governance Mechanisms for Access and Use of Data in Public Health Crises: Call for Action

I. PROBLEM

Effective access to and use of relevant data to inform decision making is of utmost importance in a public health crisis. The COVID-19 pandemic demonstrated that access to and use of data on health care, epidemiological indicators, behaviour and mobility, supplies of essential goods for managing the crisis etc. are not always possible. Furthermore, it was difficult to assess compliance with and the effect of measures taken to curb the pandemic. There are two key problems: First, high quality data is often not available; second, where high quality data exists, it can often not be used in a meaningful way. The COVID-19 pandemic highlighted problems that are also likely to affect responses to other public health crises such as floods, earthquakes, release of chemical pollution or radiation, and power outages. With regard to these examples, we define the term “public health crisis” as an **unusual or unexpected event with potentially severe consequences for the health of a large part of the population.**

The **ideal state of affairs** in fighting a public health crisis is for competent government agencies and other **relevant actors to get reliable answers to relevant questions.** To this end, they must be able to tap into

relevant data (personal and non-personal) that is stored with other government agencies or private actors. A promising approach to achieving this goal is to distinguish between data sharing in crisis and data sharing in non-crisis. If these two states are distinguished, there is **no need for prospective data sharing**, i.e. relevant data need not be pooled in a central system, and there is no need to grant access to such data in a state of non-crisis. But there is need **for shareable data**, which requires building an infrastructure and establishing a legal framework that enable data sharing in the event of a crisis. Shareable data may always be useful – but is an imperative in a public health crisis.

In such a crisis, many questions require **real-time and spatially differentiated answers.** For example, where do risks emerge? Who is at risk? How are people at risk behaving? Where are critical assets (e.g. rescue equipment) and infrastructure (e.g. emergency rooms) located and what is their current capacity? Those are just a few examples of questions that would benefit from tapping into existing data streams from individuals, health care providers, private companies, or federal and cantonal government agencies. However, as the COVID-19 pandemic has demonstrated, such data is currently not readily available.

Three main reasons inhibit access to and use of relevant data: **(i) technical barriers**, in particular that data cannot be used properly when required to fight a public health crisis, mainly due to difficulties related to reporting and aggregate key indicators; **(ii) legal barriers**, especially through data protection law, which sets narrow limits on the use of personal (health) data, in particular the use of personal data for a purpose other than that for which it was originally collected (secondary use); and **(iii) societal barriers**, such as a lack of data literacy and a lack of trust in a large part of the population regarding the processing of personal (health) data.

This **call for action** aims to outline the main issues related to effective access to and use of data in a

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public health crisis, and to present workable solutions to remedy the current shortcomings. It aims to outline a promising approach to fight such a crisis, but it does not discuss specific use cases within the health care sector (e.g. access of government agencies to data collected by physicians). Obviously, the implementation of the approach in Switzerland will have to take into account developments at the international and European level, particularly with regard to standards. While this call for action focuses on public health crises, the approach outlined may also serve as a model for fighting other crises. This call for action does not address the funding needed to implement the solutions proposed by various health care providers such as hospitals, physicians and pharmacies. We are well aware that funding is a key issue, but we believe that it is a political question that must be solved by the competent federal and cantonal authorities. While not addressing all relevant issues, this call for action shows that all present problems could be solved if there were sufficient will to do so.

II. OBSTACLES

1. Technical barriers

The most important barrier to the effective and meaningful use of data in a public health crisis is the **lack of standardisation**. Data necessary to react to a such crisis is held by various actors such as general practitioners, hospitals, cantonal (health) authorities and federal offices, and especially by the Federal Office of Public Health (FOPH) and the Federal Statistical Office (FSO). These actors use various (medical) data record and management systems (“data systems”) and data collection processes. The lack of standardisation causes important **lock-in effects**, and the lack of governance and enforcement can further contribute to those effects. Medical data systems are very expensive and sometimes used for many years. Feeding the data is also costly, which is why providers of such systems are rarely replaced. Lock-in effects reduce competition between suppliers of medical data systems, and thus contribute to high prices and lack of interoperability. More specifically, the following technical barriers prevent the use of existing data in a public health crisis:

- a) **Lack of machine-readable (structured) digital data:** Much of the data is not available electronically or in a format that is easily machine readable (e.g. physicians’ notes). Much is still done by hand. This also applies to notifications that must be made to the

federal government and the cantons for certain diseases. In such cases, there is often no electronic reporting option.

- b) **Lack of agreement on uniform data format:** The above-mentioned actors store and process data in various formats, thus preventing mutual conversation as the data has no uniform syntax. Although the syntax is often well defined in the medical sector, it is not used consistently.
- c) **Lack of agreement on uniform data semantics:** The above-mentioned actors store and process data using individual semantics. Although the semantics are often well defined in the medical sector, there are several data system providers that apply different semantic standards.
- d) **Lack of interoperability:** Interoperability also suffers from the fact that the systems used by the various actors do not have compatible interfaces. Worse, there is no incentive to enable interoperability, and therefore part of the existing software is designed so that data export is not possible.
- e) **Lack of data overview:** The use of various data systems also prevents an overview of the kinds of data available and where they can be found. This in turn prevents a rapid response in the event of a public health crisis.

Example

Real-time spatial data on health-seeking behaviour (e.g. purchasing of over-the-counter medications or primary care consultations) may be informative about the local dynamics of a public health crisis. Existing solutions for reporting health data to public authorities (e.g. the Sentinella reporting system for diseases) only cover some of the potentially relevant data. Technical barriers prevent effective access and use of most data that is collected by health care providers (e.g. hospitals, physicians’ offices and pharmacies) and by cantonal and federal government agencies.

2. Legal barriers

There are various legal barriers to the effective and meaningful use of data in a public health crisis. Many result from the application of data protection law that regulates all processing of personal data. Anonymisation would allow for an unlimited use of data, but effective anonymisation of health data has become very difficult, if not impossible. Moreover, anonymisation is not always desirable in a public health crisis, as it may prevent health care providers from providing services to individuals in need.

- a) **Principle of legality:** The principle of legality requires that government agencies process data only on a legal basis. The use of data by government agencies to fight a public health crisis is often not possible within the current legal framework, as most legal bases for the processing of personal data do not cover such secondary uses. While the federal law on epidemics provides a broad legal basis for the processing of personal data by private and public actors to fight the spread of a communicable disease, there is no such basis for other public health crises.
- b) **Purpose limitation:** Several data protection principles complicate access to and use of personal data during a state of crisis. The most important is the principle of purpose limitation stating that personal data may only be used for the intended purpose at the time of acquisition.

- c) **Proportionality:** Other problematic principles are the principle of proportionality and, as a consequence, the principle of data minimisation and storage limitation. According to these, data should only be processed to the extent necessary and should be deleted as soon as it is no longer needed.
- d) **Discrepancies between federal law and cantonal laws:** The legal provisions that apply to the processing of personal data differ significantly between the federal and cantonal levels, and amongst the various cantons. As a result, personal data can be processed for some purposes by government agencies at the federal level but not at the cantonal level, and vice versa. These differences hinder the exchange of data during a state of crisis.
- e) **No crisis mode:** Data protection law applies equally to all situations and does not have any special provisions that would apply in the event of a crisis (e.g. to allow for uses to fight a crisis and to ensure faster action).

3. Societal barriers

There are also various societal barriers:

- a) **Data literacy:** Today, most people perceive the collection and use of personal data solely as a risk and a threat that they cannot understand and control, thereby ignoring that data is a key resource for decision making, research and innovation in the digital society. To overcome this perception, data literacy (i.e. the ability to critically collect, manage, evaluate and use data) must be improved. This also includes the ability to adequately assess and mitigate the risks that may be caused by the processing of personal data.
- b) **Public trust:** A major issue is the lack of trust among the public regarding the use of their data by public authorities and private companies. The lack of trust derives from the fact that once the data is disclosed to public or private actors, people no longer know how and to what extent the data flow is controlled, documented and secured. Although this information is provided by public authorities and private companies, the flow of information towards the public seems to be disrupted, leading to public unawareness and lower levels of trust.
- c) **Fear of data misuse:** Parts of the public fear that data is used for purposes other than those initially communicated (i.e. that data collected to inform health policy for the public good will be used by private companies for their own benefit). Moreover, the public debate on the collection, storage and use

Example

In most public health crises, real-time spatial data on health-seeking behaviour cannot be used by cantonal and federal authorities as they lack a legal basis (principle of legality) and would use data for other purposes than the ones it was collected for (principle of purpose limitation). In addition, some potentially useful data (e.g. data on purchasing of over-the-counter medication in pharmacies) may never have been collected or may already have been deleted (principle of data minimisation and storage limitation).

of personal data is dominated by a focus on the risks involved, while the benefits for individuals and society at large are often ignored.

Example

Individuals know little about how private companies and government agencies collect, store and use their personal data. This uncertainty can result in fears concerning data misuse, data security breaches and discrimination, and a lack of overall trust in health system and state activities. This is especially the case for data that is considered to be personal data, such as real-time spatial data on health-seeking behaviour.

III. SOLUTION

The challenges mentioned above can be addressed. Sometimes this can be done through appropriate measures within the respective area, but often combined approaches will be necessary (i.e. measures that affect the technical, legal and societal aspects).

1. Technical aspects

The solution is based on the distinction between **shared data and shareable data**. Data is only shared in the event of a crisis, under certain conditions and in a certain way. Data continues to be stored and analysed in a decentralised manner. Often, shared data no longer has a personal reference. If it still does, privacy-preserving technologies can be applied (e.g. the concept of differential privacy that adds noise to the systems such that the probability that an individual can be identified is kept low).

Shareability implies that data is available electronically, in a predefined format and in an adequate spatial and temporal aggregation, whilst still preserving individual privacy; that it can be aggregated with limited human intervention and in real-time; and that the data or derived results can be shared and pooled on demand through a predefined channel or interface. To overcome the lack of standardisation, **legal provisions requiring**

and enforcing standardisation of data formats and semantics in the health sector must be implemented. First steps have been taken in this regard within the federal administration; these efforts must be continued and expanded to private companies operating in the health sector. Standard setting should be a bottom-up process led by the various actors in the health care system, but lawmakers will have to intervene if those actors are unable to define the standards. The standards that are to be implemented make it possible to share and access data in the event of a crisis. In addition, they reduce existing **lock-in effects**, because they ensure lower switching costs and intensify competition. As the nature of a future public health crisis is unknown today, the effort of standardisation should encompass as much data as possible and not be limited to a minimal data set. More specifically, the following are needed:

- a) Obligation for all actors in the health care sector to **record all data digitally and in a shareable manner**. Compliance with these standards would serve as a condition for a product or system to be allowed on the Swiss market.
- b) Binding standards that ensure data has a minimum **uniform syntax**. Such standards will be implemented through appropriate governance and enforcement mechanisms, in particular through homologation and certification bodies appointed by public authorities (e.g. the specialised body in charge of the management and interoperability of government data).
- c) Binding standards that ensure data has a minimum level of **uniform semantics**. Such standards will be implemented through appropriate governance and enforcement mechanisms, as described above. These standards are already being developed in certain sectors (e.g. minimum standards for health-related data from hospitals and laboratories).
- d) Systems must be **interoperable** (i.e. have the necessary **interfaces** to communicate with each other). For this, a minimum **interoperability interface** must be defined and implemented by all health care actors. Such requirements will be implemented through appropriate governance and enforcement mechanisms, as described above.
- e) The existing obligations to **notify data collections** must be expanded to ensure consistent reporting and an up-to-date compilation of data collections

including those of private companies operating in the health sector. In addition, information about interfaces should be provided, to allow for the automated execution of queries during the crisis.

Example

If the solutions for the technical and legal aspects were implemented, real-time spatial data on health-seeking behaviour (e.g. purchase of over-the-counter medications or primary care consultations) would be recorded digitally and in a shareable manner using uniform syntax and semantics. The systems used by federal and cantonal government agencies and private companies active in the health sector would be interoperable, and information about existing data collections and interfaces would be available. This would allow relevant data to be shared in the event of a public health crisis, and enable government agencies and other relevant actors to obtain reliable answers to relevant questions.

2. Legal aspects

While some of the problems require adaptations of data protection laws, others may be solved through improved interpretation of existing laws. In general, the focus of data protection law should be less on the regulation (and prevention) of data processing and sharing, and more on appropriate conditions for sharing and processing. The question shall no longer be “if” data may be shared and processed, but “how” it can and should be shared and processed. This includes adequate measures regarding the protection of privacy, particularly regarding data security and the avoidance of specific harm that may arise for the individuals concerned. In addition to the solutions proposed here, certain governance issues must be solved, specifically the allocation of skills and tasks amongst federal and cantonal authorities, and how these authorities cooperate. In addition, it is vital to establish the criteria for defining a state of crisis as well as the authority that applies the criteria and declares the state of crisis. While we recognise that these are key issues, we believe that they cannot be solved in the

abstract but must be addressed when implementing the solutions suggested in this call for action. With regard to the legal aspects, the following are needed:

- a) **A specific legal basis** for the processing of personal data by government agencies that takes effect in a **crisis mode** must be established. Such legal basis should be provided in federal and cantonal data protection laws to allow government agencies to process all data needed to fight a public health crisis. First steps have been taken in the new Swiss Federal Data Protection Act which will contain a legal basis for the processing of personal data, if processing is needed to protect the life or physical integrity of an individual and there is no time to ask for consent. This provision, however, is focused on an individual in urgent need of assistance, and cannot provide a sound legal basis for the processing of large amounts of personal data for the duration of a public health crisis.
- b) A specific legal basis for the processing of personal data in a public health crisis would overrule the **principles of purpose limitation and proportionality** with regard to government agencies. A similar result could be achieved for private actors by recognising that the processing of personal data in a crisis can be based on an overriding public interest which would justify a breach of data protection principles. In addition, it must be ensured that no consent of individuals and no approval by ethics committees are needed to process data for the purpose of fighting a public health crisis. In return, processing must be strictly limited to the purpose of fighting the crisis, and the use of data for other purposes must be prohibited.
- c) The existing **discrepancies between cantonal and federal law** must be eliminated, and the same conditions must apply to all actors during a state of crisis. A sole competence of federal law during a state of crisis is also conceivable.
- d) **A crisis mode** with adequate control measures must be established. In this mode, the government agencies would temporarily have additional competencies accompanied by confidence-building and safety measures. The crisis mode must have a clearly defined wind-down process and/or a sunset date. Additionally, **control mechanisms and compensation options** in the event of harms must be set. A control mechanism could be exercised by the Fed-

eral Data Protection and Information Commissioner (FDPIC), which could be supported by a crisis-specific expert panel (with or without decision-making power). The FDPIC should only take decisions after consultation with other relevant government agencies. As always, such decisions are subject to judicial review. The control could be complemented by special **(alternative) dispute mechanisms** which provide for an easily accessible mechanism in case of data disputes, particularly for compensation in the event of actual harm (e.g. in the form of a “lump-sum compensations” for certain foreseeable categories of personality rights violations).

Example

If solutions for technical and legal aspects were implemented, real-time spatial data on health-seeking behaviour could be used by cantonal and federal government agencies on a specific legal basis in the event of a public health crisis, regardless of the purpose for which the data was collected. More relevant data would be available due to the relaxation of the principles of data minimisation and storage limitation. The sharing of data between cantonal and federal authorities would not be compromised by differences between cantonal and federal law. Specific control mechanisms, compensation options and dispute mechanisms would ensure that individuals receive compensation in the event of actual harm caused by the processing of personal data about them.

3. Societal aspects

In general, the public trusts the health system in anticipation of a net benefit for the individual, the public and the system overall. By showing trust, the public legitimises health system activities such as data sharing and data use. Communication of health system actors and the exchange of information with the public about data sharing is critical for building trust. The information that health care actors communicate should describe past comparative positive experiences of data sharing, and present abilities of actors to develop a trustworthy data sharing system in Switzerland and explain future actions on how trustworthy data sharing in the next public health crisis will be achieved. In addition to building trust in the health system, data literacy must be promoted.

- a) **Data literacy** must be promoted at all levels of the society. A data literate society would be able to make informed decisions about how data handling (e.g. in the health system) should be organised, to assess the implications of data policy decisions and to evaluate the validity of inferences drawn from data. In the future, data literacy will be as necessary for active citizenship as the ability to read and write.
- b) **Public trust** must be promoted by ensuring that individuals are informed about existing accountability and control mechanisms, such as the monitoring of data processing activities of private companies and public authorities by the cantonal and federal data protection commissioners. This could be achieved through an education and information campaign.
- c) Such a campaign should inform the public about the benefits of the processing of personal data for individuals and society, the associated risks, and the possibilities and limitations of anonymisation and pseudonymisation. The public should also be informed about existing **measures to prevent data misuse**, how these measures work and what sanctions apply if they are not duly implemented. In addition, the public should be informed about the need to share data in a public health crisis, the benefits for individuals and society, and the specific control mechanisms, compensation options and alternative dispute mechanisms that apply in the event of a crisis.

Example

If solutions for societal aspects were implemented, the use of real-time spatial data on health-seeking behaviour would not only be technically possible and legally allowed, but also accepted by the public. Individuals would better understand how private companies and government agencies collect, share and use data about them to fight a public health crisis. They would also be informed about the specific control mechanisms implemented to prevent data misuse, as well as the compensation options and dispute mechanisms that apply during a public health crisis. Consequently, public trust in the health system would be promoted, even in the event of a crisis.

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ANNEX

Key Documents

European Commission

EU4Health programme 2021–2027
ec.europa.eu/health/funding/eu4health_en

European Commission

New European Interoperability Framework: Promoting seamless services and data flows for European public administrations (2017)
data.europa.eu/doi/10.2799/360327

European Commission

Proposal for a Regulation on harmonised rules on fair access to and use of data (Data Act) of 23 February 2022
digital-strategy.ec.europa.eu/en/policies/data-act

The Federal Statistical Office (FSO)

National data management NaDB
bfs.admin.ch/bfs/en/home/nadb/nadb.html

World Health Organization (WHO)

Executive Board 146/26. Data and innovation: draft global strategy on digital health. Report by the Director-General (2019)
apps.who.int/gb/ebwha/pdf_files/EB146/B146_26-en.pdf

World Health Organization (WHO)

International Health Regulations (2005)
who.int/publications/i/item/9789241580410

World Health Organization (WHO)

Global strategy on digital health 2020–2025
who.int/publications/i/item/9789240020924

ADDITIONAL DOCUMENTS

General

Bernstein Abraham/Thouvenin Florent

Pandemie als Informationskrise – Wege aus dem «Data Lockdown», in: Thier/Rühli (ed.), Weissbuch Corona, Die Schweiz nach der Pandemie, Befunde – Erkenntnisse – Perspektiven, NZZ Libro 2021, 185 et seqq.

Bund schafft Grundlagen für Datenpolitik

press release of 10 December 2021
admin.ch/gov/de/start/dokumentation/medienmitteilungen.msg-id-86392.html

European Health Data Space

ec.europa.eu/health/ehealth/dataspace_en

The Federal Chancellery

Strategy Digital Switzerland
bag.admin.ch/bag/en/home/strategie-und-politik/gesundheits-2030/gesundheitspolitische-strategie-2030.html

The Federal Council

Health policy strategy 2020–2030
bag.admin.ch/bag/en/home/strategie-und-politik/gesundheits-2030/gesundheitspolitische-strategie-2030.html

The Federal Office of Public Health (FOPH)

Strategy eHealth Switzerland 2.0
bag.admin.ch/bag/de/home/strategie-und-politik/nationale-gesundheitsstrategien/strategie-ehealth-schweiz.html

Forum Aussenpolitik (foraus)

Health Data Governance: What's in it for Switzerland?, foraus-Policy Brief December 2020
foraus.ch/wp-content/uploads/2020/12/20201216_IDH_EN_WEB.pdf

Gasser Urs/Ienca Marcello/Scheibner James/Sleigh Joanna/Vayena Effy

Digital tools against COVID-19: taxonomy, ethical challenges, and navigation aid, in: The Lancet Digital Health 2 (2020)
sciencedirect.com/science/article/pii/S2589750020301370

Gasser Urs

Perspectives on the Future of Digital Privacy, in: ZSR/RDS 134 (2015) II, p. 335 et seqq.

Gasser Urs

«Digitale Pandemie» und Recht: Annäherungen an ein globales Phänomen, in: ZSR/RDS 139 (2020), p. 181 et seqq.

Public Health Research Data Forum

Enabling Data Linkage to Maximise the Value of Public Health Research Data: full report, March 2015
iif.wellcomecollection.org/file/b24769824_Enabling_Data_Linkage.pdf

Science Academies of the Group of Seven (G7) nations

Data for international health emergencies: governance, operations and skills
royalsociety.org/-/media/about-us/international/g-science-statements/G7-data-for-international-health-emergencies-31-03-2021.pdf

Thouvenin Florent/von Wyl Viktor/Bernstein Abraham

Daten nutzen denn Daten nützen, NZZ, 14. May 2020, p. 12

Vayena Effy

Value from health data: European opportunity to catalyse progress in digital health, in: The Lancet 397 (2021)
[thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)00203-8/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)00203-8/fulltext)

Vokinger Kerstin Noëlle

Die digitale Bekämpfung von Covid-19 und die Rolle des Bundes(rates), in: SJZ 116 (2020), p. 412 et seqq.

World Health Organization (WHO)

Regional Committee for Europe, Response to the COVID-19 pandemic: lessons learned to date from the WHO European Region
apps.who.int/iris/bitstream/handle/10665/343157/71wd06e-rev1-PR-Response-Lessons-Learned-210693.pdf

Technical

Balsari Satchit/King, Mathew V./Buckee, Caroline O.

Data in Crisis – Rethinking Disaster Preparedness in the United States, New England Journal of Medicine 2021; 385:1526-1530
[nejm.org/doi/full/10.1056/NEJMms2104654?query=featured_home](https://www.nejm.org/doi/full/10.1056/NEJMms2104654?query=featured_home)

eHealth Suisse Swiss Competence and Coordination Centre of the Confederation and the Cantons

Grundlagen für interoperable Prozesse im Gesundheitswesen, Input für strategische Arbeiten von Bund und Kantonen
e-health-suisse.ch/fileadmin/user_upload/Dokumente/D/Bericht-Interoperabilitaet_de.pdf

Human Technology Foundation

Development and governance of technology-based solutions for a health crisis exit strategy, Decision support for COVID-19 initiatives
crid.be/pdf/public/8602.pdf

Ienca Marcello/Vayena Effy

On the responsible use of digital data to tackle the COVID-19 pandemic, in: Nature Medicine 26 (2020)
[nature.com/articles/s41591-020-0832-5](https://www.nature.com/articles/s41591-020-0832-5)

I14Y Interoperability platform as centrepiece of the national data management programme (NADB)

i14y.admin.ch/en/home

Swiss Personalized Health Network

Lay Summary on Development of a governance and quality management system for exchange of patient related data for research purposes
sphn.ch/wp-content/uploads/2019/11/2017DEV02_Willers_Lay_Summaries_20180117.pdf

Swiss Personalized Health Network

Semantic Interoperability Framework
sphn.ch/network/data-coordination-center/the-sphn-semantic-interoperability-framework/

Legal

All European Academies/European Academies Science Advisory Council/Federation of European Academies of Medicine

International Sharing of Personal Health Data for Research, The ALLEA, EASAC and FEAM joint initiative on resolving the barriers of transferring public sector data outside the EU/EEA
allea.org/wp-content/uploads/2021/03/International-Health-Data-Transfer_2021_web.pdf

Becker Regina/Thorogood Adrian/Ordish Johan/Beauvais Michael J.S.

COVID-19 Research: Navigating the European General Data Protection Regulation, in: J Med Internet Res 22 (2020)
[jmir.org/2020/8/e19799/](https://www.jmir.org/2020/8/e19799/)

Bellaiche Judith

Parliamentary Postulat, Nutzung anonymisierter persönlicher Daten im öffentlichen Interesse, Prüfung der Machbarkeit einer freiwilligen Datenspende
parlament.ch/DE/ratsbetrieb/suche-curia-vista/geschaefft?AffairId=20203700

Do Canto Philipp

Gesundheitsdaten in der digitalen Welt, in: sic! 2020, p. 177 et seqq.

European Commission

Commission Implementing Decision (EU) 2020/1023 of 15 July 2020 amending Implementing Decision (EU) 2019/1765 as regards the cross-border exchange of data between national contact tracing and warning mobile applications with regard to combatting the COVID-19 pandemic

eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX:32020D1023

European Commission

Commission Recommendation (EU) 2020/518 of 8 April 2020 on a common Union toolbox for the use of technology and data to combat and exit from the COVID-19 crisis, in particular concerning mobile applications and the use of anonymised mobility data

eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32020H0518

European Commission

Proposal for a Regulation of the European Parliament and of the Council on the European Health Data Space

eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52022PC0197

The European Data Protection Board

Statement on the processing of personal data in the context of the COVID-19 outbreak

edpb.europa.eu/sites/default/files/files/news/edpb_statement_2020_processingpersonaldataandcovid-19_en.pdf

European Parliament/Council of the European Union

Regulation (EU) 2022/868 of 30 May 2022 on European data governance and amending Regulation (EU) 2018/1724 (Data Governance Act)

eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32022R0868

The Federal Office of Public Health (FOPH)

Aktuelle Entwicklungen in der datengetriebenen Medizin und die damit verbundenen Herausforderungen und Aufgaben für das BAG, Bericht der Arbeitsgruppe Personalisierte Medizin des BAG

bag.admin.ch/dam/bag/de/dokumente/biomed/Biomedizinische%20Forschung&Technologie/D_Bericht_Datengetriebene-Medizin_20180423.pdf.download.pdf/D_Bericht_Datengetriebene-Medizin_20180423.pdf

Hornung Gerrit/Stroscher Jan-Philipp

Datenschutz in der Katastrophe, in: Zeitschrift für das Gesamte Sicherheitsrecht 2021, p. 149 et seqq.

Kędzior Magdalena

The right to data protection and the COVID-19 pandemic: the European approach, in: ERA Forum 21 (2021)

link.springer.com/article/10.1007%2Fs12027-020-00644-4

Martin Robert/Conseil Alexandra/Longstaff Abie et al.

Pandemic influenza control in Europe and the constraints resulting from incoherent public health laws, in: BMC Public Health 10 (2010), p. 532 et seqq.

bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-10-532

Schmitz Peter

Smarte Bekämpfung der Pandemie ist datenschutzrechtlich erlaubt, ZD-Aktuell 2020, 04404

Zwitter Andrej/Gstrein Oskar J.

Big data, privacy and COVID-19 – learning from humanitarian expertise in data protection, in: Int J Humanitarian Action 5 (2020)

jhumanitarianaction.springeropen.com/articles/10.1186/s41018-020-00072-6

Societal**The Academy of Medical Science**

Interdisciplinary research in epidemic preparedness and response: workshop report, October 2019

acmedsci.ac.uk/policy/policy-projects/multidisciplinary-research-in-epidemic-preparedness-and-response-

Data Literacy – Schweiz

Appell für eine dringliche nationale Datenkompetenz-Kampagne
data-literacy.ch/

Feri Yvonne/Roduit Benjamin

Parliamentary Motion, Implementierung einer nachhaltigen Data-Literacy-Strategie in der digitalen Transformation des Gesundheitswesens
parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20223016

Misra Archita

Advancing data literacy in the post-pandemic world, A primer to catalyse policy dialogue and action, Draft discussion paper for the 2021 PARIS21 Annual Meetings
paris21.org/sites/default/files/inline-files/DataLiteracy_Primer_0.pdf

Misra Archita/Schmidt Julia

Enhancing Trust in Data – Participatory Data Ecosystems for the Post-Covid Society, in: Shaping the COVID-19 Recovery: Ideas from OECD’s Generation Y and Z, p. 83 et seqq.
oecd.org/about/civil-society/youth/Shaping-the-Covid-19-Recovery-Ideas-from-OECD-s-Generation-Y-and-Z.pdf

Nguyen Dennis

Mediatisation and datafication in the global COVID-19 pandemic: on the urgency of data literacy, in: Media International Australia 178 (2020), p. 210 et seqq.

Rieder Beat

Parliamentary Interpellation, Nationale Datenkompetenzkampagne. Datenkompetenz (Data Literacy) ist gefragt
parlament.ch/DE/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20204173

Sander Ina

What is critical big data literacy and how can it be implemented?, Internet Policy Review 9 (2020)
policyreview.info/articles/analysis/what-critical-big-data-literacy-and-how-can-it-be-implemented

Tarrant Dave

Data literacy: what is it and how do we address it at the ODI?
theodi.org/article/data-literacy-what-is-it-and-how-do-we-address-it-at-odi

Wolff Annika/Gooch Daniel/Cavero Montaner Jose J. et al.

Creating an Understanding of Data Literacy for a Data-driven Society, Journal of Community Informatics 12 (2016) p. 9 et seqq.
oro.open.ac.uk/47779/8/1286-Article%20Text-7817-2-10-20161121%20%281%29.pdf