TEHDAS Joint Action Glossary

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0 Document info

0.1 Authors

Author	Partner
Minna Hendolin	Sitra – The Finnish Innovation Fund
Marja Pirttivaara	Sitra – The Finnish Innovation Fund

0.2 Keywords

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Table 1: TEHDAS JA Glossary

Word	Explanation	Source and/or comments
Access	Processing by a data user of data that has been provided by a data holder, in accordance with specific technical, legal, or organisational requirements, without necessarily implying the transmission or downloading of such data.	DGA COM (2020) 767 final
Administrative data	Set of units and data derived from an administrative source.	OECD
Affiliated entity	Entities affiliated to the nominated competent authority are entities or organisations that have a distinct legal personality but are linked to the nominated competent authority. A term used in Joint Actions of the 3rd Health Programme of the European Union.	Guide for applicants, grants for actions co-financed by countries participating in the third EU Health Programme (Joint Actions) (2014-2020) HP-JA-2018
Aggregated data	Data combined or collected together in summary or other form such that the data cannot be identified with any individual.	Legal Information Institute, Cornell University
Aggregated statistics	Reliably anonymised data in a statistical format.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Algorithm	Sequence of instructions or set of rules designed to complete a task or solve a problem.	UK Parliament
Anonymous data	Information which does not relate to an identified or identifiable natural person or to personal data rendered anonymous in such a manner that the data subject is not or no longer identifiable. Anonymisation is permanent and irreversible. Principles of data protection do not apply to anonymous information.	GDPR Recital 26
Artificial intelligence	(1) A baseline definition: Systems that display intelligent behaviour by analysing their environment and taking actions – with some degree of autonomy – to achieve specific goals. (2) A more advanced definition: Artificial intelligence (AI) systems are software (and possibly also hardware) systems designed by humans that, given a complex goal, act in the physical or digital dimension by perceiving their environment through data acquisition, interpreting the collected structured or unstructured data, reasoning on the knowledge, or processing the information, derived from this data and deciding the best action(s) to take to achieve the given goal. AI systems can either	White Paper On Artificial Intelligence - A European approach to excellence and trust. European Commission. COM(2020) 65 final.

| | use symbolic rules or learn a numeric model, and they can also adapt their behaviour by analysing how the environment is affected by their previous actions.

As a scientific discipline, AI includes several approaches and techniques, such as machine learning (of which deep learning and reinforcement learning are specific examples), machine reasoning (which includes planning, scheduling, knowledge representation and reasoning, search, and optimization), and robotics (which includes control, perception, sensors and actuators, as well as the integration of all other techniques into cyber-physical systems). | |
|---|---|---|
| **Artificial intelligence system** | Software that is developed with one or more of the techniques and approaches listed in Annex I and can, for a given set of human-defined objectives, generate outputs such as content, predictions, recommendations, or decisions influencing the environments they interact with. | Commission proposal for a regulation of the European Parliament and of the Council laying down harmonised rules on artificial intelligence (Artificial Intelligence Act) and amending certain Union legislative acts (COM(2021) 206) |
| **Beneficiary** | Organisation that receives EU co-funding following successful application in one of the EU's funding programmes and the signature of the related grant agreement. During the application process reference is made to the "applicant(s)". A term used in Joint Actions of the 3rd Health Programme of the European Union. | Guide for applicants, grants for actions co-financed by countries participating in the third EU Health Programme (Joint Actions) (2014-2020) HP-JA-2018 |
| **Biobank** | Collection of biological material and the associated data and information stored in an organised system, for a population or a large subset of a population. | OECD |
| **Biometric data** | Personal data resulting from specific technical processing relating to the physical, physiological or behavioural characteristics of a natural person, which allow or confirm the unique identification of that natural person, such as facial images or dactyloscopic data. | Article 4(14) of the GDPR |
| **Bodies governed by public law** | Bodies that have the following characteristics:
(a) they are established for the specific purpose of meeting needs in the general interest, and do not have an industrial or commercial character
(b) they have legal personality | DGA COM (2020) 767 final |

	(c) they are financed, for the most part, by the state, regional or local authorities, or by other bodies governed by public law; or are subject to management supervision by those authorities or bodies; or have an administrative, managerial or supervisory board, more than half of whose members are appointed by the State, regional or local authorities, or by other bodies governed by public law.	
Business model	Business model describes how an organization creates, delivers, and captures value, in economic, social, cultural or other contexts.	Wikipedia
Care	Effort made to do something correctly, safely, or without causing damage.	Merriam-Webster
Citizen science	Inclusion of non-institutional participants, in other words the general public, in the scientific process. Citizen science – where citizens become providers and users of data. This will reinforce and give new meaning to the policy of open access to publications and data. This openness should enable citizens and citizen groups to participate in evidence-based policy and decision-making. More and more Europeans hold higher education degrees. Enabled by digitalisation and knowledge, citizens are today prosumers capable of shaping the innovation process and bypassing restrictive practices of established sectors and governments. This goes well beyond citizen science and covers the entire research and innovation process.	Haklay M et al. What Is Citizen Science? The Challenges of Definition. In: Vohland K. et al. (eds) The Science of Citizen Science. Springer, Cham. 2021.
Clinical trial	Type of research that studies new tests and treatments and evaluates their effects on human health outcomes.	WHO
Clinical trial phases	There are 4 phases of biomedical clinical trials: 1) Phase I studies usually test new drugs for the first time in a small group of people to evaluate a safe dosage range and identify side effects. 2) Phase II studies test treatments that have been found to be safe in phase I but now need a larger group of human subjects to monitor for any adverse effects. 3) Phase III studies are conducted on larger populations and in different regions and countries, and are often the step right before a new treatment is approved. 4) Phase IV studies take place after country approval and there is a need for further testing in a wide population over a longer timeframe.	WHO
Cloud computing	Cloud computing is Internet-based computing: shared resources, software and information are provided to computers and other devices on-demand.	IEEE

Competent authority	The central authority of a country participating in the third EU Health programme (participating country) responsible for health or for a specific (public) health topic or any other authority to which that competence has been conferred. A competent authority may also be a regional authority, depending on the governance structure of the participating country. A term used in Joint Actions of the 3rd Health Programme of the European Union.	Guide for applicants, grants for actions co-financed by countries participating in the third EU Health Programme (Joint Actions) (2014-2020) HP-JA-2018
Confidential patient information	Information that both identifies the patient, and includes some information about their medical condition or treatment. Any of the types of data could be confidential patient information under certain circumstances.	Patient data and confidential patient information. NHS. 2021.
Consent	Consent of the data subject means any freely given, specific, informed and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her.	Article 4(11) of the GDPR
Controller	Natural or legal person, public authority, agency or other body which, alone or jointly with others, determines the purposes and means of the processing of personal data where the purposes and means of such processing are determined by Union or Member State law, the controller or the specific criteria.	Article 4(7) of the GDPR
Cross-border processing	Processing of personal data which takes place in the context of the activities of establishments in more than one Member State of a controller or processor in the Union where the controller or processor is established in more than one Member State. Or processing of personal data which takes place in the context of the activities of a single establishment of a controller or processor in the Union but which substantially affects or is likely to substantially affect data subjects in more than one Member State.	Article 4(23) of the GDPR
Cross-border healthcare	Healthcare provided or prescribed in a Member State other than the Member State of affiliation.	Directive on the application of patients' rights in cross-border healthcare 2011/24/EU
Customer data	Personal data pursuant to GDPR Article 4(1) of the Data Protection Regulation that must be kept secret by law and that is stored in a customer register or an associated administrative register as a result of social and health care customership or for processing of benefits.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Data	Any digital representation of acts, facts or information and any compilation of such acts, facts or information,	DGA COM (2020) 767 FINAL

	including in the form of sound, visual or audiovisual recording.	
Data altruism	Means the consent by data subjects to process personal data pertaining to them, or permissions of other data holders to allow the use of their non-personal data without seeking a reward, for purposes of general interest, such as scientific research purposes or improving public services.	DGA COM (2020) 767 final
Data analysis	Process of transforming raw data into usable information, often presented in the form of a published analytical article, in order to add value to the statistical output.	OECD
Data catalogue	Organized inventory of data assets in the organization. It uses metadata to help organizations manage their data. It also helps data professionals collect, organize, access, and enrich metadata to support data discovery and governance.	Oracle
Data concerning health	Personal data related to the physical or mental health of a natural person, including the provision of health care services, which reveal information about his or her health status.	Article 4(15) of the GDPR
Data controller	Controller means the natural or legal person, public authority, agency or other body which, alone or jointly with others, determines the purposes and means of the processing of personal data; where the purposes and means of such processing are determined by Union or Member State law, the controller or the specific criteria for its nomination may be provided for by Union or Member State law.	Article 4(7) of the GDPR
Data consumer	Individual, group, or application that receives data in the form of a collection. The data is used for query, analysis, and reporting.	eCommerce Wiki
Data governance	Macro level: data governance refers to the governing of cross-border data flows by countries, and hence is more precisely called international data governance. Micro level: Data management concept concerning the capability that enables an organization to ensure that high data quality exists throughout the complete lifecycle of the data, and data controls are implemented that support business objectives.	Wikipedia
Data Governance Act (DGA)	Legislative proposal of the European Commission that aims to create a framework which will facilitate data-sharing.	Proposal for a regulation of the European Parliament and of the Council on European data governance (Data Governance Act) COM (2020) 767 final

Data governance mechanisms	Examples of data governance mechanisms are defining data ownership and access, formal contract selling, user consent, or data stewards. These mechanisms are beneficial to overcome the barrier of losing control over data.	A.E. Abbas. Designing Data Governance Mechanisms for Data Marketplace Meta-Platforms. ResearchGate. June 2021.
Data holder	Legal person or data subject who, in accordance with applicable Union or national law, has the right to grant access to or to share certain personal or non-personal data under its control.	DGA COM (2020) 767 FINAL
Data hub	Collection of data from multiple sources organized for distribution, sharing, and often subsetting and sharing.	Wikipedia
Data model	Data model organizes data elements and standardizes how the data elements relate to one another.	Princeton university
Data permit	Permit pursuant to this Act to process the secret personal data specified in the permit for the purpose specified in the permit.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Data policy	Set of broad, high level principles which form the guiding framework in which Data Management can operate.	OECD
Data processing	Any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction.	Article 4(2) of the GDPR
Data processor	Natural or legal person, public authority, agency or other body which processes personal data on behalf of the controller.	Article 4(8) of the GDPR
Data provider	Organisation which produces data or metadata.	OECD
Data quality	Comprehensive view of usefulness of data to support decision making. Data quality is defined as "fitness for use" for users' needs. The OECD views quality in terms of seven dimensions: relevance, accuracy, credibility, timeliness, accessibility, interpretability and coherence. Cost-efficiency is included in the Quality Framework as the eight item.	HIMSS Dictionary of Healthcare Information Technology, OECD
Data repository	The data repository is a large database infrastructure, several databases, that collect, manage, and store data sets for data analysis, sharing and reporting.	Digital Guardian
Data request	Discovery procedure in which the requesting party asks another person for specified information or requests the production of documents.	Law Insider
Data request management system	System via which a party applying for a data permit or otherwise requesting data submits their data permit application or data request.	Act on the Secondary Use of Health and

		Social Data. Finland. 552/2019
Data security assessment body	Company, community and authority which has been approved to assess whether an information system meets the requirements on data security.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Data set	Any organised collection of data.	OECD
Data sharing	Provision by a data holder of data to a data user for the purpose of joint or individual use of the shared data, based on voluntary agreements, directly or through an intermediary.	DGA COM (2020) 767 FINAL
Data source	Specific data set, metadata set, database or metadata repository from where data or metadata are available.	OECD
Data sovereignty	Idea that data are subject to the laws and governance structures within the nation it is collected.	Wikipedia
Data subject	Natural person whose personal data is processed by a data controller or processor.	GDPR
Data user	Natural or legal person who has lawful access to certain personal or non-personal data and is authorised to use that data for commercial or non-commercial purpose.	DGA COM (2020) 767 FINAL
Data utilisation plan / Data Management Plan	Research plan, project plan or a similar plan that states the intended purpose of the data referred to in the permit application, the controller and processors of the data, the legal ground for the processing and the essential factors of the data security and data protection related to the processing throughout the lifecycle of the data, including the storage, erasure or archiving of the data.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Decentralised clinical trial (DCT)	Studies executed through telemedicine and mobile/local healthcare providers, using processes and technologies differing from the traditional clinical trial model.	Clinical Trial Transformation Initiative CTTI Recommendations: Decentralized Clinical Trials 2. 2018.
De-identification	Removal of personally identifying information in order to protect personal privacy.	Guidelines for Data De-Identification or Anonymization. Educause. 2021.
Development and innovation operations	Application and use of engineering and business data and other existing data together with the personal data referred to in this Act for the purpose of developing new or significantly improved products, processes or services.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Digital health	Broad umbrella term encompassing e-health, as well as developing areas such as the use of advanced computer sciences (for example, in the fields of "big data", genomics and artificial intelligence).	WHO
Digital health literacy (or eHealth literacy)	Digital health literacy (or eHealth literacy) is the ability to seek, find, understand, appraise health information	Norman, C. D. and Skinner, H. A. (2006a) 'eHEALS:

	from electronic sources and apply the knowledge gained to addressing or solving a health problem.	The eHealth Literacy Scale', Journal of Medical Internet Research, 8(4)
Digital sovereignty	Europe's ability to act independently in the digital world. It refers to the ability to have control over one's own digital destiny – the data, hardware and software that one relies on and creates.	Tambiama Madiega. Digital sovereignty for Europe. European Parliamentary Research Service EPRS. 2020. What is digital sovereignty and why is Europe so interested in it? World Economic Forum. 2021.
Distributed research infrastructure	Organization that enables the research community to use specific facilities, resources and services that are geographically scattered.	RI-VIS H2020 project
Economic model	Simplified description of reality, designed to yield hypotheses about economic behaviour that can be tested.	IMF
Electronic health record (EHR)	Personal data created, developed, maintained, and/or provided by clinicians, providers, and allied health providers in direct patient care. An electronic application containing health information about individuals that is used by clinicians, providers, and allied health professionals to provide direct care for the individuals.	C. Safran et al. Toward a National Framework for the Secondary Use of Health Data: An American Medical Informatics Association White Paper. J Am Med Inform Assoc. 2007 Jan-Feb. 14(1): 1–9. doi: 10.1197/jamia.M2273
Enterprise	Natural or legal person engaged in an economic activity, irrespective of its legal form, including partnerships or associations regularly engaged in an economic activity.	Article 4(18) of the GDPR
European Health Data Space (EHDS)	The creation of a European Data Space is one of the priorities of the Commission 2019-2025, including the health sector. In the Communication on "A European strategy for data" it states that the Commission will support the establishment of nine common European data spaces with one of them being the Common European health data space, which is essential for advances in preventing, detecting and curing diseases as well as for informed, evidence-based decisions to improve the accessibility, effectiveness and sustainability of the healthcare systems.	European Commission

FAIR Data principles	The FAIR Data Principles are a set of guiding principles in order to make data findable, accessible, interoperable and reusable.	Wilkinson, et al. The FAIR Guiding Principles for scientific data management and stewardship". Scientific Data. 3 (2016) 160018.
Federated database	System in which several databases appear to function as a single entity. Each component database in the system is completely self-sustained and functional.	TechTarget
Filing system	Any structured set of personal data which are accessible according to specific criteria, whether centralised, decentralised or dispersed on a functional or geographical basis.	Article 4(6) of the GDPR
Financial model	Summary of an organisation's performance, based on certain variables, that helps the business forecast future financial performance.	CFI
Funding model	Methodical and institutionalised approach to building a reliable revenue base that will support an organisation's core programs and services.	Bridgespan
Genetic data	Means personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question.	Article 4(13) of the GDPR
GDPR	General Data Protection Regulation (GDPR) is a regulation in EU law strengthening and harmonising EU/EEA procedures concerning the collection, storage, processing, access, use, transfer and erasure of personal data.	The General Data Protection Regulation (EU) 2016/679 (GDPR)
GDPR Principles	Fundamental principles imbedded within the GDPR which set out the main responsibilities for organisations.	GDPR
Governance	Governance is the exercise of political, economic and administrative authority necessary to manage a nation's affairs.	OECD
Governance model	Governance model explains the principles, organisational structure and decisional processes.	EC
Health	State of complete physical, mental and social well-being and not merely the absence of disease or infirmity.	WHO
Health care activities	Activities of health care in a country comprises the sum of activities performed either by institutions or individuals pursuing, through the application of medical, paramedical and nursing knowledge and technology, the goals of: - promoting health and preventing disease; - curing illness and reducing premature mortality;	OECD

	- caring for persons affected by chronic illness who require nursing care; - caring for persons with health-related impairment, disability, and handicaps who require nursing care; - assisting patients to die with dignity; - providing and administering public health; - providing and administering health programmes, health insurance and other funding arrangements.	
Health and social services (HSS)	Health and social services include hospital services (i.e. health services delivered under the supervision of doctors), other health services (i.e. ambulance services and residential health facilities), social services and "other" health and social services.	WHO
Health facility	Any location where healthcare is provided.	Wikipedia
Health information	All organised and contextualised data on population health and health service activities and performance, individual or aggregated, that improves health promotion, prevention, care and policy-making.	PHIRI
Health information systems	Collect data from health and other relevant sectors, analyses the data and ensures their overall quality, relevance and timeliness, and converts the data into information for health-related decision making.	WHO
Health professional	Doctor of medicine, a nurse responsible for general care, a dental practitioner, a midwife or a pharmacist within the meaning of Directive 2005/36/EC, or another professional exercising activities in the healthcare sector which are restricted to a regulated profession as defined in Article 3(1)(a) of Directive 2005/36/EC, or a person considered to be a health professional according to the legislation of the Member State of treatment.	Directive on the application of patients' rights in cross-border healthcare 2011/24/EU
Health service	Efforts made to maintain or restore physical, mental, or emotional well-being especially by trained and licensed professionals.	Merriam-Webster
Health system	All activities whose primary purpose is to promote, restore, and maintain health.	WHO: Key components of a well functioning health system. 2015.
Health technology	Any intervention that may be used to promote health, prevent, diagnose or treat disease, or for rehabilitation or long-term care. This includes pharmaceuticals, devices, procedures, and organisational systems used in health care.	Constitution of WHO: principles. World Health Organisation. 2016.
Healthcare	Health services provided by health professionals to patients to assess, maintain or restore their state of health, including the prescription, dispensation and provision of medicinal products and medical devices.	Directive of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border

		healthcare 2011/24/EU
Healthcare provider	Any natural or legal person or any other entity legally providing healthcare.	Directive on the application of patients' rights in cross-border healthcare 2011/24/EU
Health technology	Medicinal product, a medical device or medical and surgical procedures as well as measures for disease prevention, diagnosis or treatment used in healthcare.	Directive on the application of patients' rights in cross-border healthcare 2011/24/EU
Information	Information in information processing refers to knowledge concerning objects, such as facts, events, things, processes, or ideas, including concepts, that within a certain context has a particular meaning.	OECD
Information society service	Service as defined in point (b) of Article 1(1) of Directive (EU) 2015/1535 of the European Parliament and of the Council (¹).	Article 4(25) of the GDPR
Informed consent	Decision, which must be written, dated and signed, to take part in a clinical trial, taken freely after being duly informed of its nature, significance, implications and risks and appropriately documented, by any person capable of giving consent or, where the person is not capable of giving consent, by his or her legal representative. If the person concerned is unable to write, oral consent in the presence of at least one witness may be given in exceptional cases, as provided for in national legislation.	Directive relating to the implementation of good clinical practice in the conduct of clinical trials on medicinal products for human use 2001/20/EC
Input data	Needed to carry out a process or provide a service. There are two data sources, digital data and analog data. Digital input signals are used to represent items that only have two states. Analog signals are variable, they have multiple states.	HIMSS Dictionary of Healthcare Information Technology modified
International organisation	Organisation and its subordinate bodies governed by public international law, or any other body which is set up by, or on the basis of, an agreement between two or more countries.	Article 4(26) of the GDPR
International Patient Summary Data Set	Minimal, non-exhaustive set of data elements required for the international patient summary.	ISO/FDIS 27269, 3.8.3.3
Interoperability	Following the European Interoperability Framework, interoperability refers to a) a full compliance with the legal and ethical provisions in each constituent node, b) an organisation that supports knowledge exchange and software transference across nodes, c) a compatible technological environment that supports the communication between nodes and allows the deployment of the computational tasks, and d) the	New European Interoperability Framework, EC

	existence of common data models that enables semantic standardisation across data sources. In a distributed research infrastructure, interoperability is a key feature for its governance and achievements.	
Joint action (JA)	Joint action constitutes an operational action by the member states.	European Commission
Knowledge management	Processing of data carried out by a service provider in their customer, service and production processes for the purpose of supporting operations, production, financial control, management and decision-making.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Knowledge translation	The appropriate exchange, synthesis and ethically sound application of knowledge to interventions that strengthen the healthcare system and improve health.	S.E. Straus et al. Defining knowledge translation. CMAJ. 181(3-4) (2009) 165–168.
Machine learning	Branch of artificial intelligence (AI) and computer science which focuses on the use of data and algorithms to imitate the way that humans learn, gradually improving its accuracy.	IBM
Main establishment	'Main establishment' of a legal entity means the place of its central administration in the Union.	DGA COM (2020) 767 final
Medical records	All the documents containing data, assessments and information of any kind on a patient's situation and clinical development throughout the care process.	Directive on the application of patients' rights in cross-border healthcare 2011/24/EU
Member State of treatment	Member State on whose territory healthcare is actually provided to the patient. In the case of telemedicine, healthcare is considered to be provided in the Member State where the healthcare provider is established.	Directive on the application of patients' rights in cross-border healthcare 2011/24/EU
Metadata	Data collected on any activity of a natural or legal person for the purposes of the provision of a data sharing service, including the date, time and geolocation data, duration of activity, connections to other natural or legal persons established by the person who uses the service.	DGA COM (2020) 767 FINAL
National Node	National Node (NN) is an organisational entity, often linked to a national institution or governmental unit that functions as a national liaison and brings together relevant national stakeholders in the country in a systematic way. The relevant stakeholders may include, for example, the national statistical office, the national public health institutes, representatives from ministries of health, research and/or science, and others. In addition, the NN may function as a discussion and advisory forum in matters of health data and information both for national or international	INFACT JA on Health information

	matters. Examples include aspects of the governance of data, indicators and health reporting at the international level and health information stakeholders at national level.	
Non-personal data	Data other than personal data as defined in point (1) of Article 4 of Regulation (EU) 2016/679.	DGA COM (2020) 767 FINAL
Open data	Open data is data that can be freely used, re-used and redistributed by anyone - subject only, at most, to the requirement to attribute and sharealike.	Open Data Handbook
Open science	Open science refers to the mechanisms by which the findability, accessibility and use of scientific knowledge is promoted in the digital era.	University of Helsinki
Patient	Any natural person who seeks to receive or receives healthcare.	Directive on the application of patients' rights in cross-border healthcare 2011/24/EU
Personal data	Any information relating to an identified or identifiable natural person ('data subject'). An identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.	Article 4(1) of the GDPR
Personal data breach	Breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or access to, personal data transmitted, stored or otherwise processed.	GDPR
Personalised medicine	Personalised medicine refers to a medical model using characterisation of individuals' phenotypes and genotypes (e.g., molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease and/or to deliver timely and targeted prevention. Personalised medicine relates to the broader concept of patient-centred care, which takes into account that, in general, healthcare systems need to better respond to patient needs.	Council conclusions on personalised medicine for patients (2015/C 421/03)
Population Health Data / Health information	All organised and contextualised data on health and health service activities and performance, at individual or population level, that is fit-for-use and contributes to health promotion, prevention, care and policymaking.	PHIRI
Precision medicine	Precision medicine is an emerging approach for disease prevention and treatment that takes into account people's individual variations in genes, environment, and lifestyle.	Precision Medicine Initiative (PMI), United States.
Pre-processed data	Data from one or more organisations which the data permit authority for the social and health care sector	Act on the Secondary Use of Health and

	referred to in section 4 has combined into a single whole or stored in a way that has replaced the identifying information in the data with a uniform code.	Social Data. Finland. 552/2019
Prescription	Prescription for a medicinal product or for a medical device issued by a member of a regulated health profession who is legally entitled to do so.	Directive on the application of patients' rights in cross-border healthcare 2011/24/EU
Primary healthcare service	Primary healthcare services are bringing health care as close as possible to where people live and work. They address the main health problems in the community, providing preventive, curative and rehabilitative services. Besides primary care physicians also other professionals such as nurses, pharmacists, auxiliaries, and community health workers are providing these services.	OECD
Primary healthcare	Ensures people receive quality comprehensive care - ranging from promotion and prevention to treatment, rehabilitation and palliative care - as close as feasible to people's everyday environment. They include monitoring of the health of the population; promoting wellbeing and health; prevention, diagnosis and treatment of diseases, in particular public health diseases.	WHO
Primary purpose of persona/ data	Purpose for which the personal data was originally saved.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Primary source of data	Organisation or individual responsible for the collection and aggregation of data from their initial source.	OECD
Primary use of data	Use of personal health information by the organisation or entity that produced or acquired these data in the process of providing real-time, direct care of an individual.	C. Safran et al. Toward a National Framework for the Secondary Use of Health Data: An American Medical Informatics Association White Paper. J Am Med Inform Assoc. 2007 Jan-Feb. 14(1): 1–9. doi: 10.1197/jamia.M2273

Personal data	Personal data are any information which are related to an identified or identifiable natural person.	Article 4(1) of the GDPR
Personalised medicine	Personalised medicine promotes the health and wellbeing of individuals by utilising research, new technologies and a wider range of information resources.	Ministry of Social Affairs and Health, Finland
Processing	Processing covers a wide range of operations performed on personal data, including by manual or automated means. It includes the collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction of personal data.	European Commission
Profiling	Any form of automated processing of personal data consisting of the use of personal data to evaluate certain personal aspects relating to a natural person, in particular to analyse or predict aspects concerning that natural person's performance at work, economic situation, health, personal preferences, interests, reliability, behaviour, location or movements.	Article 4(4) of the GDPR
Pseudonymisation	Processing of personal data in such a manner that the personal data can no longer be attributed to a specific data subject without the use of additional information, provided that such additional information is kept separately and is subject to technical and organisational measures to ensure that the personal data are not attributed to an identified or identifiable natural person.	Article 4(5) of the GDPR
Public health	All elements related to health, namely health status, including morbidity and disability, the determinants having an effect on that health status, health care needs, resources allocated to health care, the provision of, and universal access to, health care as well as health care expenditure and financing, and the causes of mortality.	Regulation (EC) No 1338/2008
Public health monitoring and reporting	Regular collection of data on relevant components of health and its determinants in the population or in samples thereof, aimed at informing the public health policy process.	EUPHA EU Public Health Association
Public sector body	State, regional or local authorities, bodies governed by public law or associations formed by one or more such authorities or one or more such bodies governed by public law.	DGA COM (2020) 767 final
Public undertaking	Any undertaking over which the public sector bodies may exercise directly or indirectly a dominant influence by virtue of their ownership of it, their financial participation therein, or the rules which govern it. For the purpose of this definition, a dominant influence on	DGA COM (2020) 767 final

	the part of the public sector bodies shall be presumed in any of the following cases in which those bodies, directly or indirectly: (a) hold the majority of the undertaking's subscribed capital. (b) control the majority of the votes attaching to shares issued by the undertaking. (c) can appoint more than half of the undertaking's administrative, management or supervisory body.	
Quality assurance framework	Quality assurance framework is used to manage quality standards in a systematic manner, addressing processes for collection, processing, analysis and dissemination.	OECD
Raw data	Records of original observations, measurements and activities.	Medical dictionary
Recipient	Natural or legal person, public authority, agency or another body, to which the personal data are disclosed, whether a third party or not. However, public authorities which may receive personal data in the framework of a particular inquiry in accordance with Union or Member State law shall not be regarded as recipients. The processing of those data by those public authorities shall be in compliance with the applicable data protection rules according to the purposes of the processing.	Article 4(9) of the GDPR
Register of health and social services providers	The purpose of the register is to collect data on the activities of health centres, hospitals and other institutions providing inpatient care and on the clients treated in them as well as on home-nursing clients for the purposes of statistics, research and planning.	Finnish Institute for health and welfare
Representative	Natural or legal person established in the Union who, designated by the controller or processor in writing pursuant to Article 27, represents the controller or processor with regard to their respective obligations under this Regulation.	Article 4(18) of the GDPR DGA COM (2020) 767 final
Research Network	A Research Network (RN) is an active network of national and/or regional experts from several countries that perform comparative research in a specific health area (information domain).	European Health Information Portal
Restriction of processing	Marking of stored personal data with the aim of limiting their processing in the future.	Article 4(3) of the GDPR
Re-use	Use by natural or legal persons of data held by public sector bodies, for commercial or non-commercial purposes other than the initial purpose within the public task for which the data were produced, except for the exchange of data between public sector bodies purely in pursuit of their public tasks.	DGA COM (2020) 767 FINAL
Right of access	Entitles the data subjects to have access to have access to and information about the personal data being processed by the data controller.	GDPR

Secondary purpose of personal data	Processing of personal data for a purpose other than the primary purpose referred to in primary purpose of personal data.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Secondary source of data	Organisation or individual other than those responsible for the collection and aggregation of data from their initial source. Secondary sources may redistribute information received from the primary source either in their initial form or after some transformation including further aggregation, reclassification or other manipulation such as seasonal adjustment.	OECD
Secondary use of data	Secondary use of data occurs when data is used for a purpose different from the purpose for which the data was initially collected. (Note: secondary use of data is not the same as re-use of data.)	Code of Practice on Secondary Use of Medical Data in Scientific Research Projects - 27 Aug 2014 Final Draft. Innovative Medicines Initiative.
Secure hosting service	Data secure solution via which the parties can disclose and receive data that is subject to restrictions on access and use.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Secure processing environment / Secure operating environment	Physical or virtual environment and organisational means to provide the opportunity to re-use data in a manner that allows for the operator of the secure processing environment to determine and supervise all data processing actions, including to display, storage, download, export of the data and calculation of derivative data through computational algorithms.	DGA COM (2020) 767 final Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Sensitive data	Sensitive data is defined as any information that is protected against unwarranted disclosure. Protection of data may be required for legal or ethical reasons, for issues pertaining to personal privacy, or for proprietary considerations. Human data e.g. health, genetic and personal information, data that may identify a person.	CSC
Service	Performance of an action or work for the benefit of others.	Medical dictionary
Service architecture	Service architecture, or service-oriented architecture (SOA), is a software approach that uses existing services and applications to provide value to users.	Indeed
Service chain	Sequence of services where, for each adjacent pair of services, occurrence of the first action is necessary for the occurrence of the second action.	ISO
Service deliverer	Person in an organisation seen by the customer as giving the customer service.	Pearson
Service enabler	Example: Privacy as service enabler means that existing or new services are built in a privacy friendly manner, by proactively incorporating privacy protection in the technological and organisational processes.	N. Creemers et al. Profiling Technologies in Practice Applications and

		Impact on Fundamental Rights and Values. 2015.
Service infrastructure	Simplified service infrastructure definition is that it's an alternative term for "infrastructure-as-a-service" (IaaS) which is a type of cloud-based infrastructure service that gives organizations remote access to computing resources.	Compuquip
Service offerer	Party that offers to its clients services associated with a data secure operating environment.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Service organiser	Social and health care service provider that: a) has an obligation as an authority to ensure that the customer gets a service or benefit that according to law or authoritative decision is due to him or her or b) has an obligation as a private service provider to ensure that the customer who purchases the service privately is provided with the service that is due to him or her under the regulations on consumer protection.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Service package	A service package is a bundle of services that are provided together.	
Service producer	Service provider that produces a social or health care service under an agreement made with the service organiser or otherwise on behalf of the service organiser.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Service provider	Authority that organises, produces or implements social and health care or social or health services, or a private service producer referred to in the Act on Private Social Services (922/2011) or Act on Private Health Care (152/1990).	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Service provision	Service provision refers to the way inputs such as money, staff, equipment and drugs are combined to allow the delivery of health interventions.	WHO
Special categories of personal data	Personal data revealing a data subjects racial or ethnic origin, political opinions, religious or philosophical beliefs or trade union membership or the processing of genetic data, biometric data for the purposes of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation.	GDPR
Specialised health service	Specialised health care is made up of health care services in specialised fields within medicine and dentistry concerning disease prevention, examination, treatment, emergency medicine, emergency care and medical rehabilitation services.	Finnish Terminology Centre TSK
Specialised healthcare	Specialised medical care services are provided at hospitals. Specialised medical care refers to examinations and treatments, such as surgeries, provided by medical specialists at hospitals.	Ministry of Social Affairs and Health, Finland

Steering of social and health care by authorities	Statutory steering of social and health care organisations by the national social and health care authorities based on personal data and statistics collected for the purpose or on data received for the steering or supervision task on a case-by-case basis.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Supervision of social and health care by authorities	Statutory supervision of social and health care professionals and units by the national social and health care authorities.	Act on the Secondary Use of Health and Social Data. Finland. 552/2019
Supervisory authority	Independent public authority which is established by a Member State pursuant to Article 51 of the GDPR.	Article 4(21) of the GDPR
Support service	Services which are not directly related to patient care but, indirectly contribute in patient management.	
Test set	A test set in machine learning is a secondary (or tertiary) data set that is used to test a machine learning program after it has been trained on an initial training data set.	Techopedia
Third party	Natural or legal person, public authority, agency or body other than the data subject, controller, processor and persons who, under the direct authority of the controller or processor, are authorised to process personal data	Article 4(10) of the GDPR
Training set	Training set is the material through which the computer learns how to process information.	Techopedia
Use case	A software and system engineering term that describes how a user interacts within a system to accomplish a particular goal. A use case acts as a software modelling technique that defines the features to be implemented and the resolution of any errors that may be encountered.	Techopedia
Validation set	Set of data used to train artificial intelligence (AI) with the goal of finding and optimizing the best model to solve a given problem.	TechTarget

Useful glossaries

1. University College London UCL. GDPR – Glossary of terms and definitions. https://www.ucl.ac.uk/legal-services/gdpr-glossary-terms-and-definitions

2. European Medicines Agency. The General Data Protection Regulation1: Secondary Use of Data for Medicines and Public Health Purposes. Discussion Paper for Medicines Developers, Data Providers, Research-Performing and Research-Supporting Infrastructures. http://www.encepp.eu/events/documents/Discussionpaper.pdf Accessed 2021-09-23.

3. European Data Protection Supervisor. Glossary. https://edps.europa.eu/data-protection/data-protection/glossary_en

4. Phiri https://www.phiri.eu/glossary

5. HealthyCloud https://docs.google.com/document/d/14AWDnr9SFVz_7FzL31fA6toPEjh8YvTTv8aZxKyFtJw/edit?usp=sharing

6. X-eHealth https://www.x-ehealth.eu/concepts/