ERDERA
European Rare Diseases
Research Alliance

Amsterdam UMC

Benefits and challenges of data sharing

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About me

Full Professor of Medical Informatics – Reusable Health Data at Amsterdam UMC

Principal Educator on FAIR Data

Principal Investigator on Reusable Health Data

Benefits and challenges of data sharing

- Purposes of data sharing
- What “data sharing” is
- The future of data sharing: European Health Data Space (EHDS)
- Data sharing challenges
- Data sharing benefits

Purposes of data sharing

in rare disease research

- Data islands / silos are too small to extract **information** from
  - Insufficient **cases** for (ultra)rare conditions, or for subgroup analysis
  - Insufficient **parameters** / attributes to assess conclusions

Purposes of data sharing

in rare disease research

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  - Insufficient **parameters** / attributes to assess conclusions

- Sharing data can result in more cases, i.e., a **longer** data set.
- Sharing data can result in more parameters, i.e., a **wider** data set.
- Sharing data can result in more missings, i.e., a **sparser** data set.

Participant	Role	Country of current residence	Affiliation	Topic of Interest
1	NCIT:C19495	ISO 3166-2:NL	ror:05grdyy37	All RDs, Hematologic diseases, Neuromuscular diseases
2	NCIT:C93178	ISO 3166-2:BE	ror:05s4nk876	Rare bone diseases
3	NCIT:C55334	ISO 3166-2:NL	ror:05grdyy37	GSD
4	NCIT:C64735	ISO 3166-2:BE	ror:05s4nk876	Celiac artery compression syndrome, Renal nutcracker syndrome, Superior mesenteric artery syndrome, May-Thurner syndrome
5	NCIT:C93442	ISO 3166-2:NL	ror:05grdyy37	PKU and allied metabolic disorders

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5	NCIT:C93442	ISO 3166-2:NL	ror:05grdyy37	PKU and allied metabolic disorders
6	NCIT:C33055	ISO 3166-2:BE	ror:05s4nk876	Facio-scapulo-humeral muscular dystrophy (FSHD)
7	NCIT:C48888	ISO 3166-2:NL	ror:05grdyy37	Relapsing Polychondritis, RP
8	NCIT:C48537	ISO 3166-2:BE	ror:05s4nk876	Neuromuscular diseases (NMD)
9	NCIT:C67214	ISO 3166-2:NL	ror:05grdyy37	All RDs
10	NCIT:C80499	ISO 3166-2:BE	ror:05s4nk876	Prader Willi Syndrome and Rare Diseases
11	NCIT:C30011	ISO 3166-2:NL	ror:05grdyy37	Marfan Syndrome, Loeys-Dietz Syndrome, (vascular) Ehlers-Danlos Syndrome and related Connective Tissue Disorders (MFS, LDS, vEDS, CTD)
12	NCIT:C43884	ISO 3166-2:BE	ror:05s4nk876	The list of conditions is very long, therefore I offer some overview main thematic disease groups and sub themes: rare endocrine conditions>>Adrenal, disorders of Calcium & phosphate,Genetic disorders of Glucose & Homeostasis, Genetic Endocrine Tumour Syndromes, Growth & Genetic Obesity Syndromes, Hypothalamic and Pituitary Conditions,Sex Development & Maturation, Thyroid
13	NCIT:C21161	ISO 3166-2:NL	ror:05grdyy37	Ehlers-Danlos syndrome (EDS)
14	NCIT:C62302	ISO 3166-2:BE	ror:05s4nk876	All Rare diseases
15	NCIT:C16487	ISO 3166-2:NL	ror:05grdyy37	thrombotic thrombocytopenic purpura (TTP)
16	NCIT:C91379	ISO 3166-2:BE	ror:05s4nk876	Multidisplinary Care Group ERN-EURO NMD.
17	NCIT:C59865	ISO 3166-2:NL	ror:05grdyy37	hereditary angioedema (HAE)
18	NCIT:C11223	ISO 3166-2:BE	ror:05s4nk876	Craniofacial conditions eg craniosynostosis

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Participant	Role	Country of current residence	Affiliation	Topic of Interest	V1	V2	V3	V4	V5	V6	V7	V8	V9	V10	V11	V12	V13	V14	V15	V16
1	NCIT:C19495	ISO 3166-2:NL	ror:05grdyy37	All RDs, Hematologic diseases, Neuromuscular diseases	438	611	52	517	951	47	359	539	390	93	603	138	341	82	417	382
2	NCIT:C93178	ISO 3166-2:BE	ror:05s4nk876	Rare bone diseases	941	511	512	484	944	759	436	388	97	374	560	659	667	246	105	484
3	NCIT:C55334	ISO 3166-2:NL	ror:05grdyy37	GSD	439	377	598	138	515	752	709	82	509	486	847	52	652	95	742	881
4	NCIT:C64735	ISO 3166-2:BE	ror:05s4nk876	Celiac artery compression syndrome, Renal nutcracker syndrome, Superior mesenteric artery syndrome, May-Thurner syndrome	893	490	106	217	446	469	505	898	695	116	519	86	812	1	387	787
5	NCIT:C93442	ISO 3166-2:NL	ror:05grdyy37	PKU and allied metabolic disorders	497	169	249	995	586	318	932	243	35	224	187	182	342	977	624	867

Participant	Role	Country of current residence	Affiliation	Topic of Interest	V1	V2	V3	V4	V5	V6	V7	V8	V9	V10	V11	V12	V13	V14	V15	V16
1	NCIT:C19495	ISO 3166-2:NL	ror:05grdyy37	All RDs, Hematologic diseases, Neuromuscular diseases	438	611	52	517	951	47	359	539	390	93	603	138	341	82	417	382
2	NCIT:C93178	ISO 3166-2:BE	ror:05s4nk876	Rare bone diseases	941	511	512	484	944	759	436	388	97	374	560	659	667	246	105	484
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6	NCIT:C33055	ISO 3166-2:BE	ror:05s4nk876	Facio-scapulo-humeral muscular dystrophy (FSHD)	575	513	925	180	3	549	24	994	337	78	185	258	485	566	631	843
7		ISO 3166-2:NL	ror:05grdyy37	Relapsing Polychondritis, RP	249	64	315		241		32			474	417	17	747	87	480	224
8	NCIT:C48537			Neuromuscular diseases (NMD)	239	271	910	75	445	781	733	166	744	994			353	957	612	728
9	NCIT:C67214	ISO 3166-2:NL	ror:05grdyy37	All RDs	229	480	21	898	947		153		930		52	219	678	725	10	992
10	NCIT:C80499			Prader Willi Syndrome and Rare Diseases																
11	NCIT:C30011	ISO 3166-2:NL			938	847	486	462	304	98	801	581	835	150	967	720	648	20	787	824
12		ISO 3166-2:BE																		
13	NCIT:C21161	ISO 3166-2:NL			954	121	168									195	753	730	626	275
14			ror:05s4nk876		152	319	301	85			439	970	562	457	774	230	136	654	778	581
15	NCIT:C16487			thrombotic thrombocytopenic purpura (TTP)	183	889	967	620	739	291		574		945		778		823	794	174
16	NCIT:C91379		ror:05s4nk876	Multidisplinary Care Group ERN-EURO NMD.	247	833	523	111	859	547	478	250	829	997	505	984	422	250	63	993
17	NCIT:C59865	ISO 3166-2:NL	ror:05grdyy37		970						702	782	562	161	161	715	695	471	6	398
18	NCIT:C11223	ISO 3166-2:BE	ror:05s4nk876	Craniofacial conditions eg craniosynostosis	776	447	219	986	68	941								580	966	137

Other data sharing/reuse: Open data

- Increasingly open data are made available by governments and organizations

Research and innovation

Our digital future

Open Science

An approach to the scientific process that focuses on spreading knowledge as soon as it is available using digital and collaborative technology. Expert groups, publications, news and events.

The EU's open science policy

Open Science is at the centre of European research policy. Policies, initiatives and structures are developed and implemented to open up European science and research to make them more efficient and productive, seamless, transparent and robust as well as responsive to policy and society needs and expectations.

https://research-and-innovation.ec.europa.eu/strategy/strategy-research-and-innovation/our-digital-future/open-science_en

EU

European data

data.europa.eu

https://data.europa.eu/en

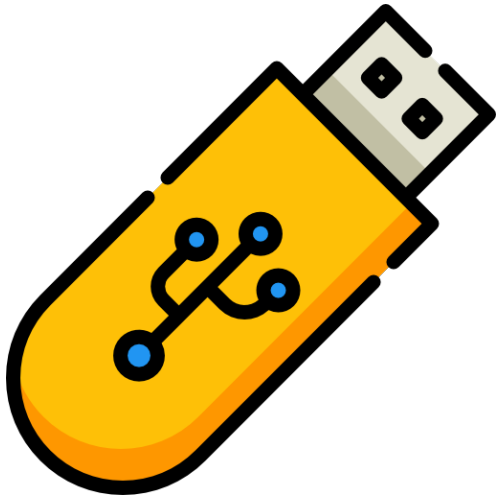
Other data sharing/reuse: Open data

- Increasingly open data are made available by governments and organizations

- Geographical data: population density, urbanization
- Social-economic status: postal code as proxy
- Aggregate data: characteristics of population, disease prevalence, treatment costs

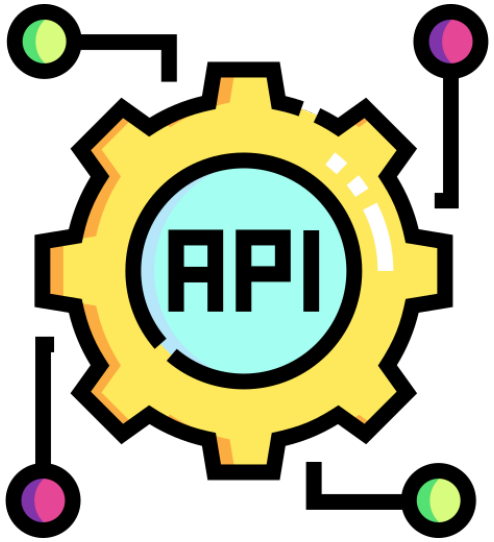
“data sharing”

Old-style: copy-paste data



Source: https://www.flaticon.com/free-icons/usb
Usb icons created by Freepik - Flaticon

Contemporary: data data visiting



Source: https://www.flaticon.com/free-icons/api
Api icons created by Freepik - Flaticon

European Health Data Space (EHDS)

Into force as of today, March 26, 2025; implementation deadline 2031!

What is the timeline for the implementation of the EHDS Regulation?

On 5th March 2025, the European Health Data Space Regulation was officially published in the Official Journal of the European Union. It enters into force on 26 March 2025, marking the beginning of the transition phase towards application.

https://health.ec.europa.eu/ehealth-digital-health-and-care/european-health-data-space-regulation-ehds_en

EHDS

- Primary use
- Secondary use

What is the EHDS Regulation about

Unlocking the future of health data in Europe

The European Health Data Space (EHDS) is a cornerstone of the European Health Union and the **first common EU data space** dedicated to a specific sector as part of the European strategy for data.

The EHDS Regulation aims to establish a common framework for the use and exchange of electronic health data across the EU. It enhances individuals' access to and control over their personal electronic health data, while also enabling certain data to be reused for public interest, policy support, and scientific research purposes. It fosters a health-specific data environment that supports a single market for digital health services and products. Additionally, the regulation establishes a harmonised legal and technical framework for electronic health record (EHR) systems, fostering interoperability, innovation, and the smooth functioning of the internal market.

The EHDS will:

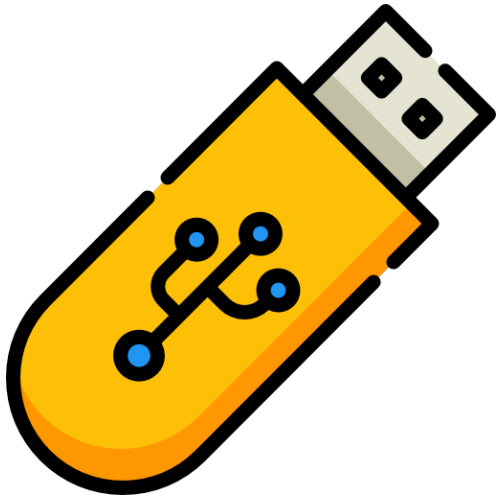
1. empower individuals to access, control and share their electronic health data across borders for the healthcare delivery (primary use of data);
2. enable the secure and trustworthy reuse health data for research, innovation, policy-making, and regulatory activities (secondary use of data);
3. foster a single market for electronic health record (EHR) systems, supporting both primary and secondary use.

By doing so, the EHDS will enable the EU to benefit from the full potential offered by a safe and secure exchange, use and reuse of health data to benefit patients, health professionals, researchers, regulators, and innovators.

https://health.ec.europa.eu/ehealth-digital-health-and-care/european-health-data-space-regulation-ehds_en

“data sharing” in EHDS

Article 47: Data request



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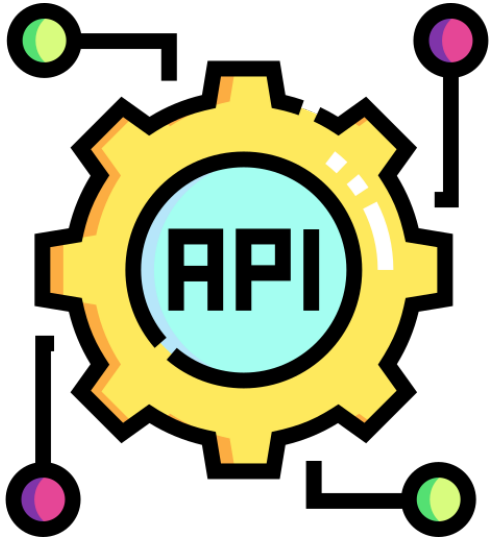
Article 45: Data access applications



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Api icons created by Freepik - Flaticon

EHDS regulations

Data holders

- Must publish what data they have (not: must publish their data!)
- Must make data available upon reasonable request, at reasonable cost

Data sharing challenges and benefits

	Benefit	Challenge
Data holder	• Contributor to advancement of science and practice • Broader network – reciprocity • “Credits”, e.g., data citations	• Ensuring privacy • Preventing abuse • Compute facility (e.g., training AI)
Data “seeker”	• Potentially many data sets available • Possibility of more advanced (subgroup) analysis	• Understanding data • Understanding data quality • Possibly a data holder for resulting data
Society	• Better health and care	• Trust

Summary

- Purposes of data sharing: lengthening and broadening data, at the cost of lower data quality
- Data sharing used to be copy/paste, but moves towards data access
- European Health Data Space (EHDS) provides regulations for data holding, requesting, accessing
- Data sharing challenges: ensuring proper use; understanding data & data quality; establishing trust
- Data sharing benefits: accelerating research; improved health & care

Contact info

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