

European Strategy for data

Fields marked with * are mandatory.

Introduction

Europe is undergoing a digital transition that is changing our societies and economies at an unprecedented speed. Data is at the core of this transformation. It has an impact on all economic sectors and also on the daily lives of citizens.

The aim of the European strategy for data is to create a single European data space: a genuine single market for data, where personal as well as non-personal data, including confidential data, are secure. This will make it easier for businesses and public authorities to access an almost infinite amount of high-quality data to boost growth and create value, while reducing the carbon footprint of the EU economy.

To fulfil this ambition, the EU can build its single market for data on a strong legal framework in terms of data protection, freedom to provide services and of establishment, fundamental rights, safety and cyber-security – and this will be further stimulated by a large degree of interconnection in digital public services. In addition, the EU has a strong industrial base and a recognised technological capacity to build safe and reliable complex products and services, from aeronautics to energy, automotive, medical equipment and digital.

The Commission is putting forward a European data strategy that benefits society and the entire European digital economy. It puts the citizen at the centre of the data-driven economy while ensuring that European companies and public authorities can capitalise on the data they generate and also have better access to the data generated by others.

You can consult the European data strategy here (<https://ec.europa.eu/info/strategy/priorities-2019-2024/europe-fit-digital-age/european-data-strategy>). You are invited to read this document prior to completing the questionnaire.

This public consultation will help shape the future policy agenda on the EU data economy. It will feed into possible Commission initiatives on access to and re-use of data.

It is structured in two sections. The objective of Section 1 is to collect views on the data strategy as a whole. Section 2 is divided into sub-sections. It aims to collect information on three specific aspects announced in the data strategy:

- how data governance mechanisms and structures can best maximise the social and economic benefits of data usage in the EU
- the EU-wide list of high-value datasets that the Commission is to draw up under the recently adopted Open Data Directive
- the role of self-regulation to implement rules on data processing

Depending on your answers, the questionnaire may take approximately 10 minutes.

This consultation will close on 31 May 2020, end of the day.

About you

*Language of my contribution

English

*I am giving my contribution as

Other

*First name

Vania

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*Organisation name

255 character(s) maximum

EuroHealthNet

*Organisation size

Small (10 to 49 employees)

Transparency register number

255 character(s) maximum

Check if your organisation is on the transparency register

(<http://ec.europa.eu/transparencyregister/public/homePage.do?redir=false&locale=en>). It's a voluntary database for organisations seeking to influence EU decision-making.

48562122691-12

*Country of origin

Please add your country of origin, or that of your organisation.

Belgium

***Publication privacy settings**

The Commission will publish the responses to this public consultation. You can choose whether you would like your details to be made public or to remain anonymous.

Anonymous

Only your type of respondent, country of origin and contribution will be published. All other personal details (name, organisation name and size, transparency register number) will not be published.

Public

Your personal details (name, organisation name and size, transparency register number, country of origin) will be published with your contribution.

I agree with the personal data protection provisions (https://ec.europa.eu/info/law/better-regulation/specific-privacy-statement_en)

Section 1: General questions on the data strategy

Over the last few years, digital technologies have transformed our economy and society, affecting all sectors of activity and the daily lives of all Europeans. Data is at the centre of this transformation, and more is to come as the volume of data produced in the world is growing rapidly.

Do you agree that the European Union needs an overarching data strategy to enable the digital transformation of the society?

- Yes
 No

“More data should be available for the common good, for example for improving mobility, delivering personalised medicine, reducing energy consumption and making our society greener.” To what extent do you agree with this statement?

- Strongly agree
 Somewhat agree
 Neutral
 Somewhat disagree
 Strongly disagree
 I don't know / no opinion

Do you think that it should be made easier for individuals to give access to existing data held about them, e.g. by online platform providers, car manufacturers, producers of wearables, voice assistants or smart home appliances, to new services providers of their choosing, in line with the GDPR?

- Yes

No

Which mechanism(s) do you think would help achieve this?

- A compelling offer to use the data that brings benefits to the individuals
- Practical solutions that allow individuals to exercise control, such as mobile and online dashboards or apps
- Additional rights in law
- Other
- I don't know / no opinion

If other, please specify

200 character(s) maximum

To improve data/digital literacy and encouraging the use of Apps to monitor health data actions at community level (eg.: coaching from GPs) resulted effective

Have you faced difficulties in recruiting data professionals (workers who collect, store, manage, analyse, interpret and visualise data as their primary or as a relevant part of their activity) during the last 2 years?

- Yes
- No

'General data literacy across the EU population is currently insufficient for everyone to benefit from data-driven innovation and to become more active agents in the data economy.' To what extent do you agree with this statement?

- Strongly agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly disagree
- I don't know / no opinion

One area of study are difficulties experienced in accessing and use data from other companies. With the following questions we seek to further examine the importance and the nature of data access issues in business-to-business situations.

Have you had difficulties in using data from other companies?

- Yes
- No

A specific class of data are non-personal data generated by smart machines or devices connected to the Internet-of-Things in professional use, such as smart tractors used in farms or smart robots in use in a factory. Data generated by such machines or devices are typically 'co-

generated' by several parties, such as: manufacturer of a smart device, lawful user of the smart machine or device etc.

'It is currently challenging to define solutions on the allocation of the rights to use data coming from smart machines or devices that are fair for all parties concerned'. To what extent do you agree with this statement?

- Strongly agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly disagree
- I don't know / no opinion

'The EU should make major investments in technologies and infrastructures that enhance data access and use, while giving individuals as well as public and private organisations full control over the data they generate.' To what extent do you agree with this statement?

- Strongly agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly disagree
- I don't know / no opinion

'The development of common European data spaces should be supported by the EU in strategic industry sectors and domains of public interest (industry/manufacturing, Green Deal, mobility, health, finance, energy, agriculture, public administration, skills).' To what extent do you agree with this statement?

- Strongly agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly disagree
- I don't know / no opinion

Are there general comments you would like to make about the data strategy?

300 character(s) maximum

Easier access and share of data do not necessary guarantee public and patient safety and wellbeing. Issues of data protection, anonymisation and privacy should be better addressed to avoid harms from private interests

Section 2.1 - Specific questions on future actions: Data governance

The use of data in the society and the economy raises a series of questions of legal, ethical, organisational and technical nature. Many angles need to be looked at in order to fully reap the benefits of the use of data without harm.

With the term 'data governance' we seek to refer to the set of legal, organisational and technical rules, tools and processes that determine the use of data by the public sector, business, individuals, civil society organisations, researchers.

This may translate into establishing mechanisms for data governance at European level which may support data-driven innovation in different ways:

- At cross-sector level, it could identify the need for standards to facilitate data-sharing, including for the various actions to be taken in this regard (identification, authentication, access control). It could identify use cases in which cross-sector data re-use is supported by standardisation. It could provide technical guidance on technologies for lawful processing of data in accordance with data protection legislation, the need to protect of commercially sensitive information as well as competition law.
- At sector-specific level, data governance could be developed, building on existing structures and coordination mechanisms.

'Data governance mechanisms are needed to capture the enormous potential of data in particular for cross-sector data use.' To what extent do you agree with this statement?

- Strongly agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly disagree
- I don't know / no opinion

Standardisation

Significant interoperability issues impede the combination of data from different sources within sectors, and even more so between sectors. One such issue is the absence of a consistent description of the data, including information on how it has been gathered. This can impact on data discoverability and on the capacity to evaluate data quality. Another issue is the differences between data models used for similar or identical information assets. This constitutes a barrier for re-users, both commercial and from academia. Standardisation is one of the means to respond to these challenges.

'The re-use of data in the economy and society would benefit greatly from standardisation to improve interoperability.' To what extent do you agree with this statement?

- Strongly agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly disagree

- I don't know / no opinion

'Future standardisation activities need to better address the use of data across sectors of the economy or domains of society.' To what extent do you agree with this statement?

- Strongly agree
 Somewhat agree
 Neutral
 Somewhat disagree
 Strongly disagree
 I don't know / no opinion

Which of the following elements do you consider to be the most useful in terms of standardisation?

- Metadata schema
 Metadata variables (semantic interoperability at the metadata level), including ontologies, controlled vocabularies and agreed thesauri
 Data formats
 Common data models
 Data exchange protocols
 Application Programming Interfaces (APIs)
 Licences or licence terms
 Other
 I don't know / no opinion

If other, please specify

200 character(s) maximum

Standardisation should make sure that the way variables are described a void inequalities and do not create discrimination

What role should EU or national government bodies take in standardisation?

- Provide necessary funding in order to ensure open standards
 Take an active role in the prioritisation and coordination of standardisation needs, creation and updates
 Be directly involved in defining standards
 Provide funding to test draft standards in practice and develop tools to implement them early-on
 Other
 Governments should not have a role in standardisation
 I don't know / no opinion

If other, please specify

200 character(s) maximum

Regulators should take an active role in ensuring that standardisation includes high levels of data protection and anti-discrimination principles

Secondary use of data

Sensitive data (e.g. health data) stored in public databases has a high potential for re-use for the public interest. However, it is normally not possible to open such data as 'open data' and specific efforts are necessary on the side of the public sector data holder. Some statistical offices have put structures in place for processing of statistical micro-data for research. In some countries, similar approaches are taken for certain social services or health information. With these questions we seek to understand whether such approaches should be broadened to other types of data and what types of services should be offered.

'Public authorities should do more to make available a broader range of sensitive data for R&I purposes for the public interest, in full respect of data protection rights.' To what extent do you agree with this statement?

- Strongly agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly disagree
- I don't know / no opinion

Which of the following should public authorities do to facilitate data re-use:

- Help the re-user to identify the exact authority that is holder of a specific set of data (one-stop-shop)
- Ensure that the request for data access is processed faster, within agreed deadlines
- Assess whether the re-use of the data could potentially harm the interests of others (of the persons/companies whose data is being used) for concrete use-cases
- Be able to provide anonymisation of specific data for concrete use-cases
- Offer the possibility to process data within a secure environment it makes available, so that the user does not need to obtain a copy of the data
- Clarify from the outset the legal rules on the purposes for which the data can be used
- Provide for recourse mechanisms to challenge decisions on one or several of the above.
- Other
- I don't know / no opinion

Data altruism

Data altruism is about making it easier for individuals to allow the use of the data they generate for the public good, if they wish to do so, in full compliance with the GDPR and namely on the basis of consent as a legal basis. This is sometimes referred to as 'data donation', a term that could be misunderstood to mean that the consent to the processing of such data in question cannot be withdrawn. Article 7 of the GDPR provides that consent can always be withdrawn and there is no intention to change this rule for 'data altruism'.

Do you think that law and technology should enable citizens to make available their data for the public interest, without any direct reward?

- Yes
- No
- I don't know / no opinion

Do you think there are sufficient tools and mechanisms to “donate” your data?

- Yes
- No
- I don't know / no opinion

In which of the following domains do you see potential for the use of ‘contributed’ data:

- For health-related research
- For aspects relating to the city/municipality/region I live in, including for example improving mobility, to improve environmental challenges that can be addressed through action at local or regional level
- For other public interest purposes
- None of the above
- I don't know / no opinion

If for other public interest purposes, please specify

200 character(s) maximum

To improve outreach of vulnerable/isolated communities. To facilitate civic participation (eg.: volunteering)

Data intermediaries

In the data economy, novel intermediaries such as ‘data marketplaces’ or ‘data brokers’ are increasingly aiming to support business-to-business data sharing with a range of services such as match-making, offering dedicated sharing platforms, including technology on controlled access and use, as well as legal support.

‘Such intermediaries are useful enablers of the data economy.’ To what extent do you agree with this statement?

- Strongly agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly disagree
- I don't know / no opinion

Section 2.2 - Specific questions on future actions: identification of high-value datasets

The recently adopted Directive 2019/1024/EU (<https://ec.europa.eu/digital-single-market/en/european-legislation-reuse-public-sector-information>) (Open Data Directive) introduces the concept of high-value datasets (HVDs), defined as documents the re-use of which is associated with important benefits for society and the economy (e.g. job creation, new digital services, more efficient and evidence-based policy making). Under the directive, the Commission is required to adopt an implementing act setting out a list of specific high value datasets within the thematic categories listed in Annex I to the directive (geospatial; earth observation and environment; meteorological; statistics; companies and company ownership; mobility). The directive specifies that those datasets shall be made available for re-use free of charge, in machine-readable formats, provided via application programming interfaces (APIs) and, where relevant, as bulk download.

The answers to the questions below will help the Commission draw up an EU-wide list of specific high-value datasets.

'The establishment of a list of high-value datasets, to be made available free of charge, without restrictions and via APIs, is a good way to ensure that public sector data has a positive impact on the EU's economy and society.' To what extent do you agree with this statement?

- Strongly agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly disagree
- I don't know / no opinion

Apart from the potential to generate socio-economic benefits, please indicate the relevance of the following additional factors to be taken into account when selecting datasets for the future list of high value datasets:

	Very relevant	Relevant	Neutral	Not relevant	Not relevant at all	I don't know / no opinion
The re-use of the dataset would increase if it was provided free of charge.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
The dataset belongs to a thematic area in which there are few EU-level requirements for opening up data.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>

The re-use of the dataset would increase if its availability under uniform conditions was ensured across the entire EU.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
The re-use of the dataset would increase if it was available via an application programming interface (API).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>

If other factors: please specify

200 character(s) maximum

Under the Open Data Directive, specific high-value datasets will have to be available free of charge, in a machine-readable format, provided via APIs and, where relevant, provided as a bulk download. Please indicate the relevance of each of the other arrangements indicated below to improve the re-usability of specific high-value datasets.

	Very relevant	Relevant	Neutral	Not relevant	Not relevant at all	I don't know / no opinion
Licensing and other terms applicable to re-use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Standardised formats of data and metadata	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Possibility of user feedback	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Specific technical arrangements for dissemination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>

If other arrangements, please specify:

200 character(s) maximum

Health and social vulnerability sensitive datasets should not be made free of charges, certainly not to privates. Precautionary principle is strongly advised and access should be protected by law

EU programmes may provide funding to enhance the availability and re-use of high-value datasets across Europe. For each of the following activities, please indicate how relevant it is to support them.

	Very relevant	Relevant	Neutral	Not relevant	Not relevant at all	I don't know / no opinion
Improving the quality (e.g. machine-readability) and interoperability of the data/metadata	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Ensuring sustainable data provision via application programming interfaces (APIs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Engaging with re-users (promoting the data, co-defining use-cases)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>

If other activities, please specify:

200 character(s) maximum

Funding should be allocated to set up solid and secure infrastructures for datasets at national level. These should ensure that access for private interests is limited and highly regulated

According to your experience and the expected potential of concrete datasets, indicate up to three specific datasets that should be listed in each of the thematic categories of high-value datasets, as referred to in Article 13(1) of the Open Data Directive:

	Specific datasets
Geospatial	

Earth observation and environment	
Meteorological	
Statistics	
Companies and company ownership	
Mobility	

Section 2.3 - Specific questions on future actions: the (self-/co-)regulatory context of cloud computing

Data processing that underpins data sharing, in particular in common European data spaces will increasingly be performed in cloud and edge infrastructures. Such infrastructures can present cost-effective alternatives and, in the case of edge computing, enable real-time data processing in a connected device. Cloud and edge services are covered by European rules like the General Data Protection Regulation and the Free Flow of Non-personal Data Regulation, and implementation of these rules can happen by means of self-regulatory schemes like codes of conduct. To ensure that cloud and edge services offered in Europe are secure, user friendly and compliant with the rules, the applicable rules should be implemented by service providers in an appropriate and transparent way.

Does your organisation use and/or provide cloud or edge services?

- Yes, my organisation **uses** cloud or edge services
- Yes, my organisation **provides** cloud or edge services
- None of the two

Does your organisation use:

- Cloud
- Edge
- Both cloud and edge

Please explain why you do not use cloud, edge or neither of the two:

200 character(s) maximum

Do you believe the cloud market currently offers the technological solutions that you need to grow and innovate your business?

- Yes
- No

Do you feel that your organisation's sensitive data is adequately protected and secured by the cloud services you use?

- Yes
- No

Please specify the problems

200 character(s) maximum

Sensitive data in our organisation is kept on local servers to avoid risks of hacking

Have you experienced problems in the context of the current functioning and constitution of the market for cloud services in Europe?

- Yes
 No

Do you perceive risks emerging from the current functioning and constitution of the market for cloud services in Europe?

- Yes
 No

Does your organisation have flexibility to procure/adopt new and innovative cloud solutions if they emerge on the market?

- Yes
 No

Is this related to:

- Technical barriers
 Legal/contractual barriers
 Economic/cost barriers
 Security barriers
 Other barriers

If economic/cost barriers, please specify

200 character(s) maximum

Being no-profit our organisation has limited finances

If other barriers, please specify

200 character(s) maximum

Digital literacy is a barrier to use new tools. Benefits are not always clear

Is your organisation aware of self-regulatory schemes for cloud/edge services (for example, codes of conduct or certification schemes)?

- Yes
 No

How do you believe market awareness of these schemes could be raised?

300 character(s) maximum

Do you believe a self-regulatory approach is appropriate to identify best practices to apply EU legislation or self-regulation?

- Yes
 No

Please explain why:

200 character(s) maximum

In the field of health, evidence has shown that precautionary principle guarantees better safeguards than self-regulation. When clouds would store sensitive health data, hard regulation is needed

Would it be beneficial for your organisation if applicable rules for cloud and edge would be bundled and corresponding information made available by the European Commission?

- Yes
 No
 I don't know / no opinion

Thank you for your contribution to this questionnaire. In case you want to share further ideas on these topics, you can upload a document below.

Please upload your file

PP_Digital_Health_Literacy_LR.pdf

Final comments

Enclosed you will find our Digital health literacy briefing published in 2019. While the issues addressed in this document are not all related to this consultation, many challenges we address in the briefing coincide with barriers for the effective development of data systems (such as digital divide or privacy).
We truly believe that in the design and development of EU digital and data strategies, focus on skills, secure and equitable access and anti-discriminatory mechanisms are crucial to ensure best outcomes and that everyone can benefit from them.

Contact

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