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*On 7 May 2020, the CPME Executive Committee adopted the 'CPME response to Public Consultation on the European Data Strategy' (CPME 2020/043 FINAL).*

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**CPME response to Public Consultation on European Data Strategy**

# European Strategy for data

Fields marked with \* are mandatory.

## Introduction

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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](#). 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

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\* Language of my contribution

- Bulgarian
- Croatian
- Czech
- Danish
- Dutch
- English
- Estonian
- Finnish
- French
- Gaelic
- German
- Greek
- Hungarian
- Italian
- Latvian
- Lithuanian
- Maltese
- Polish
- Portuguese
- Romanian
- Slovak
- Slovenian
- Spanish
- Swedish

\* I am giving my contribution as

- Academic/research institution
- Business association
- Company/business organisation
- Consumer organisation
- EU citizen
- Environmental organisation
- Non-EU citizen
- Non-governmental organisation (NGO)
- Public authority
- Trade union
- Other

\* First name

Sara

\* Surname

Roda

\* Email (this won't be published)

sara.roda@cpme.eu

\* Organisation name

*255 character(s) maximum*

Standing Committee of European Doctors (CPME)

\* Organisation size

- Micro (1 to 9 employees)
- Small (10 to 49 employees)
- Medium (50 to 249 employees)
- Large (250 or more)

Transparency register number

*255 character(s) maximum*

Check if your organisation is on the [transparency register](#). It's a voluntary database for organisations seeking to influence EU decision-making.

9276943405-41

\* Country of origin

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

- |                                      |  |                                     |  |
|--------------------------------------|--|-------------------------------------|--|
| <input type="radio"/> Afghanistan    | <input type="radio"/> Djibouti           | <input type="radio"/> Libya         | <input type="radio"/> Saint Martin                     |
| <input type="radio"/> Åland Islands  | <input type="radio"/> Dominica           | <input type="radio"/> Liechtenstein | <input type="radio"/> Saint Pierre and Miquelon        |
| <input type="radio"/> Albania        | <input type="radio"/> Dominican Republic | <input type="radio"/> Lithuania     | <input type="radio"/> Saint Vincent and the Grenadines |
| <input type="radio"/> Algeria        | <input type="radio"/> Ecuador            | <input type="radio"/> Luxembourg    | <input type="radio"/> Samoa                            |
| <input type="radio"/> American Samoa | <input type="radio"/> Egypt              | <input type="radio"/> Macau         | <input type="radio"/> San Marino                       |
| <input type="radio"/> Andorra        | <input type="radio"/> El Salvador        | <input type="radio"/> Madagascar    | <input type="radio"/> São Tomé and Príncipe            |
| <input type="radio"/> Angola         | <input type="radio"/> Equatorial Guinea  | <input type="radio"/> Malawi        | <input type="radio"/> Saudi Arabia                     |
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| <input type="radio"/> Antarctica     | <input type="radio"/> Estonia            | <input type="radio"/> Maldives      | <input type="radio"/> Serbia                           |

- Antigua and Barbuda
- Argentina
- Armenia
- Aruba
- Australia
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- Azerbaijan
- Bahamas
- Bahrain
- Bangladesh
- Barbados
- Belarus
- Belgium
- Belize
- Benin
- Bermuda
- Bhutan
- Bolivia
- Bonaire Saint Eustatius and Saba
- Bosnia and Herzegovina
- Botswana
- Bouvet Island
- Brazil
- British Indian Ocean Territory
- British Virgin Islands
- Brunei
- Bulgaria
- Burkina Faso
- Burundi
- Cambodia
- Eswatini
- Ethiopia
- Falkland Islands
- Faroe Islands
- Fiji
- Finland
- France
- French Guiana
- French Polynesia
- French Southern and Antarctic Lands
- Gabon
- Georgia
- Germany
- Ghana
- Gibraltar
- Greece
- Greenland
- Grenada
- Guadeloupe
- Guam
- Guatemala
- Guernsey
- Guinea
- Guinea-Bissau
- Guyana
- Haiti
- Heard Island and McDonald Islands
- Honduras
- Hong Kong
- Hungary
- Mali
- Malta
- Marshall Islands
- Martinique
- Mauritania
- Mauritius
- Mayotte
- Mexico
- Micronesia
- Moldova
- Monaco
- Mongolia
- Montenegro
- Montserrat
- Morocco
- Mozambique
- Myanmar /Burma
- Namibia
- Nauru
- Nepal
- Netherlands
- New Caledonia
- New Zealand
- Nicaragua
- Niger
- Nigeria
- Niue
- Norfolk Island
- Northern Mariana Islands
- North Korea
- Seychelles
- Sierra Leone
- Singapore
- Sint Maarten
- Slovakia
- Slovenia
- Solomon Islands
- Somalia
- South Africa
- South Georgia and the South Sandwich Islands
- South Korea
- South Sudan
- Spain
- Sri Lanka
- Sudan
- Suriname
- Svalbard and Jan Mayen
- Sweden
- Switzerland
- Syria
- Taiwan
- Tajikistan
- Tanzania
- Thailand
- The Gambia
- Timor-Leste
- Togo
- Tokelau
- Tonga
- Trinidad and Tobago

- Cameroon
- Canada
- Cape Verde
- Cayman Islands
- Central African Republic
- Chad
- Chile
- China
- Christmas Island
- Clipperton
- Cocos (Keeling) Islands
- Colombia
- Comoros
- Congo
- Cook Islands
- Costa Rica
- Côte d'Ivoire
- Croatia
- Cuba
- Curaçao
- Cyprus
- Czechia
- Democratic Republic of the Congo
- Denmark
- Iceland
- India
- Indonesia
- Iran
- Iraq
- Ireland
- Isle of Man
- Israel
- Italy
- Jamaica
- Japan
- Jersey
- Jordan
- Kazakhstan
- Kenya
- Kiribati
- Kosovo
- Kuwait
- Kyrgyzstan
- Laos
- Latvia
- Lebanon
- Lesotho
- Liberia
- North Macedonia
- Norway
- Oman
- Pakistan
- Palau
- Palestine
- Panama
- Papua New Guinea
- Paraguay
- Peru
- Philippines
- Pitcairn Islands
- Poland
- Portugal
- Puerto Rico
- Qatar
- Réunion
- Romania
- Russia
- Rwanda
- Saint Barthélemy
- Saint Helena Ascension and Tristan da Cunha
- Saint Kitts and Nevis
- Saint Lucia
- Tunisia
- Turkey
- Turkmenistan
- Turks and Caicos Islands
- Tuvalu
- Uganda
- Ukraine
- United Arab Emirates
- United Kingdom
- United States
- United States Minor Outlying Islands
- Uruguay
- US Virgin Islands
- Uzbekistan
- Vanuatu
- Vatican City
- Venezuela
- Vietnam
- Wallis and Futuna
- Western Sahara
- Yemen
- Zambia
- Zimbabwe

\* 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](#)

## Section 1: General questions on the data strategy

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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 additional rights in law, please specify

*200 character(s) maximum*

Right for a “clean data slate” at the age of 18, safeguarding health data as as determined by the data subject him/herself (Cont. in final comments)

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

What was the nature of such difficulties?

- Impossibility to find companies to supply data of relevant quality
- Denied data access
- Prohibitive prices or other conditions considered unfair or prohibitive
- Technical aspects relating to both data interoperability and transfer mechanisms
- Other
- I don't know /no opinion

If other, please specify

*200 character(s) maximum*

Need to have broader data in research areas.

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*

Clear purposes for access and use, robust governance models, stronger safeguards and enforcement of data subject rights are paramount to avoid misuse by or distrust in governments, rogue employees or private entities with commercial interests in detriment of the data subject. (Cont. final comments).

## **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*

Assurances must be made that standardisation for interoperability purposes does not translate into regulating medical practice or diminishing the scope of the delivery of healthcare services. (Cont.)

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*

The concern of the previous response is mirrored herein.

### **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

If other, please specify

*200 character(s) maximum*

Authorities should foster trust in the sharing of health data. To this end, they should foresee the involvement of research ethics committees or ethics review boards (Cont. final comments).

### **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

For which of the following purposes would you be willing to make data available:

- 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*

The above questions are ambiguous. CPME assumes that the questions are directed to individuals and we reply in that vein: provision of healthcare varies across Member States (Cont. final comments).

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*

Idem previous comment.

What would support the usefulness of ‘data altruism’ mechanisms as a means to build up data pools for research and innovation:

- A standard form for obtaining consent (and, where necessary, requesting data portability) from the individual in line with the GDPR
- A European approach to obtaining consent that is compliant with the GDPR
- Public registers of persons that are willing to make available some of their data for research or innovation purposes
- The existence of intermediary infrastructures such as personal data spaces /wallets/stores controlled by each individual from which the data could be retrieved
- Additional EU legislation on data altruism relating to deceased persons
- Information campaigns sensitising individuals on the subject matter, e.g. via clinical practitioners

- Measures to mitigate inherent bias in the data collected through this means
- Other

If other, please specify

200 character(s) maximum

There is a significant workload involved in providing clinical data on deceased persons to ensure compliance with both ethical and confidential obligations. (Cont. final comments)

### 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](#) (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 checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     |
| The dataset belongs to a thematic area in which there are few EU-level requirements for opening up data.                | <input checked="" type="radio"/> | <input type="radio"/>            | <input type="radio"/>            | <input type="radio"/> | <input type="radio"/> | <input 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 checked="" type="radio"/> | <input type="radio"/>            | <input type="radio"/> | <input type="radio"/> | <input 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 checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input 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.

|  |  |          |         |  |  |                |
|--|--|----------|---------|--|--|----------------|
|  |  | Relevant | Neutral |  |  | I don't know / |
|--|--|----------|---------|--|--|----------------|

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

If other arrangements, please specify:

*200 character(s) maximum*

Please specify which specific technical arrangements for dissemination:

*200 character(s) maximum*

Dedicated websites and links made to such websites via national competent authorities.



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 checked="" type="radio"/> | <input type="radio"/>            | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     |
| Ensuring sustainable data provision via application programming interfaces (APIs)          | <input type="radio"/>            | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     |
| Engaging with re-users (promoting the data, co-defining use-cases)                         | <input checked="" type="radio"/> | <input type="radio"/>            | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     |

If other activities, please specify:

200 character(s) maximum

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

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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

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

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 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*

There is already some concern about compliance of cloud service providers with important EU rules such as data protection, as outlined in the EU Data Strategy.

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

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## Final comments

The EU data strategy is a long-term plan where several conditions are still uncertain. It is presented at a very abstract level making it difficult to foresee practical direct consequences that could impair the provision of healthcare services by physicians or erode doctor-patient relationship, in particular patient's trust.

CPME welcomes the EU ambition of becoming a leading role model for a society empowered by data to make better decisions in business and the public sector.

However, certain conditions need to be ensured:

- Easier access to individual's data, specifically patients' data, needs to be surrounded by strong legal safeguards and level of security.
- Nudging techniques or dark patterns should not be used or supported.
- Further assurances need to be put in place to ascertain if access was given by a child, without collecting appropriate parental consent.
- As we are exposing children to an online environment where opting-out is no longer possible, contributing to the 'datafication' of their lives, a new right should be developed – the right for a "clean data slate" at the age of 18. Starting at early age at home as entertainment, to continue at school with several educational platforms and tools to which children need to participate in order to learn, the constant and regular contact to the online environment can have vast implications and possible long-term consequences for their well-being, development and social dynamics, opportunity and life chances. As a result, children should be granted the right to demand companies to delete any personal information collected about them, as data subjects, prior to the age of 18, safeguarding health data as determined by the data subject him/herself.
- Clear purposes for access and use, robust governance models, stronger safeguards and enforcement of data subject rights are paramount to avoid misuse by or distrust in governments, rogue employees or private entities with commercial interests in detriment of the data subject. For example, involve research ethics committees for secondary use of health data or impose GDPR certification for certain processing operations. An EU Code of Conduct for processing of personal data in the health sector is welcome. The principles of Taipei and Helsinki declarations should be embedded in such a Code.
- Assurances must be made that standardisation for interoperability purposes does not translate into regulating medical practice or diminishing the scope of the delivery of healthcare services, which must continue to be provided in accordance with patient needs and evidence-based medicine reflecting technical and scientific progress. Clarification is also required on who will bear the costs of digital health transformation. Guarantees are needed that physicians should not bear such costs as it may be detrimental to the general access to healthcare.
- Authorities should foster trust in the sharing of health data. To this end, they should foresee the involvement of research ethics committees or ethics review boards when the legal base to share personal data is other than consent of the data subject. The default position for provision of information should be

made on anonymisation, which should be irreversible and legally guaranteed. Pseudonymisation, if necessary, can be only in accordance with the national medical practitioner regulator.

- The notion on 'public interest' is vague and can be misused. In order to foster 'data altruism' there needs to be trust and assurance that the data will be used for the public good. It is not clear how this will be achieved in the data strategy, specially also when anonymisation techniques have known limitations. Furthermore, the questions in Section 2.1. in relation to data altruism are ambiguous. CPME assumes that the questions are directed to individuals and we reply in that vein: provision of healthcare varies across Member States with some city/municipality/ regions potentially providing healthcare. Equally, social care needs may influence and be influenced by healthcare at these aforementioned levels. Moreover, there is a significant workload involved in providing clinical data on deceased persons to ensure compliance with both ethical and confidential obligations. There would need to be a recognition by resourcing this workload.

- In the area of digital skills and general data literacy, considering the objective of expanding the digital talent to 1 million digital specialists, it would be important to foster a specific register for these workers, who should abide to ethically-based codes of conducts and be subject to regulatory and/or disciplinary sanctions.

## Contact

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