

COCIR response to the consultation on Open Data – Availability of Public Datasets ¹

(inception impact assessment)

COCIR welcomes the opportunity to provide feedback to the consultation on the availability of public datasets as provided for by Article 14 of the Open Data Directive.

COCIR appreciates that the availability of High Value Datasets is a cornerstone of the European Strategy for Data and an essential resource to enhance the value of the envisioned common European data spaces.

The value of data for the healthcare sector

Public sector information is highly relevant for the healthcare sector and COCIR looks forward to the prospect of the availability of High Value Datasets in a European Health Data Space.

Data is crucial to inform and develop clinical insights and medical technologies. Availability of public datasets can contribute to more efficient, effective and sustainable health systems.

This has not only been the case for healthcare practice in general, this has also become very apparent during this ongoing pandemic crisis where the availability of data has been vital to make the right conclusions and decisions.

General principles on the availability of High Value Datasets

COCIR is fully supportive of the principles laid down in the Open Data Directive with regard to the availability of High Value Datasets.

In addition, COCIR would like to formulate following general principles for the availability of High Value Datasets:

1. ***High value datasets should imply high quality of the datasets*** - The value of data is not only dependent on the availability of data, more important is the availability of high quality data. Data quality, data provenance and interoperability are essential aspects that should be guided by European or international standards and that should act as elemental criteria to make the re-use of data effective.
2. ***Availability of public datasets should work cross-border*** - In order to maximise the potential re-use and value of the public datasets, the availability of high value datasets should be available cross-border.
3. ***Availability of datasets should come with minimal delay*** - Whereas the availability of historical and longitudinal data is very valuable, efforts are also needed to make public datasets available in real-time or with minimal delay to facilitate short- or mid-term actions / outcomes.
4. ***Equal access to High Value Datasets for all actors and all sectors*** - Difficulties in accessing public data are not limited to or specific for SMEs or non-commercial organisations. The economic and societal impact created by the availability of High Value Datasets can only be maximised if all actors have equal access to these datasets. In turn, this will also generate new models of cooperation leading to a more vibrant and dynamic data economy.

¹ <https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12111-Open-data-availability-of-public-datasets>

Next to that, availability of High Value Datasets should be accessible cross-sector. This is particularly relevant for healthcare where many diseases are caused by or affected by environmental or socio-economic factors.

5. ***Prior assessment and consultation with private sector partners in case of particular concerns***
 - In cases where High Value Datasets incorporate private sector information and there are concerns related to intellectual property rights, personal data protection and confidentiality, security and legitimate commercial interests, there should be a comprehensive assessment and consultation with related private sector partners prior to any disclosure.

Availability of health-related information

COCIR is aware the implementing acts on High Value Datasets are limited by the thematic areas listed in the Open Data Directive. While not the main subject of this consultation COCIR would like to strongly express again the need to reconsider the applicable list of thematic areas.

COCIR recommends that the European Commission makes use of its delegated powers to include health information as a thematic category.

Health-related High Value Datasets in the Statistics category

Notwithstanding the current situation COCIR considers there is opportunity to include health-related datasets as part of the “Statistics” category.

COCIR would like to encourage the European Commission to include High Value Datasets for instance on population health data, health system effectiveness and availability of healthcare resources

Such datasets could include for example statistical information on

- Mortality (by demographics, by geography, etc.)
- Morbidity (diagnosis-related groups (DRGs), ICD-10s (International Classification of Diseases), etc.)
- Projections (5-10-15 years) of conditions, morbidities and cost
- Longitudinal data:
- Aggregated costs to healthcare providers (by DRGs, or by ICD-10, ...)
- ICU bed occupancy
- Hospital bed occupancy
- # of GP visits (by geography, by day or by week)
- # of ER visits (by geography, by day or by week)
- Prevalence and incidence of procedure/treatment categories

Availability of such and other data will help support decisions in the public and private sector that aim to deliver the most value to society and to patients, providing the best care possible while minimising costs and health system inefficiencies.

Final considerations

COCIR would like to emphasise the need for sufficient funding in order to create the appropriate conditions for availability of High Value Datasets. European instruments like the Digital Europe Programme and the Connecting Europe Facility can play an elemental role in improving interoperability and interconnectivity.

COCIR remains fully committed to work with the European Commission, the EU Member States and other relevant stakeholders to increase the meaningful use and re-use of public sector information in order to foster a competitive and strong European digital health sector, to support the resilience and capacity of health systems and to improve health outcomes for patients.



COCIR References

[European Health Data Space: Towards A Better Patient Outcome](#)

[COCIR response on the data governance framework of common European data spaces](#)

[COCIR input on the European Strategy for Data](#)

About COCIR

COCIR is the European Trade Association representing the medical imaging, radiotherapy, health ICT and electromedical industries.

Founded in 1959, COCIR is a non-profit association headquartered in Brussels (Belgium) with a China Desk based in Beijing since 2007. COCIR is unique as it brings together the healthcare, IT and telecommunications industries. www.cocir.org