INFACT
Joint Action on Health Information

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FACT SHEET INTEROPERABILITY
WP10

Key outputs

1. Interoperability is a key factor for establishing a holistic European health data infrastructure able to translate data, information and knowledge.

2. Semi-structured in-depth interviews were conducted with key opinion leaders from different European cross-border projects that dealt with sharing, linking and managing health data. The development of a distributed infrastructure was the pillar of the European Interoperability Framework (EIF) and the FAIR principles was piloted.

3. Qualitative analysis results of our semi-structured in-depth interviews enable us to better understand the enablers and the barriers to the cross-border linkage and sharing of health data through four interoperability layers (legal, organisational, semantic and technical). Feasibility of complying with GDPR and Ethical principles was assessed, adapting to the organizational specificities of each data hub, assuring semantic interoperability across hubs and developing technological interoperability and feasibility of the development of the FAIR principles has been also tested.

4. Recommendations and publications of our results which are derived from key opinion leaders from different European cross-border projects that dealt with sharing, linking and managing health data will enable better optimization and utilization of health information systems across Europe and will facilitate development of health information and research infrastructure based on cumulative experiences and know-hows from key opinion leaders. Pilot cases on federated infrastructure and recommendations that derive from them will facilitate the implementation and development of federated infrastructure and will facilitate the deployment of the distributed solutions for data linkage, data extraction, data analysis and data reporting.

Background and Rationale

Health data allows us to create a holistic view of the overall healthcare system, enables us to conduct research and provides the basics for creating health policies. Every year there is more and more health data being generated on the European level, yet not all of that data is being utilized to its fullest potential because of the lack of interoperability. Interoperability is a key factor for establishing a holistic European health data infrastructure able to translate data, information and knowledge. The objective of our package was to map out and assess cross-national inspirational experiences on data reuse for both public health research and monitoring initiatives as well as to pilot interoperability in a number of topics relevant to public health research, using a variety of data sources from a number of locations.

Proposal

Semi-structured in-depth interviews were conducted with key opinion leaders from different European cross-border projects that dealt with sharing, linking and managing health data with a goal to better understand the enablers and the barriers to the cross-border linkage and sharing of health data through four interoperability layers (legal,

organisational, semantic and technical). Semi-structured interviews were conducted via webcam using GoToMeeting software, recorded and transcribed. Transcripts of the semi-structured interviews were analyzed qualitatively by framework analysis. The development of a distributed infrastructure was the pillar of the European Interoperability Framework (EIF) and the FAIR principles was piloted.

Preliminary results

Achieving interoperability with health data is a long process with many obstacles. Most key opinion leaders emphasize legal and semantic interoperability layer as a main barrier, while key opinion leaders no longer see technical interoperability as a barrier unless practicing physicians and patients are involved. Organisational interoperability was less understood by key opinion leaders, we are yet to analyze if it was due to our interview structure or duo to lack of understanding of organisational interoperability.
Other barriers, which were emphasized by key opinion leaders, were lack of funding, differences in health data in countries with decentralized governments and different interpretations of the GDPR, which varied between countries, between different regions of a country and between different institutions. Other enablers, which were emphasized by key opinion leaders, were univocal health data in countries with centralized governments, pre-existing legislation for a specific topic in certain countries and continuation to a work done by pre-existing project.
Feasibility of complying with GDPR and Ethical principles was assessed, adapting to the organizational specificities of each data hub, assuring semantic interoperability across hubs and developing technological interoperability and feasibility of the development of the FAIR principles has been also tested.

Recommendations for sustainability

The results of qualitative analysis of our semi-structured in-depth interviews will serve as basis for publishing recommendations and publications which are derived from key opinion leaders from different European cross-border projects that dealt with sharing, linking and managing health data which will enable better optimization and utilization of health information systems across Europe and will facilitate development of health information and research infrastructure. The recommendations and publications have the advantage of sustainability because they will serve as basis for health policies and for improving interoperability of health information systems. Pilot cases on federated infrastructure and recommendations that derive from them will facilitate the implementation and development of federated infrastructure and will facilitate the deployment of the distributed solutions for data linkage, data extraction, data analysis and data reporting.