OPEN DATA

A RISING OPPORTUNITY FOR RARE DISEASES

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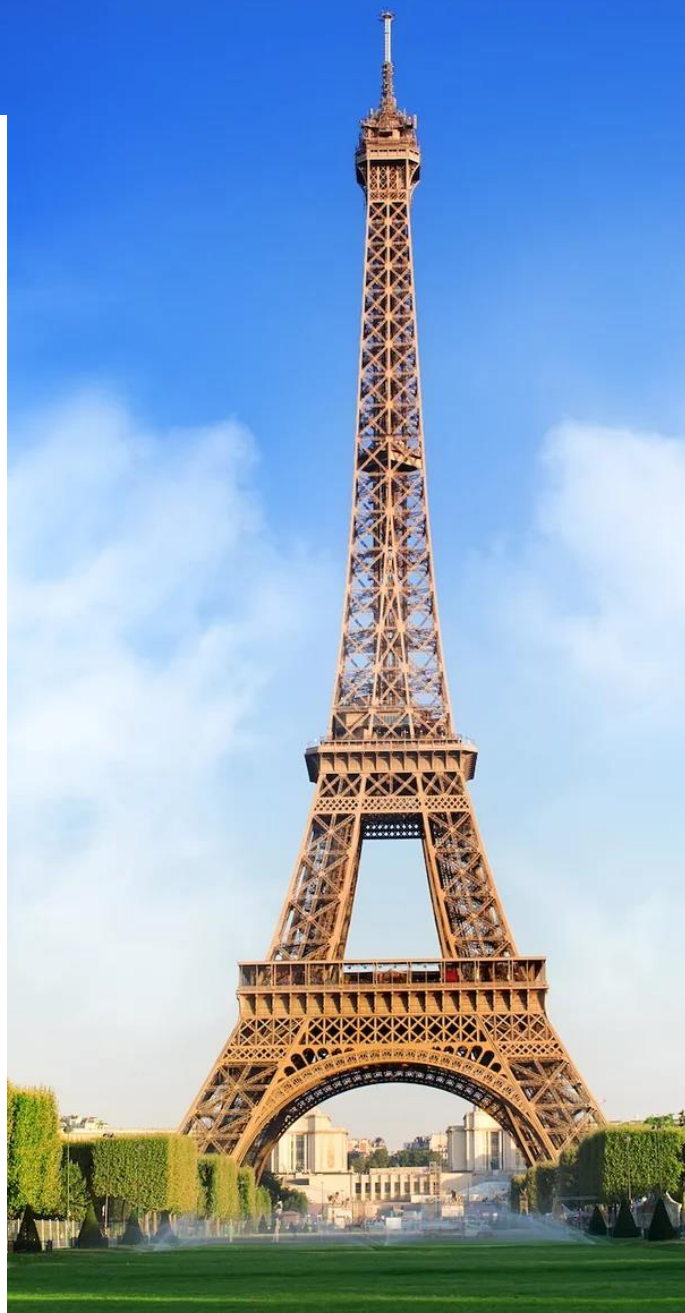
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OPEN DATA: A RISING OPPORTUNITY FOR RARE DISEASES

Open Data is defined as "data that can be freely used, anywhere, for any purpose" according to the Open Knowledge Foundation[1]. The publication of data is motivated by the belief of a stronger co-operation across Europe that can bring massive benefits to citizens, businesses, and public administrations. Open data can have a positive impact in various areas, such as healthcare, food safety, education, climate control and intelligent transport systems. Nowadays, it is considered an essential resource for economic growth, competitiveness, innovation, job creation and societal progress.

Increasing numbers of Open Data are made available on the Internet by several organizations. As an example, the European Data Portal has almost quintupled the amount of data it references, going from 240,000 to 1,153,633 datasets[2] since its creation in 2015. This database is included in the general approach initiated by the Open Data European Directive created in 2003 that encourages EU member states to make as much information available in the public sector.

Open data is broadly applicable in various sectors and especially in Healthcare. Sharing data publicly can help researchers to strengthen the health of a city, a state, a nation, or the world by preventing catastrophic events[3]. As COVID-19 is striking health care systems, many countries started publishing data and developed tools to make the data more intuitive enabling their response to the emergency. One of the most notorious examples is the COVID-19 dashboard developed by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University[4]. Its primary goal is to present the data in a way that will help the user understand it, analyze trends, and drive stakeholders to make informed decisions.

What about Open Data in the rare disease area?

The small number of subjects, the low coverage in terms of population and the biases of the other French national databases at disposal (PMSI[5] or SNIIRAM[6] for example) do not allow us to ensure strong population studies in the context of rare diseases. In order to tackle this issue, the implementation of data collections specific to rare diseases was initiated and became a European effort in the early 2000's. Orphanet[7] and its database Orphadata[8] has progressively grown into a network of 41 countries from Europe and around the world. At a national level, in France, the National Plan for Rare Diseases 2 (2011-2016) has set up a priority project: The National Data Bank for Rare Diseases (BNDMR)[9] that gathers data from several databases like BaMaRa, DPI or RaDiCo and many others[10]. As it concerns personal data, guidelines still have to be made to define a strict framework to a suitable use in open data.

This project makes it possible to better document rare diseases, helps to organize the health care system and facilitates research in rare disease area. In the long run, the BNDMR will integrate the largest French healthcare database: Health Data Hub (HDH).

To be continued …

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