HARNESSING THE POWER OF REAL WORLD DATA (RWD)

From conceptual vision to tangible value – EIT Health will launch RWD initiatives that are robust, inform valid healthcare decisions and demonstrate potential to be scaled up, thus establishing a framework for EU leadership in access and analysis of RWD.

Rationale

Despite the promise of significant benefits, the potential of available healthcare data remains largely untapped, primarily due to the huge challenges associated with combining and analysing the vast range of different sources of real world data to provide meaningful information that will ultimately improve the lives of patients and citizens on a large scale. Real world data responds to the demand for real world evidence to enhance randomised controlled data. RWD encompasses big data as well as discreet and specifically designed observational data collection. Our network has access and ownership of unique potential real world datasets, including "big data".

According to the expert group for Study on Big Data in Public Health, Telemedicine and Healthcare on the European Commission, "Big Data in Health refers to large routinely or automatically collected datasets, which are electronically captured and stored. It is reusable in the sense of multipurpose data and comprises the fusion and connection of existing databases for improving health and health system performance. It does not refer to data collected for a specific study"[1]. "The value chain of Big Data consists of generating and collecting data, storing and processing, and, finally of the distribution and analysis of the relevant data"[1,2].

The growing use of electronic health information systems and digital patient data in both research and clinical practice has led to the generation of data worldwide. The applications of data can derive from retrospective analysis and prospective monitoring[1]. The impact of these applications goes from improving prevention to treatment, from affecting population to individual level, from quality to cost, from safety of current practice to prediction of future outcomes.[1, 3-6]

From EIT health we want to focus on Access to RWD and Early Diagnosis through Predictive Analytics. From a data management point of view, Data Access is one of the main issues Europe needs to address[7] to unleash the potential of a real cross-border system. RWD sources have the potential of being marketable. From a disease management point of view, Early Diagnosis through Predictive Analytics has already demonstrated both economic and health value for systems and patients respectively[8].

EIT Health Focus Area

Activities executed within EIT Health in the Focus Area

Activities should demonstrate valid early diagnosis conclusions by applying novel predictive analytical techniques, drawing upon multiple datasets, particularly across borders and responding to demands that RWD is trusted, ethically drawn upon and representative. Activities must use validated patient reported outcomes instruments where applicable.

1. Identify and establish the validity of multiple, complementary data sets
2. Demonstrate robust, repeatable routes to obtain timely access
3. Demonstrate examples of early diagnosis through application of applicable analytical techniques including algorithms
4. Involve patient experience data in a relevant way to influence the decision-making process
5. Training workers in data acquisition, data access and analysis skills

Outcomes

Activities in this focus area need to demonstrate they achieve majority of the outcomes listed below. Any activity will establish the new standard in a specific disease area. Only those solutions that are scalable and sustainable will be considered. Activities must use validated patient reported outcomes instruments.

1. New services and products that capture data value and:
   a. Give trustable and proven preventive interventions
   b. Bring efficiency to the HC system
   c. Drive down costs for payers

2. Better and faster health data access of patients, population and Healthcare Professionals that:
   a. Is proven reliable across geographies
   b. Is representative and dynamically adapts to the individual patient
   c. Are recognisable and trusted data sources
   d. Meets current ethical standards

3. Smoothly integrated data-friendly products and services that:
   a. Use tested algorithms and technological tools
   b. Normalise RWD results interpretation by reviewers
   c. Generate economic and health value in the short and mid-term – reduce costs

References
1. Study on Big Data in public health, telemedicine and healthcare. European Commission; 2016.
2. OECD. Exploring data-driven innovaiton as a new source of growth: Mapping the policy issues raised by "big data". OECD Publishing, 2013.
3. Barrett MA, Humblet O, Hiatt RA, Adler NE. Big Data and Disease Prevention: From Quantified Self to Quantified Communities. Big Data. 2013;1(3): 168-75.
4. Hay SI, George DB, Moyes CL, Brownstein JS. Big Data Opportunities for Global Infectious Disease Surveillance. PLoS Medicine. 2013;10(4): e1001413.
5. Murdoch TB, Detsky AS. The inevitable application of big data to health care. JAMA. 2013;309(13): 1351-2.
6. Klimek P. Big Data, Complexity, und Gesundheit in Österreich. n.d.
7. Big Data in Healthcare. European Parliament, 2015. Access in June 2018. http://www.healthparliament.eu/big-data/
8. David Crockett, 4 Essential Lessons for Adopting Predictive Analytics in Healthcare. https://www.healthcatalyst.com/predictive-analytics-healthcare-lessons/