FAIR data for next generation management: a multidisciplinary MS repository providing proof-of-concept evidence

Liesbet M. Peeters[1] (main author)

Ilse Lamers[1], Dirk Valkenborg[2], Peter Feys[1], Veerle Somers[1], Annemie Spooren[1], Veronica Popescu[3], Niel Hens[2], Paul Matthews[4], Christoph Thalheim[5], Bart van Wijmeersch[1,3] & Niels Hellings[1]

1. Biomedical Research Institute, Hasselt University, Belgium
2. Center of Statistics, Hasselt University, Belgium
3. Revalidation and MS center, Overpelt, Belgium
4. Data Science Institute, Imperial College Londen, United Kingdom
5. European Multiple Sclerosis Platform, Schaarbeek, Belgium

Multiple sclerosis (MS) is a progressive demyelinating and degenerative disease of the central nervous system with symptoms depending on the disease type and the site of lesions and is featured by heterogeneity of clinical expressions and responses to treatment strategies. An individualized clinical follow-up and multidisciplinary treatment is required. Transforming the population based management of today into an individualized, personalized and precision level management is a major goal in research. However, a complex and unique interplay between genetic background and environmental exposure in each case likely determines clinical heterogeneity. To reach insights at the individual level, extensive amount of data is required. Many databases have been developed over the last few decades, but access to them is limited, data is acquired in different ways and differences in definitions and indexing and software platforms preclude direct integration. Most existing (inter) national registers and IT platforms are strictly observational or focus on disease epidemiology or access to new disease modifying drugs. Here, a method to revolutionize management of MS to a personalized, individualized and precision level is outlined. The key to achieve this next level is FAIR data. We outline a ***FOUR C- plan*** (=Collect, Connect, Complete and Construct) and show how this plan is implemented in a multidisciplinary MS repository providing proof-of-concept of this plan.