HARMONIzation and integrative analysis of regional, national and international Cohorts on primary Sjögren’s Syndrome (pSS) towards improved stratification, treatment and health policy making

Acronimo: HarmonicSS
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Abstract: The overall scope of the HarmonicSS project is to bring together the largest well characterized regional, national and international longitudinal cohorts of patients with primary Sjögren’s syndrome (pSS) and to share data from different countries to semantically interlink and harmonize them into an integrative pSS cohort structure. HarmonicSS vision is to create an International Network and Alliance of partners and cohorts, entrusted with the mission of addressing the clinical and health policy unmet needs in pSS. Moreover, the aim of the project is to create a platform with open standards and tools designed to enable secure storage, governance, analytics, access control and controlled sharing of information at multiple levels to make results of analyses and outcomes comparable across centers and sustainable through Rheumatology associations. In addition, tools for specific diagnostic procedures (e.g., ultrasonography image segmentation), patient selection for clinical trials and training will be also provided. The study of pSS has a significant impact on the healthcare systems. Indeed, pSS is a relevant disease not only due to its clinical impact but also as one of the few “model” disease to link autoimmunity, cancer development (lymphoproliferation) and the pathogenetic role of infection.