Motivation

HarmonicSS’ vision is to create an international network and alliance of partners and cohorts entrusted with the mission to address the unmet needs in primary Sjögren Syndrome. The partners will work together to create and maintain a platform with open standards and tools, designed to enable secure storage, governance, analytics, access control and controlled sharing of information at multiple levels along with methods to make results of analyses and outcomes comparable across centers and sustainable through Rheumatology associations.

Challenges & Highlights

The role of the L3S Research Center is to support the project in all issues related to privacy, security and ethics coming up within the project. Consequently, three major branches of law will be analyzed: first, the law on data protection and data security, second, the Intellectual Property Rights (IPRs), and third, for patient selection in clinical trials. Specific attention will be attributed to the ongoing reform of the European data protection framework. The major questions will revolve around secondary use of patient data and integration of data into the HarmonicSS platform, access and roles of usage, and authorization in an ethically and legally complaint manner. The implications of the legislation on IPRs will also be considered. A main goal is to reconcile the IPRs of partners and third-party rights holders with the requirements for data sharing.

Potential applications & future issues

HarmonicSS project may benefit the healthcare and medical research community by providing (i) future storage of data of prospective pSS patients from the project’s network, (ii) extension to other diseases since pSS is one of the few “model” diseases to link autoimmunity, cancer development (lymphoproliferation) and the pathogenetic role of infection and (iii) sustainability in conducting multinational clinical trials on new treatments.

Project abstract:

The overall concept of the HarmonicSS project is to bring together the largest well-characterized regional, national and international longitudinal cohorts of patients with Primary Sjögren Syndrome (pSS), including those participating in clinical trials. Taking into consideration the ethical, legal, privacy and IPR issues for sharing data from different countries, the project will semantically interlink and harmonize the cohorts into an integrative pSS cohort structure in the cloud.

Project duration:
31.12.2018

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Members:
forgo
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Project manager:
Iryna Lishchuk

Project type:
Horizont 2020

URL:
http://harmonicss.eu/

Research Area:
Web Governance

Status of the Project: