

A lay summary of “Blueprint for harmonizing non-standardized disease registries to allow federated data analysis – prepare for the future”

There are several registries across Europe that collect important data from patients with severe asthma that are treated with new therapies. Unfortunately, each single country usually has a limited number of patients, limiting the ability to answer important research questions.

SHARP seeks perform studies on a large, pan-European scale. Therefore, an objective of SHARP is to combine the data from nationwide severe asthma registries. This is complicated by the strict privacy regulation and the different methods of capturing data in the registries.

To overcome this complication, SHARP seeks to implement a so-called ‘federated analysis platform’, which can be used to analyze data, without the data leaving each individual country.

In the ‘Blueprint study’, we described the process, experiences with and difficulties of implementing this federated analysis platform. We also provided a blueprint for other research group that wish to undertake a similar approach towards data analyses. The blueprint covers organizational, financial, conceptual, technical, analytical and research aspects and discusses both the challenges and the lessons learned. We concluded that all in all, setting up a federated data network is a complex process that requires thorough preparation, but above all, it is a worthwhile investment and shows great potential for emerging applications of artificial intelligence and federated learning.

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