EMIF Deliverable 9.5: Final evaluation results and roadmap for future development

Executive summary

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This deliverable is the final deliverable from Work Package 9. In this deliverable, we review all the evaluations of the Platform conducted over the past five years, and detail evaluations performed since Deliverable 9.4. We also propose a revised roadmap for electronic health records studies distinguishing between "bespoke studies" and "standard studies". A study that is unique and requires a unique protocol is a "bespoke study". Even though each such study is unique, there are protocol templates available to make protocol generation, review and approval more efficient and consistent. "Standard studies" currently include the following pre-specified epidemiological categories: incidence & prevalence, treatment pathways and patterns, disease and patient characteristics. Protocols for "standard studies" are largely pre-filled, with a limited set of pre-specified definitions and criteria to be determined and are as such expected to follow an EMIF fast-track approach. We also describe the tools that we have developed to support the "bespoke" and "standard" roadmaps to improve efficiency, tools for the standardization of processes such as templates, and tools for information to new users such as videos.

We evaluated the current stage of development of the Platform, in terms of level of integration of the roadmap and support provided by EMIF. Resulting from this evaluation and based on the experience of conducting the different Use Cases, we proposed guideline timelines for "bespoke studies" and for "standard studies".

A brief account of the current status of completion of the different Use Cases is included, which shows that most Use Cases have been completed and are at the manuscript writing stage and some have already been published. Some Use Cases are still ongoing and will be completed after the completion of the IMI project.

A real-life study is expected to be initiated to test out all aspects of the EMIF Platform including contractual and financial transactions and will be completed after completion of the IMI project. This will provide valuable insights on a potential sustainable future of the EMIF Platform post IMI project.

The tools and processes that have been developed for the EMIF Platform enable more studies to be carried out and to be conducted more efficiently and to a consistent and high quality. Furthermore, the EMIF Platform is expected to engender increased trust between researchers, including researchers from the biopharmaceutical area, and data custodians, academia and the public at large. Use of the tools and processes is strongly encouraged for future studies so that the full benefits of the EMIF Platform are realized. They are particularly significant in multi-database studies but also present for single-database studies.

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In conclusion, it is hoped that the EMIF Platform will be used widely and maintained and further developed, in all aspects, including tools and processes, research communities with sharing best practice and expansion of data sources to be included.

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