EMIF Deliverable 15.1: Report on business models for data exploitation in biosciences

Executive summary

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Healthcare decision makers are increasingly using real-world data providing evidence to demonstrate the value of an intervention and to support and monitor changes in clinical practice and or policy decisions.

The United States and United Kingdom and others have started the collection of realworld data many years ago. Real-world data initiatives arise on a national scale in Europe. Yet there is no European framework to gather and use real-world data according to strict governance and privacy regulations.

Secondary use of these data currently already provides great value in the area of drug safety and outcomes research, comparative effectiveness research, cost-effectiveness studies, and epidemiology.

There is a big interest to link disparate data sources to increase the power of real-world data and to generate richer and more detailed clinical information across the entire continuum of patient care. In Europe, some data providers are starting to move beyond siloed datasets towards sophisticated linkage and integration of multiple data sources, looking for a more holistic picture of patient treatment across different sites of care.

Even though a considerable amount of relevant patient health information does exist, it typically resides in a variety of systems with different data definitions in different locations, thereby inhibiting ready and efficient access from a central place.

These current trends and challenges in health care and patient data provide EMIF with a unique opportunity. There is an increased openness between healthcare stakeholders and a general awareness that data sharing is key to enhance R&D innovation and productivity.

EMIF will provide opportunities for the pharmaceutical sector and for the healthcare sector in general.

In Work Package 15 we started to design a business model for EMIF. We will follow a 5step iterative approach. The first iteration took place in a workshop that was held in October 2013.

As a first step, we determined the unmet needs for data in clinical research and care domains. In a second step, the ecosystem of collaborating partners and competing agents potentially delivering the unmet needs was mapped out. In a third step, making use of proposed business model archetypes, a business model for EMIF delivering its value proposition within the ecosystem was determined. EMIF can follow several business model types in parallel. To gain insight into some of these archetypes, a few institutions were invited to explain their model. The focus for this was the juxtaposition of

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non-profit vs for-profit ventures. IMEC is a non-profit organisation operating in collaborative Technology Platform

Developer and Solution Developer models used in micro- and nano-electronics. Cegedim and Pharmo on the other hand are for-profit organisations that could be categorized as Solution Provider and Solution Component Provider business model in health data.

In a fourth step, the EMIF governance structure was discussed. Finally, in a fifth step a WP15 roadmap of collaborative work was agreed to refine and operationalize the initial design concepts facilitated during the workshop.

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