

D6.1 Assessment review of the existing sustainability models

777450 - PARADIGM

***Patients Active in Research and Dialogues
for an Improved Generation of Medicines***

WP6 Sustainability Strategy

Lead contributor	Eva Molero (13 SYNAPSE) <i>emolero@synapse-managers.com</i>
Other contributors	Mathieu Boudes (1 EPF)
	Elisa Ferrer (2 EURORDIS)
	Virginie Hivert (2 EURORDIS)
	Luca Bertoglio (13 SYNAPSE)
	Roslyn Schneider (27 PFIZER)
	Wolf See (19 BAYER)
	Maartje Mangelaars (22 JANSSEN)
	Tanja Keiper (25 MERCK)
	Vinciane Pirard (31 SANOFI)

Due date	31/10/2018
Delivery date	09/11/2018
Deliverable type	R
Dissemination level	CO

Description of Action	Version	Date
	3	11/10/2018

Table of Contents

Table of Contents	2
Document History	3
Definitions	4
1. Publishable Summary	5
2. Introduction: Why the assessment review?	5
3. The process / methodology.....	6
4. The interviews with selected initiatives	8
5. Conclusions and recommendations	9
6. Next steps: feeding into T6.3 and the sustainability roadmap.....	14
7. Annexes	15
Annex 1: Brief desk research on initiatives identified.....	15
Annex 2: Interviews discussion guide.....	31
Annex 3: Reports for each initiative	36

1. Publishable Summary

PARADIGM has analysed existing sustainability models in patient/civil society engagement initiatives, in the medical / drug discovery and development fields and in other domains such as education, social entrepreneurship, NGOs helping refugees, etc. Through desk research and a series of interviews common topics have been identified and categorized according to three sustainability dimensions that all have to be addressed (culture, processes and resources). Based on this, learnings and recommendations for PARADIGM have been derived. Representatives of nineteen initiatives have been interviewed. The main recommendations to be considered moving forward revolve around the concepts of transparency, trust building, keeping consistency with vision and mission, involvement of all stakeholders, open communication, solid governance, flexibility / agility, finding complementarity with existing resources while avoiding duplication. Other aspects that were emphasised by various initiatives, concern the importance of a supportive legal framework, the development of sound metrics to assess value, the need for diverse sources of funding to ensure financial independence and the importance of fair compensation to participants.

The learnings from this benchmarking exercise will serve as input to task 6.3. *Cross evaluation of the ecosystem and needs, and definition of potential models to address sustainability of outcomes and concepts of PARADIGM*, which will develop potential sustainability models for PARADIGM.

2. Introduction: Why the assessment review?

PARADIGM sustainability strategy within WP6 aims to develop and deliver a comprehensive business plan and associated roadmap for PARADIGM that allows sustainable patient engagement (PE) throughout the three key decision-making points of the development of medicinal products (prioritisation of research, early dialogue with regulators & HTA bodies and design of clinical trials) including new services, activities and resources. The tasks of WP6 have been carefully laid out to ensure the robustness of a resulting business plan and this includes initial phases where relevant inputs are collected before building potential sustainability scenarios.

The inputs of the different stakeholders with respect to sustainability has been gathered via the survey conducted in WP1 in the initial months of the project.

Additionally, a benchmarking analysis of the sustainability models of various initiatives in other ecosystems was conducted, in order to derive learnings from sustainability strategies which are applied in the open innovation fields and in other sectors outside patient engagement such as environment, NGOs helping refugees, education, etc.

The rationale for looking at experiences outside of the Patient Engagement (PE) field is explained by the fact that we would like to get fresh ideas and inspiration and learn about relevant experiences in other domains. We wanted to go beyond studying (only) the models already well-known in the PE community and analyse the potential for transferability to the outcome(s) of PARADIGM.

While studying these models, we elicited inspiring solutions, strategies, business models, operations, etc. that have made other initiatives' sustainability successful (long-term survival). The idea was to go "behind the scenes" and understand the modus operandi and the issues faced for sustainability, not only what is communicated publicly about the vision and mission.