

The **Synergist**

# **External Projects**

2018 report



# Intro from CEO

2018 marked an important shift for The Synergist. The credibility, trust and success accumulated over several years, and the established platforms we incubate, host and drive, present opportunities for us to join other collective platforms.

In the context of building efficient ecosystems on societal issues, it is critical to connect and collaborate with related initiatives such as public-private partnerships (PPP).

We are happy to offer tools, data, and expertise as well as the strong commitment of our whole team. Together we can accelerate progress, reduce duplication, empower others, increase sustainability and help to create a resilient system in the long term - beyond the lifespan of a project or PPP.

This is why we committed to PARADIGM and Share4Rare, and why we are adding new projects in 2019 on maternal health (Conception) and cohort studies (Synchronos). Other new project are cooking too - stay tuned in 2019!

**Nicholas Brooke,**  
Chief Executive Officer,  
The Synergist



**PARADIGM is a 34-partner European funded Innovative Medicines Initiative - a public-private-partnership that focuses on driving systematic, effective, sustainable and measurable patient engagement that is also meaningful to the patient community.**

The work focuses specifically on three “decision-making points” where tools and guidances are still proportionately underdeveloped compared to other areas (i.e. clinical trials): research priority setting, the design of clinical trials, and early dialogues with regulators and Health Technology Assessment.

Key deliverables will be a co-prioritised list of needs and expectations, from which a set of minimum criteria for effective patient engagement will be co-created. The gap analysis for patient engagement practices and guidances that meet those criteria will be performed and a toolbox will be created to bridge the gaps identified. In addition, to ensure that patient engagement practices are truly effective and impactful, a monitoring & evaluation framework will be created based on existing M&E tools. To complete the toolbox, sustainability considerations for PE will also be made available by the end of the project, together with multiple study findings throughout the project timeline.

The Synergist brings the expertise of effective and impactful co-creation through shared leadership and plays a key role in co-leading two work streams that 1) focus on the co-creation of the minimal criteria for patient engagement activities to meet the stakeholders’ needs and expectations and 2) the communication and dissemination of the project’s outputs, in order to ensure broad reach and high adoption for the expected tools. In the first year of the project, we have conducted a stakeholder needs survey with over 500 responses, co-authored the report of the results and co-organised a well functioning communications team for PARADIGM activities. In addition, we can celebrate the intangible success of relationships built, networks connected and knowledge communicated and shared to ensure we contribute to breaking down silos.

The 3-year timeline is short for this project, but the enthusiasm and drive to achieve and exceed the goals set has been exceptional from the get-go. The Synergist is proud to be a partner in this truly co-creative partnership.

# Team members active in PARADIGM



**Nicholas Brooke**  
Executive Director



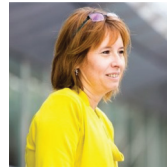
**Chi Pakarinen**  
Project Manager



**Roxana Radu**  
Communications  
Manager



**Gulwish Ahmed**  
Communications  
Assistant



**Danielle Derijcke**  
Program Manager

## PARADIGM partners They made all this possible

A total of **33 partners** have decided to join forces to support and push forward our initiatives. This represents a major change in philosophy that has already started generating significant output on all projects.





The power of this project lies in its community. The objective is clear: creating a platform where rare disease patients, caregivers and clinicians can find much-needed support, while contributing data to the research efforts taking place in the field. The Synergist helped the co-creation process throughout 2018, whilst supporting the platform design and development with product development expertise.

The consortium performed extensive desk research of behavioural studies, scientific publications and empiric conclusions, and transformed it into a concrete description of the very different people affected by rare diseases - patients and caregivers in different diagnostic stages, as well as patient advocates, clinicians and researchers in the field. We looked at their current behaviour, possible needs, and ways to address them. The analysis served as a basis for all future co-creation activities. We then organized and delivered 3 co-creation workshops to support the Share4Rare platform development. In the first workshop we focused on a deep needs analysis, trying to better understand the lives of affected people - from the impact a rare disease diagnosis has on one's life, to how they use internet services and digital platforms. The second workshop focused on an extensive and interactive feedback session on a first version of platform design and interaction model used in the platform. Based on our previous experiences, the third and final workshop focused on the unique values of the Share4Rare platform, as well as more specific needs that patients and caregivers have.

In 2019 our collaboration will continue during the launch and growth of the Share4Rare platform. The Synergist will provide its communication and product marketing expertise, as well as valuable contributions in developing and delivering an engagement plan - a comprehensive set of tools and techniques meant to generate and maintain the user's engagement in the platform, offering value at every step of the way.

# Team members active in Share4Rare



**Nicholas Brooke**  
Executive Director



**Helena Harnik**  
Programmes  
Director



**Roxana Radu**  
Communications  
Manager



**Aaron Hoyles**  
Programme  
Manager

## Share4Rare partners They made all this possible

A total of **7 partners** have decided to join forces to support and push forward our initiatives. This represents a major change in philosophy that has already started generating significant output on all projects.



# Upcoming projects

## Conception & Synchronos

For exactly the same reasons as we joined PARADIGM and Share4Rare, we have joined two new successful consortia - SYNCHROS and CONCEPTION - that are starting in 2019.

It is part of our mission to build efficient ecosystems on societal issues. SYNCHROS aims to deliver better integrated patients cohorts and registries, while CONCEPTION will explore medicine and pregnancy/breastfeeding. These initiatives are ideally suited to our collaborative instincts. Our way of working, along with our direct experience and networks in these fields, make The Synergist the perfect partner for these initiatives.

These topics are a perfect fit for us: areas where good work is under way but greater collaboration is needed to join the dots of a disjointed ecosystem. If we continue to take a fragmented approach we will continue to get fragmented results. The Synergist is here to change that.

**Nicholas Brooke,**  
CEO The Synergist





## IMI Conception

We are pleased that CONCEPTION has been approved by the EU-funded Innovative Medicines Initiative. CONCEPTION will improve monitoring and communication of medication safety in pregnancy and breastfeeding.

This five-year project aims to tackle the fragmented landscape around medication in pregnancy and breastfeeding. The project will focus specifically on informing women, HCPs and other stakeholders about the use of medication during pregnancy and breastfeeding, and to better understand the possible effects of taking medication during pregnancy and breastfeeding through scientific research and a biobank network.

The Synergist will bring its co-creation expertise to this project and will analyse the landscape of available information sources about drug use in pregnancy. Together with our agile approach and expertise in impactful digital communication, we will support CONCEPTION's objective to develop an EU centralised digital knowledge bank for latest information about drug use before and during pregnancy and breastfeeding. We will also work towards engaging with HCPs and women, and support dissemination of information to educate the general public. In order to deliver maximum possible value and impact to the target audiences, the Synergist will support the consortium gather insights from key stakeholders on their needs and will also help define sustainable structure and outcome for the project.

The kick-off of this project will happen in early April.



## Synchros

SYNCHROS (SYnergies for Cohorts in Health: integrating the ROle of all Stakeholders) is an EU-Funded - Horizon 2020 project that focuses on establishing a sustainable European strategy for the development of the next generation of integrated population, patient and clinical trial cohorts, thereby contributing to an international strategic agenda for enhanced coordination of cohorts globally.

This three-year project aims to map the cohort landscape in Europe and large international initiatives, identify best methods for integrating cohort data followed by the solutions to address challenges arising in integrating data across patient, clinical trial and population cohorts. The project will also focus on stakeholder dialogues to discuss 1) best practise to overcome practical, ethical, legal and 2) methodological challenges in networking and integrating data across patient, clinical trial and population cohorts. SYNCHROS will also focus on making sustainable recommendations on standards to improve future sample, data collection and data sharing methods and disseminate this information so as to contribute to defining an international strategic agenda for better coordination of cohorts globally.

The Synergist will bring its expertise to the project and support the objective of taking stock of new and emerging data collection technologies and their types. This would include new exposures as well as the health risks attached to them. We will also analyse the potential impact of these data collection technologies on the development of future cohort studies and consider the need to optimise the integration of data.

2018



**Overall Impact**

# Introduction

We believe collective action is the most untapped source of progress on societal issues. We believe in mutual collaboration and community, in joining forces and in building synergies to deliver on the challenges we face.

Investing in collaboration and collective action today means succeeding tomorrow. Maintaining a fragmented approach will continue to deliver a fragmented, inefficient or suboptimal impact.

2018 has been another important milestone in combining new skills, experiences, methodologies and tools. Neverbefore have we had such a well-balanced ecosystem for tackling complex societal issues. At the Synergist, we have developed Synapse - a mapping and collaborative suite dedicated to empowering collective platforms and their ecosystem. It is a key asset that, combined with offline collaborative best practices, blurs traditional boundaries and creates new opportunities.

We are still learning, we are still building capacity, and in 2019 we will continue this journey. However, armed with our combined experience, a growing team, and the power to develop tools together with 71 partners, we have never been so close to a scalable model that could be quickly applied to any societal issue.

We, The Synergist team and all involved partners, contributors, individuals and organizations, are working to make it happen.

## **The Synergist Team**

Chi, Roxana, Eric, Jean-Christophe, Helena, Leticia, Danielle, Gulwish, Daniela, Laila, Geoffroy, Loic, Bernadette, France, Anne-Marie, Danielle, Gary, Marie-Neith, Lise and Nicholas

# Context

Since its inception, The Synergist has aimed to achieve maximum impact for all its initiatives, delivering benefits to as many stakeholder groups and individuals as possible.

This can be seen in The Synergist's choice of focus areas and in the high-impact co-creation methods used. Yet, assessing the results of (new) methods and the outputs of (eco)system-wide initiatives is not an easy task. We have therefore decided to apply the Social Return on Investment (SROI) methodology to our projects, in order to create a strong foundation for any impact-related analysis or result we achieve.

## Not sure what The Synergist is all about?

Check out [www.thesynergist.org/about](http://www.thesynergist.org/about) for more information.



# Methodology

The SROI methodology has a strong track record and is increasingly being applied to all activities and businesses that want to accurately monitor and improve their social impact.

In short, it aims to measure impact at the level of the people whose lives are changed by the activity to be monitored, and to assess the extent to which resources correctly used to generate their maximum positive impact. The powerful effect of this methodology is that it fosters an iterative process: from the beginning of an initiative to its end, impact has to be measured and resources have to be (re-)allocated to improve positive impact.

At the Synergist, we have started applying this methodology to all our projects. Its iterative pattern matches our agile structure very well and guides our decision-making.

# From Theory To Reality

## The Synergist's Impact

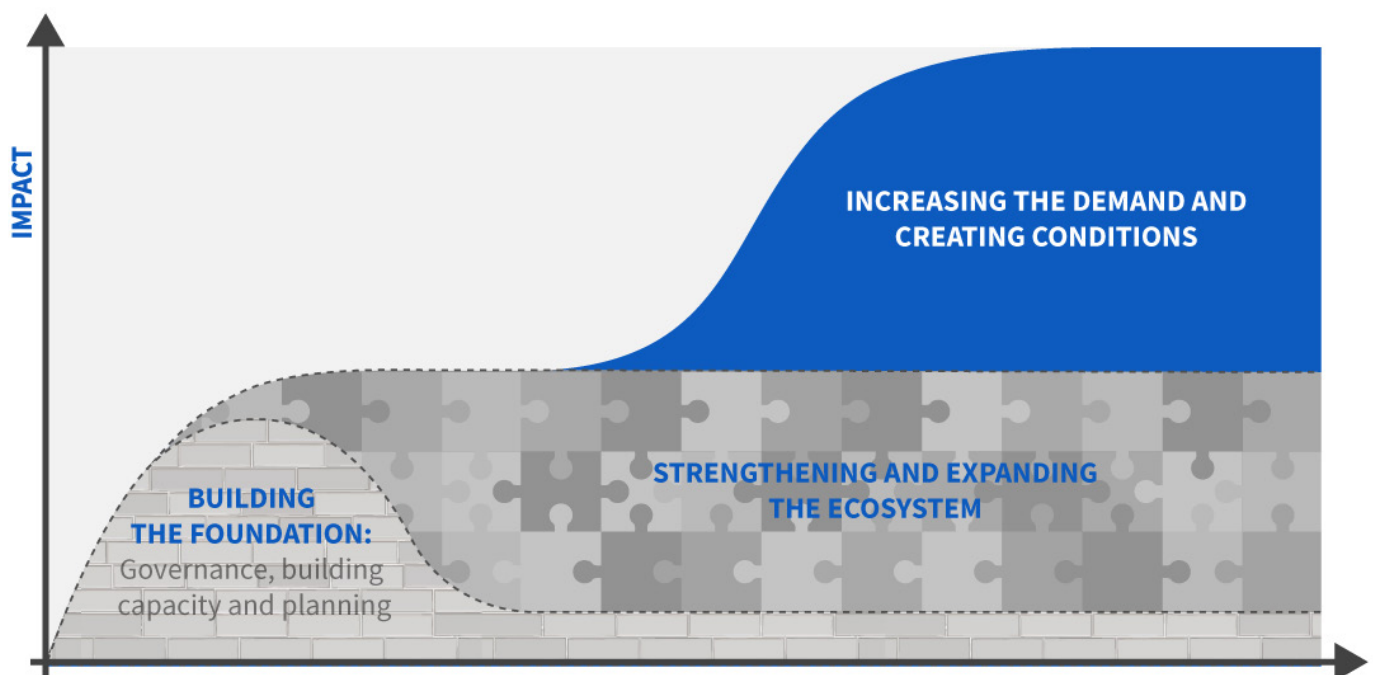
We have streamlined the above project structure across all our projects. The first step is to establish the backbone of the project, including the tools, processes and governance the project team will use.

Once this initial phase has been completed, ongoing project activities embed impact measurement making sure day-to-day activities and overall strategy remain aligned, while generating maximum impact.

On top of this, we strive to synergise other initiatives, filling the gaps coming from a fragmented approach, and delivering impact and outputs far beyond what any isolated initiative could reach.

In 2018, we have initiated impact measurement surveys for new initiatives for Break Dengue and PFMD. We have created a structure to encompass feedback from end-users/beneficiaries into our pilot projects as a commitment to deliver maximum positive impact. In the PFMD project we have started measuring the amazing powerful impact that synergizing with other stakeholders' initiatives can generate.

We are proud that PFMD has been acknowledged as one of the major Patient Engagement initiatives globally, enabling the program to advance the global patient engagement ecosystem. This convergence of various initiatives and efforts, leadership and energy generates very powerful results. The change is happening!



# Highlights

## Meaningful numbers

**2**

new projects

**7**

new partners, bringing us to a total of **71**

**43**

total partners (owned projects)

**1.252**

experts in patient engagement ecosystem

**1.206**

experts in dengue ecosystem

**154**

experts in maternal health ecosystem

**706.601**

total visits on our project websites

**2.725.560**

social media reach (total)

**239.574**

social media engagement (total)

**5**

new team members

**22**

team members in total

## Financial Report

	Project Turnover (€)	Project Expenses (€)	In-kind hours	In-kind contribution (€)
Break Dengue	150.000	233.642	700	45.500
Motherhood Collective Impact Programme (MCIP)	145.000	126.332	50	3.250
Patient Focused Medicines Development (PFMD)	995.000	934.301	1.229	79.885
PARADIGM	181.276	150.909		
Share4Rare	80.750	101.588		
European Projects	262.026	252.497		

# Partners

## They made all this possible

A total of **71 partners** have decided to join forces to support and push forward our initiatives. This represents a major change in philosophy that has already started generating significant output on all projects.





[www.TheSynergist.org](http://www.TheSynergist.org)