



The Synergist

Leading Systematic Co-impact on Societal Issues

The Synergist 2018 report

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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

2018



Overall Impact

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 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

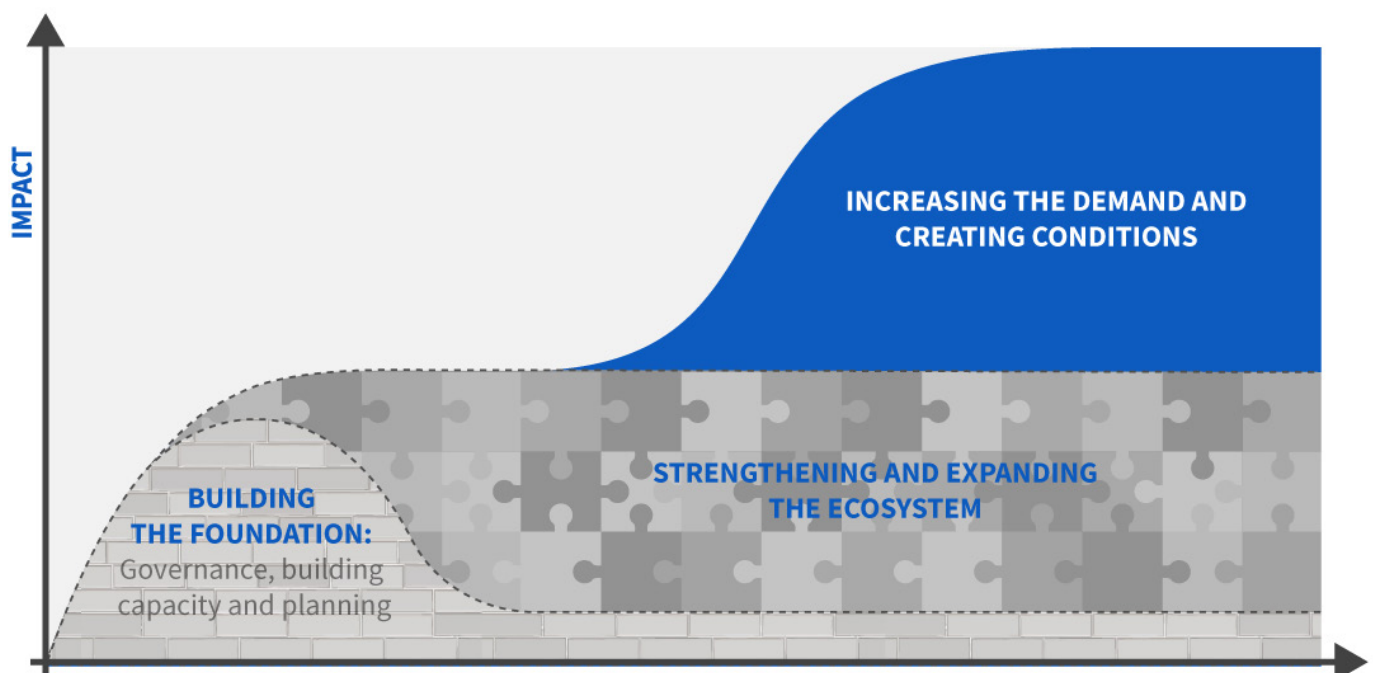
We have streamlined the above project structure across all our projects. The first step is to establish the backbone of the project, including the tools, processes and governance the project team will use.

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
PatientFocused 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.



2018



**PATIENT FOCUSED
MEDICINES DEVELOPMENT**

Message from the Programme Director

We are now witnessing a paradigm shift in patient engagement. Instead of contemplating the risk of doing patient engagement, growing numbers of decision-makers in medicines development are speaking of the risks of not doing patient engagement.

Behavioral science, patient engagement capacity, and real-world evidence support the evolution towards a new model that integrates patient engagement at all levels. With FDA building expectations of patient input and how to generate it, we are approaching a tipping point where co-creation with patients is on the verge of becoming the default option throughout the system.

Momentum is behind the patient engagement community and we are now getting into the nuts and bolts of making patient engagement work. Whether it's the WECAN initiative on reasonable legal agreements between patient advocates and drug companies; forthcoming initiatives to determine the Fair Market Value of patient input; the EU-backed PARADIGM partnership; or the patient-centric focus of The Economist Intelligence Unit's new report on the future of drug development, it is clear that patient engagement is becoming internalised by the medicines development system.

PFMD has been playing its part in driving change in the patient engagement community. 2018 was a pivotal year for our collaborative initiative, preparing the way for a new phase in our shared history - where we can build on the Patient Engagement Quality Guidance as the robust foundation to develop more specific 'How-to' material, training modules, contract templates and fair market value assessment, plain language summaries, and more.

Nicholas Brooke,
Chief Executive Officer,
The Synergist

Achievements

PFMD membership

PFMD saw its membership grow by 5 organisations in 2018.

The membership is now 30 strong, welcoming Servier, Arthritis Foundation, Sant Juan de Deu Research Foundation, American Migraine Foundation, and Sheffield Biomedical Research Centre. This has increased the project's geographic and stakeholder group reach.



The Patient Engagement Quality Guidance

The framework-building work stream produced Patient Engagement Quality Guidance that has been shared within and beyond organisations, referred to in conferences and used as a tool to plan patient engagement projects and assess the quality of ongoing and completed projects.

The co-developed Patient Engagement Quality Guidance has been embraced by the patient engagement community which has shared it internally and beyond and utilised it for patient engagement projects. These initiatives spanned the full medicines-development continuum, the lifecycle of medicines, and care continuum in both health and social research. Member organisations have adopted it for various purposes, on a project basis or as a tool to design, assess and manage all their patient engagement activities. Other non-member companies have simply downloaded the document and worked through it step by step.

Currently, the Patient Engagement Quality Guidance is in the piloting phase with 5 projects in Europe and the United States by 2 organisations with diverse expertise including patient advocacy, medical affairs, pharmaceuticals, research and charity, healthcare services and consultancy. The outcomes of these projects will help us understand and explore the impact Patient Engagement Quality Guidance can bring to users. It can also improve its usability and help us incorporate it into Synapse, allowing you to manage all your patient engagement projects in one place.

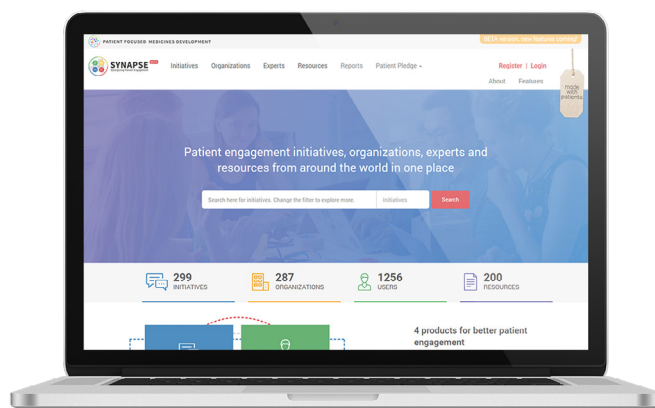


To continue building the patient engagement Metaframework, the public consultation that was conducted over the summer of 2018 gave us valuable information on how and which of the 150 patient engagement activities identified in the literature review phase should be prioritised. The consultation received 133 responses from 26 countries (taking us beyond the Europe and US) with all stakeholder groups represented.

Another relevant output of 2018 was the Book of Good Practices, which offers a set of 8 cases that exemplify one or more of the 7 Patient Engagement Quality Criteria introduced in the Patient Engagement Quality Guidance. We will continue to feed it as a source of best practices and case studies for ongoing and new patient engagement projects.

SYNaPsE

The SYNaPsE platform has evolved from mapping patient engagement initiatives to also connecting the whole patient engagement ecosystem of experts and their organisations to initiatives and related resources. The platform has grown 18% from 2017 in initiatives and 30% in organisations, further adding to the diversity of the tool.

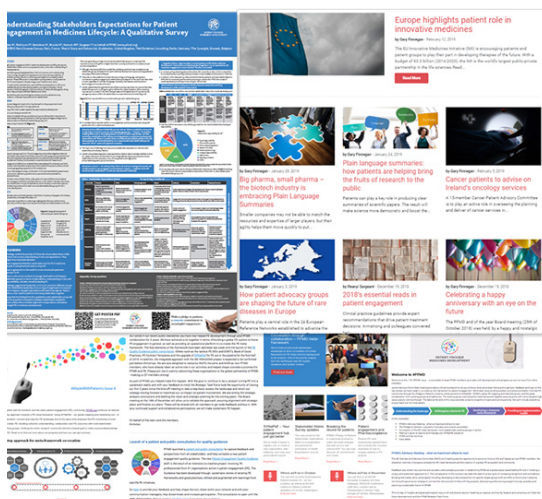


This kind of growth tells us the impact Synapse has for those working in patient engagement - it can bring efficiency and productivity to companies and organisations by enabling users to share their patient engagement projects, knowledge and reports in one coordinated place, available 24/7. A new relationship management function is piloted to allow any user to map, connect and now operate patient engagement. This allows them to shape, plan and assess patient engagement projects with partners, to keep tracks of relationship with partners and who they have been in touch with within your organization, and finally to aggregate the bigger picture of your organization's activities and its performance.

Reach and impact

In terms of reach and impact, PFMD Communication in 2018 has focused on reaching not only the patient engagement enthusiasts, but also the early majority that might not yet have fully embraced patient engagement.

In order to advance a more systematic, high quality and meaningful patient engagement, we need to create a mindset shift on a larger scale and not talk only to the “converted”. PFMD’s relevance and reputation continues to grow with a milestone publication on understanding stakeholders’ expectations of patient engagement across the medicines lifecycle. PFMD also published 45



insightful blogs, of which 22 were guest posts from members and collaborators receiving over 7,000 views by the patient engagement community. Constant communication with members and other interested groups has always been one of the focal points for PFMD and this continued in 2018 with 7 internal and external newsletters sent out reaching more than 4,000 patient engagement enthusiasts. Moreover, PFMD participated in 18 external conferences all over the globe, of which 12 included speaking opportunities.

2018 was a pivotal year for our collaborative initiative, preparing the way for a new phase in our

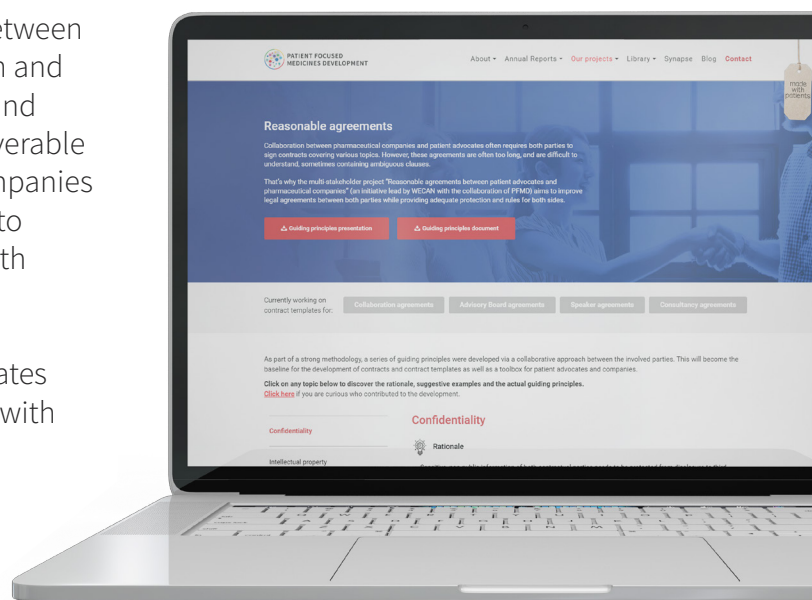
shared history - where patient engagement goes mainstream. Various initiatives within the patient engagement landscape have begun aligning with PFMD, joining efforts to maximise the global impact. This collective approach will be both a cause and a consequence of patient engagement going mainstream.

Reasonable agreements project

To ensure adoption and viable partnership between pharmaceutical companies and patient advocates, WECAN with the support of PFMD, initiated the multi-stakeholder project “reasonable agreements between patient advocates and pharmaceutical companies” (RAPP).

The project aims to improve legal agreements between both parties while providing adequate protection and rules for all sides. Collaboration between PFMD and WECAN on RAPP has produced the very first deliverable - “The Guiding Principles” - that aims to help companies working with patients and patient organisations to formulate agreements that are reasonable for both parties.

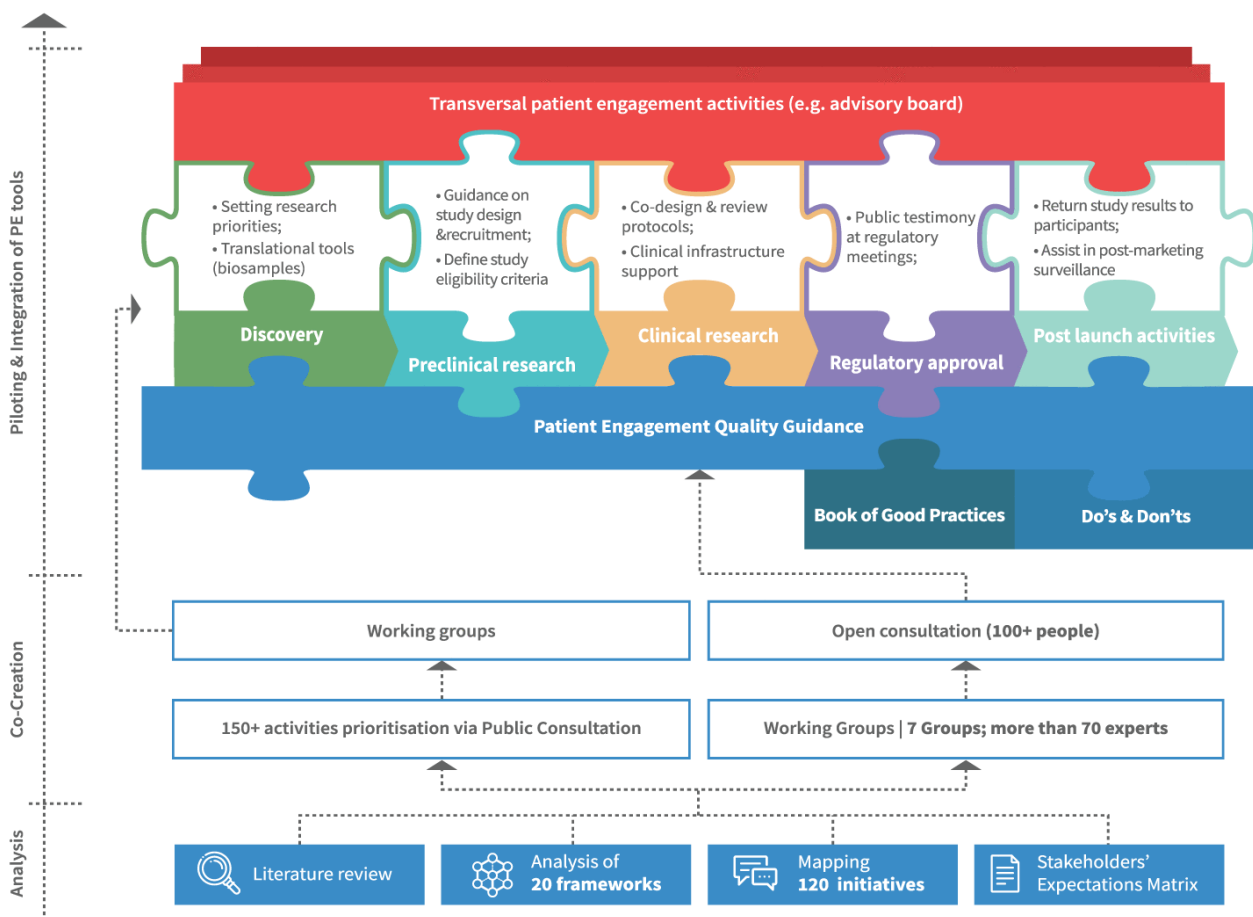
The work continues with drafting contract templates that can be adopted by all stakeholders, starting with contract templates for Patient Advisory Boards and then collaboration, consulting and speaking agreement.



2019 Approach

The need for PFMD remains present and is even increasing.

Since the beginning, PFMD has developed a systematic approach that ensures co-creation upon existing knowledge and balanced collaboration with all relevant stakeholders. Not only does this approach allow us to work in iterations and involve many collaborators in the co-creation process, it also prevents us from deviating from agreed objectives as checkpoints are frequent in each iteration.



And finally, it allows us to move away from the isolated and fragmented practices to bring all good practices into a unified coherent framework. The next step in making patient engagement happen systematically sees PFMD building on existing working groups to deliver “How-to Modules” for patient engagement activities, skills and development phases. We are taking a collaborative leadership role in defining and co-creating a patient engagement training programme for the pharmaceutical industry.

The planned training will be developed to take into account the complexities in big and small companies as well as the differing needs of patient engagement capacity-building in every company. The content and delivery method of the training will be created to match user and company needs. Interested people and organizations have the opportunity to join this work in 2019.

PFMD will focus on expanding the patient engagement ecosystem through strategic collaborations with other stakeholders who are working towards the same goal. This translates into continued positive discussions with the FDA on potential synergies, in particular about the system changing work on Patient Focused Drug Development (PFDD) in increasing the demand and creating the conditions for all stakeholders to adopt PE systematically. Specifically, the opportunities to support the ongoing Clinical Outcomes Assessment (COA) project will be the starting point in 2019.

One of the most exciting projects in 2019 will be the collaboration with European and US-based groups to develop a calculator for fair market value (FMV) compensation for patient input and expertise. PFMD will be the international connection to the regional work groups - the National Health Council (NHC), EFPIA Think Tank, and WECAN - and will act as the platform to globalise the FMV solutions created. First outcomes are expected in the summer.

The PFMD Team

Board members and PFMD team

The PFMD Board consists of:



Nicola Bedlington
Secretary General,
European Patients
Forum



Veronica Todaro
Vice President,
National Programs,
Parkinson's Disease
Foundation



Graeme Johnston
Patient Advocate,
Individual/ Patient



Alexandra Moutet
Global Head of
Patient Affairs, UCB



Roslyn Schneider
Global Patient
Affairs Lead, Pfizer



Andrew Benzie
Secretary General,
EHead Of Patients
In Partnership
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VP, US Regional
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**Katherine
Capperella**
Global Patient
Engagement
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Rebecca Vermeulen
Head Global Medical
Liaisons and
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Roche



Elisa Ferrer
Patient
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EURORDIS



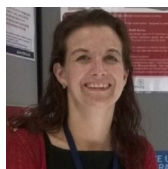
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Lode Dewulf
Consultant,
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**Laura
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Begoña Nafria Escalera
Patient Engagement In
Research Coordinator,
Hospital Sant Joan De Déu

The PFMD Executive Team consists of:



Marc Boutin
Chief Executive
Officer, National
Health Council



Jan Geissler
Director, EUPATI



Tony Hoos
Head Of Medical,
Europe, AMGEN

The PFMD Team consists of:



Nicholas Brooke
Executive Director



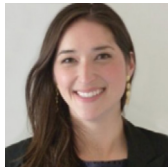
Eric Blanchet
Operations Director



Loïc Bonnevie
Product Owner and
Functional Analyst
(Freelance)



**Jean-Christophe
Capelle**
Financial Director



Helena Harnik
Programmes
Director



Chi Pakarinen
Project Manager



Roxana Radu
Communications
Manager



**Anne-Marie
Hamoir**
Head Of
Membership
And Project
Management



Gulwish Ahmed
Communications
Assistant



**Leticia Erenas
Ardanza**
Project
Coordinator



Lise Brooke
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**Bernadette
Hendrickx**
Scientific Advisor



Ify Sargeant
Editor In Chief



Geoffroy Ryckaert
Head Of IT



Laila Deeb
Web Developer

Our partners

They made all this possible

A total of **30 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.



2018

✱ Break Dengue

Message from the Programme Director

2018 was a year of momentum for the program. We've been working to advance multiple activities to build a dengue ecosystem and create the conditions for better dengue control.

The Break Dengue team is particularly proud of our work to co-create projects and ensure that they make a measurable impact on the ground in communities affected by dengue. Take a look at 2018 and a preview at what's ahead for the new year.

Helena Harnik,
Programmes Director

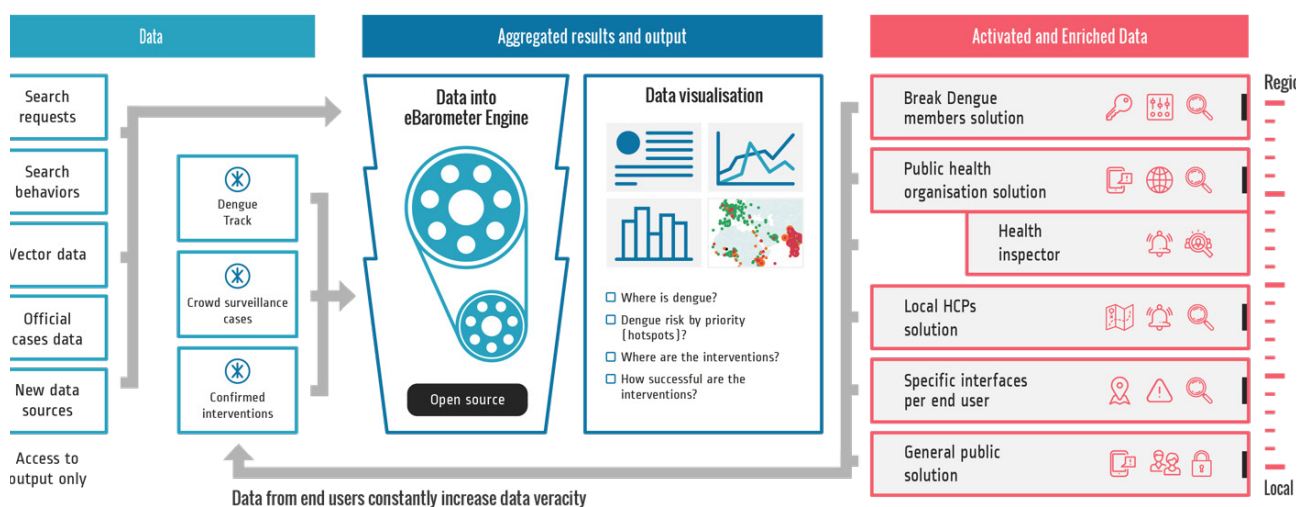
Achievements

eBarometer

In 2018 Break Dengue advanced the co-design of a groundbreaking step in dengue surveillance, the dengue eBarometer.

It is a close to real-time and actionable surveillance system, where AI meets citizens. It involves all dengue stakeholders - from citizens and HCPs in the field, to the developers of new technologies and public health authorities.

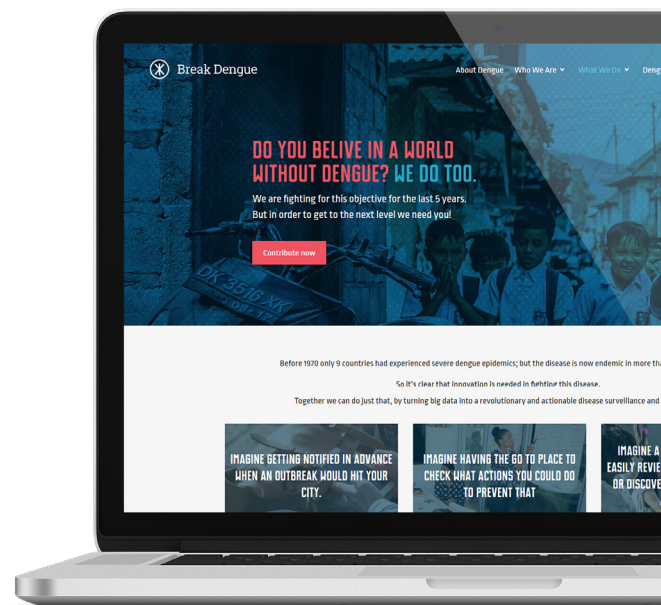
We have defined the Minimum Viable Product for the eBarometer with a plan for development and a tentative launch planned for February 2019.



Needs Analysis survey

In 2018 we launched a needs analysis public consultation and impact measurement survey to understand what end-users of the eBarometer care about and what real impact would mean to them in the context of dengue surveillance.

This will also help inform the program's future activities with our stakeholders and build a solution that is exactly targeted to their needs. The first step is a public survey that was sent to healthcare professionals, public health officials and members of the general public from dengue endemic countries. A dedicated survey was provided to Key Opinion Leaders including the participants of Dengue VOICE.



World Dengue Day campaign

Break Dengue and the International Society for Neglected Tropical Diseases (ISNTD) have joined forces to bring your voice to the 74th United Nations General Assembly with an Open Letter petitioning the UN to designate a World Dengue Day.

The World Dengue Day campaign is being used to engage and activate citizens from endemic communities to take specific, meaningful action to fight dengue.



2019 Approach

Our efforts over the past year have laid the groundwork for 2019 by focusing on co-creating projects that our communities are asking for. Break Dengue seeks to objectively measure the impact of these projects and use these measurements to design and revise the projects to ensure their success.

Based on the results of our analysis of the needs of dengue-impacted communities, Break Dengue is focusing on the following strategic priorities in 2019:

- Building capacity, by developing new partnerships across projects that introduce fresh expertise to the program and diversify the program's funding.
- Building and empowering the ecosystem. We continue to build the eBarometer through a co-creation process with partners. The objective is to launch the first proof-of-concept and a dashboard for users. An additional action point to further build the dengue ecosystem is delivering a petition to the United Nations to designate a World Dengue Day in order to engage and activate citizens from endemic communities across the globe to take specific, meaningful action to fight dengue.
- Creating the conditions for new solutions by mobilizing communities and citizen scientists on the ground with projects in dengue-impacted communities.

The Break Dengue Team

Board members and Break Dengue team

The Break Dengue Advisory Board consists of:



Marnix Van Loock
Associate Scientific
Director at Janssen,
Pharmaceutical



**Bernadette
Hendrickx**
CEO and Founder
SAHB Consulting



Lode Dewulf
Medical
Coordinator,
Doctors of the
World (Medecins du
Monde) Belgium

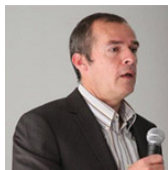


Dr. Lulu Bravo
Professor of Pediatric Infectious
and Tropical Diseases at the
College of Medicine, University of
the Philippines Manila

The Break Dengue Team consists of:



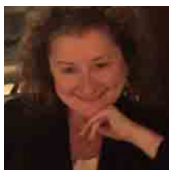
Nicholas Brooke
Executive Director



**Jean-Christophe
Capelle**
Financial Director



Helena Harnik
Programmes
Director



Martina O'Regan
Talent
Development and
Happiness Manager



Aaron Hoyles
Program Manager



**Daniela Luzuriaga
Ubilla**
Project Coordinator



Roxana Radu
Communications
Manager



Gulwish Ahmed
Communications
Assistant



**Bernadette
Hendrickx**
Scientific Advisor



Gary Finnegan
Chief Editor,
Break Dengue

Our partners

They made all this possible

A total of **4 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.



2018



Motherhood Collective
Impact Programme

Message from the Programme Director

2018 marked the most important milestone of our program to date, the launch of the Maternal Health Synapse. We believe that the Maternal Health Synapse has the potential to be game-changing in the field of maternal and neonatal health. An approach that has already shown huge success with the Patient Focused Medicines Development initiative, Synapse maps and categorises maternal health initiatives, actors, organisations and knowledge on a global level within one platform.

Joining the Maternal Health Synapse will help make your initiative visible to others, and will also enable you to find the right partner, organisation, initiative or resource, and showcase achievements and best practices. Currently in beta, Synapse is the culmination of several years of work including on other health issues, and with your feedback will continue to be improved and developed in the coming months.

This year was also an opportunity for the Alliance for Maternal Health Equality members to take a step back and refocus the program strategy. Through a task force, working sessions and with the support of experts, we defined a joint Policy Ask which we also opened for public consultation. The Policy Ask for the Alliance is: free antenatal care for all women in Europe on the basis of the 2016 World Health Organization (“WHO”) Recommendations on Antenatal Care for a Positive Pregnancy Experience.

Safe Motherhood Week 2018 was the biggest yet with a launch at the World Convergences Forum in Paris. We continued our #MakeMotherhoodCount campaign to collect stories from real women and their families on their motherhood experience, with a special focus on Romania. Our campaign reached over half a million people globally and next year we seek to make an even greater impact by collaborating with more organisations via Synapse.

Looking ahead to 2019, we will begin an important collaboration as part of the Innovative Medicines Initiative (IMI) project ConcePTION, to provide improved tools and methods to generate more valuable, reliable and timely information to HCPs and pregnant and lactating women about medication use during and after pregnancy. We look forward to bringing our expertise in building collective partnerships for collective impact to this important topic.

Helena Harnik,
Programmes Director

Achievements

Creation and Launch of the Maternal Health Synapse

Launched during Safe Motherhood Week 2018 and built in partnership with the Sanofi Espoir Foundation, Maternal Health Synapse maps and categorises maternal health initiatives, actors, innovators and problem-solvers on a global level within one platform.



This allows the creation an interactive and rich directory of people and projects that will facilitate exciting new collaborations and reduce duplication of effort. Ultimately it will become a crowdsourced, global, actionable community on maternal health. Currently in beta, we will continue to make improvements, including the addition of a “marketplace” feature matching urgent maternal health needs with resources. Since launch, more than 150 maternal health leaders have joined from more than 95 organisations, sharing 38 initiatives and 87 resources.

Alliance for Maternal Health Equality joint Policy Ask and Public Consultation

The Alliance agreed a joint Policy Ask and potential legal mechanisms to achieve it.

The Policy Ask of the Alliance for Maternal Health Equality is: free antenatal care for all women in Europe on the basis of the 2016 World Health Organization (“WHO”) Recommendations on Antenatal Care for a Positive Pregnancy Experience.



This was developed through several working meetings of a taskforce and feedback from the members of the Alliance for Maternal Health Equality. It was supported by expert guidance and feedback from UzoMadu and Thomas Tindemans from Hill & Knowlton, and Irina Trichkovska and Pierre Pechoux from White & Case.

A public consultation campaign launched during Safe Motherhood Week to seek feedback on the Policy Ask gathered positive endorsements. Following the conclusion of the public consultation, a strategy building meeting will take place with the members of the Alliance and experts to define concrete next steps to achieve this Ask.

Biggest Ever Edition of Safe Motherhood Week

2018 marked the third and biggest ever edition of Safe Motherhood Week.

The week featured the launch of the Maternal Health Synapse at the World Convergences Forum in Paris (3-4 October) with the support of the Sanofi Foundation Espoir and the launch of a public consultation campaign to influence the legal framework in Europe to create a better environment for mothers. We brought the #MakeMotherhoodCount campaign to collect real stories about women, their families and their motherhood experience to Romania with over 30 personal stories from mothers focusing on “Commonalities in Motherhood”.

This was complemented by over 90 blog posts contributed by influencers, advocates and mothers. The #SafeMotherhoodWeek campaign reached over 569,554 people with more than 5,000 engagements across all channels, with media reaching 9.3 million people in the Europe and US.



Successful launch of the Maternal Health Synapse in Paris, at the World Convergences Forum (3-4 September) with **25+ organisations joining the platform**



Implemented a comprehensive editorial plan to support the advocacy and awareness efforts with over **90** blogs contributed by influencers, advocates and mothers



Digital campaign in Eastern Europe with **over 30 personal stories** from mothers focusing on “Commonalities in Motherhood” as an overarching theme #MakeMotherhoodCount



Launched a **Public Consultation campaign** to influence the legal framework in Europe to create a better environment for mothers

✓ #SafeMotherhoodWeek campaign reached over **569.554** people with more than **5.000** engagements across all channels

✓ Media outreach (press release distribution) to over **9.3 million** people (Europe & US) and **269** interactions

✓ Over **13.136** views of the Sanofi Foundation video across SMW channels



2019 Approach

Until now, our energy has been focused on building a strong program foundation together with our partners. We have also started to make important progress in bringing together different actors in maternal health to speed up problem solving and avoid duplication.

In 2019 - 2021, we will take a more conscious focus on increasing demand and creating better conditions for high quality maternal health, including through activities to increase awareness of the gaps and issues that still exist today and which cut across all geographies and cultures.

We will expand Safe Motherhood Week globally and will build a more diverse partnership base using connections made through the Maternal Health Synapse to co-create and connect different stakeholder activities. Through the Alliance for Maternal Health Equality, we will translate the shared Policy Ask into a policy strategy that aims to put the issue of universal access to maternal care high on the European policy agenda and influence the legal framework in Europe to create a better environment for mothers.

We will also continue to populate and develop the Maternal Health Synapse to identify and characterise the maternal health stakeholder ecosystem, helping to reduce fragmentation within this active field. Tools to be developed will include a “marketplace” feature to match urgent maternal health needs with resources. We also plan to host a competition and award for the best maternal health initiative on Synapse to identify best practices and interventions that could be scaled up and applied to other settings and geographies.

From 2019, will have an important role to play in the IMI project ConcePTION, where our contribution will be focused on stakeholder engagement, sustainability and outreach to provide improved tools, information and methods to HCPs and women on medication use during pregnancy and breastfeeding.

The Motherhood Collective Impact Team

Board members and MCIP team

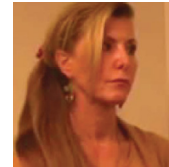
The Motherhood Collective Impact Advisory Board consists of:



Bernadette Hendrickx
Scientific Advisor



Lode Dewulf
Consultant,
Permanent Guest



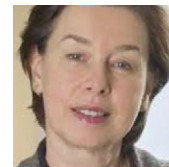
Roumyana Petrova-Benedict
IOM Senior Regional
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At EPF



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Advocacy Officer
At IPPF



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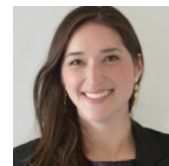
The Motherhood Collective Impact Team consists of:



Nicholas Brooke
Patient
Engagement
Manager,
EURORDIS



Daniela Luzuriaga Ubilla
Project
Coordinator



Helena Harnik
Programmes
Director



Gulwish Ahmed
Communications
Assistant



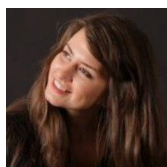
Danielle Barron
Chief Editor,
Motherhood
Projects



Roxana Radu
Communications
Manager



Lise Brooke
Growth Hacker



Diana Zaharia
Communications
Manager

Our partners

They made all this possible

A total of **13 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.



2018

External projects

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 (Synchros). 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 & Synchros

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.



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