Societal Synergies

The Synergist 2017

Annual Report

The Synergist

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Message from the Executive Director

At The Synergist, we have a vision of a world in which we tackle societal issues in the most efficient manner possible. We seek to accelerate progress on various issues by creating collaborative platforms that collectively address inefficient, fragmented and broken systems. Currently, too many systems address only in part the issues they are meant to solve, and duplication and waste is endemic.

Maternal health, dengue fever and patient engagement are all societal issues approached from different perspectives in different countries by different stakeholders. Across each of these, we are breaking down artificial and limiting boundaries. By applying a systematic approach and building efficient, digitally native ecosystems, we are able to address issues through collaboration and aggregation of other initiatives and approaches that so far have operated in isolation.

Our programmes - Patient Focused Medicine Development, Break Dengue, the Motherhood Collective Impact Programme - are not just another set of initiatives on these topics. Rather, they complement what is already in motion: efficiently bringing together all the current pieces of the puzzle and filling any gaps that may exist.

In 2017 we have further developed our co-impact model by building on its strengths (including the methodology, collaborative leadership, tools) and by applying learnings from one project across all our projects to build economies of scale. This has helped us develop a more sustainable model to deliver real impact.

I am pleased to share our activities and results for 2017 with you. Our partners, members and volunteers have brought so much to all our programmes through their activities and support for our approach. It has truly been a collective effort. Alongside them, the team at The Synergist has worked extremely hard to bring our vision to life, overcoming development challenges and navigating very different perspectives, needs and expectations. I am immensely proud of our platforms, members and our team, who together truly reflect change and are driving meaningful action on essential societal issues.

This is their work,
Nicholas Brooke, CEO The Synergist

Our Impact

Maternal Health, Dengue Fever and Patient Engagement are interminable societal issues. It is unlikely that there will be a point in time in which we cannot further improve women's health, further decrease the burden of dengue or improve new medicines development for with patients. The Synergist believes a systematic approach is required to deal with these types of challenges, we which we seek to do across different levels:

- **At the overall Synergist ecosystem level, where we seek to create a robust and replicable model for collaboration on societal challenges**
- **At the individual initiative ecosystem level (Break Dengue, Patient Focused Medicines Development, Motherhood Collective Impact Programme)**
- **Through specific projects that benefit from collaboration and digital synergies and which create new opportunities, tools and solutions to face societal issues**

The Synergist Ecosystem

A total of44 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. Our corporate partners especially are getting out of the competitive mode in order to have a positive societal impact and operate in a positive societal environment. We believe the full benefits of co-creation and collaboration are yet to be seen.

open IDEO
WHITE & CASE
INVOLVE
DIA
PARKINSON'S UK CHANGE ATTITUDES. FIND A CURE. JOIN US.
Takeda
LEUKEMIA PATIENT ADVOCATES FOUNDATION
John Snow LABS
EPF European Patients Forum
HealthMap Global Health, Local Information
malaria consortium disease control, better health
National Kidney Foundation
EURORDIS Rare Diseases Europe
THE GLOBAL HEALTH NETWORK Enabling research by sharing knowledge
C101 CANCER101
FasterCures A CENTER OF THE MILKEN INSTITUTE
EUPATI European Patients' Academy on Therapeutic Innovation
Society for Participatory Medicine
AHF
HTAi
BRUXELLES invest & export
SANOFI
Bayer CropScience
SANOFI PASTEUR
Roche
AstraZeneca
gsk GlaxoSmithKline
MSD
janssen PHARMACEUTICAL COMPANIES OF Johnson&Johnson
AMGEN
Pfizer
Parkinson's Disease Foundation
EPF European Parliamentary Forum on Population & Development
MotherToBaby Medications & More During Pregnancy & Breastfeeding Ask The Experts
mummys star
PUTTING PATIENTS FIRST NATIONAL HEALTH COUNCIL
IPPF
ucb
MSD MSD for mothers
IOM • OIM INTERNATIONAL ORGANIZATION FOR MIGRATION
UNFPA
PS Pregnancy Sickness Support
NOVARTIS
Hill+Knowlton Strategies

2
new projects

9
new partners,
bringing us to a total of **44**

1.782.500 €
of funding raised

2,197
experts in our
ecosystem

479.234
people actively engaged
on social media

5.079.23
visits on our
project websites

105
editorial pieces

1
scientific publication

265.437
followers of our
social channels

15.284.506
people seeing our messages
on social media

Impact at the collaborative platform or project level is described in the sections specific to each initiative:

- **Patient Focused Medicines Development**
- **Break Dengue**
- **Motherhood Collective Impact Programme**

Financial report

	Patient Focused Medicines Development (PFMD)	Break Dengue	Motherhood Collective Impact Programme (MCI)*
Project Turnover (€)	1.030.000	390.000	210.000
Project Expenses (€)	641.421	165.695	95.466
In-kind hours	1.935	200	100
In-kind contribution (€)	125.775	13.000	6.500

*The Synergist has been investing money in MCI, by charging a significantly lower fee than the market price to enable sustainability of the project.

Bringing The Synergist vision to life

The Synergist is a social venture that addresses a growing need to collectively face societal issues by addressing broken or inefficient systems and accelerating societal (co-)impact.

The Opportunity

With globalisation, the digital age and increased mobility, we now collectively possess more knowledge, capability and capacity to solve the world's most challenging social issues than ever before. Yet complex issues cannot be solved in isolation. The sheer number, variety and interests of stakeholders on any given issue makes it difficult to focus everyone's expertise and resources on a shared goal.

As the societal landscape evolves rapidly, the time has now come now for key stakeholders to engage in societal issues as a responsibility but also as a benefit to their organisation in an environment that puts their sustainability at stake.

BlackRock's Message: Contribute to Society, or Risk Losing Our Support*

"Society is demanding that companies, both public and private, serve a social purpose," he wrote in a draft of the letter that was shared with me. "To prosper over time, every company must not only deliver financial performance, but also show how it makes a positive contribution to society."

Laurence D. Fink,
founder and chief executive of BlackRock

*https://www.nytimes.com/2018/01/15/business/dealbook/blackrock-laurence-fink-letter.html

Our Solution

The Synergist is an independent, neutral backbone and incubator bringing together the right people, organisations, and institutions to focus on solving societal issues both personally and with technology. We foster an organized and collaborative environment that enables collective impact by: co-defining a shared vision, goals and strategies with members; bringing on board new partners; establishing and maintaining a transparent and balanced governance structure; coordinating all activity and bringing to life concrete projects and solutions that have been shaped with and complemented by members.

An open and issue-centric ecosystem	An identity backbone	Strategic projects and deliverables addressing gaps
• A robust and agile partnership governance model • The Synapse Digital Suite to identify and bring together people and projects, match solutions to resources, and solve specific need • Expert communities online and offline	• An independent Editorial Board • Strong digital channels and storytelling • Online engagement and community mobilisation	**Advocacy:** Examples include Global Dengue Day; Matrix for Maternal Health Performance. **Tools:** Examples include framework for patient engagement; reputation toolkit for patient organizations, online repositories. **Innovative solutions:** Examples include accurate and actionable dengue surveillance based on big data, crowd surveillance; Patient Engagement Portfolio Management Software

Our assets

- A proven model to fix broken systems
- Strong internal, transversal expertise and experience in building collaborative partnerships for collective impact
- A neutral backbone allowing diverse stakeholders to collaborate together
- Bringing people together around one shared goal – they leave their individual goals at the door
- Harnessing the power of digital. We bring the partnership concept to the digital age, with products and models adaptable to a variety of issues
- Shared services and expertise across projects to help learning and achieve economies of scale
- Agile, startup approach to deliver value and impact quickly, efficiently and iteratively
- Development of proprietary tools to support collaborative partnerships
- A strong network of quality partners who share our values
- Quality, objective communications to drive culture change
- (Re)investing in projects to build sustainability
- An international and multicultural team

What?

7 projects. 44 partners.

Countless impact stories. A determined and motivated team.

PATIENT FOCUSED MEDICINES DEVELOPMENT

Break Dengue

ALLIANCE FOR MATERNAL HEALTH EQUALITY

Motherhood Collective Impact Programme

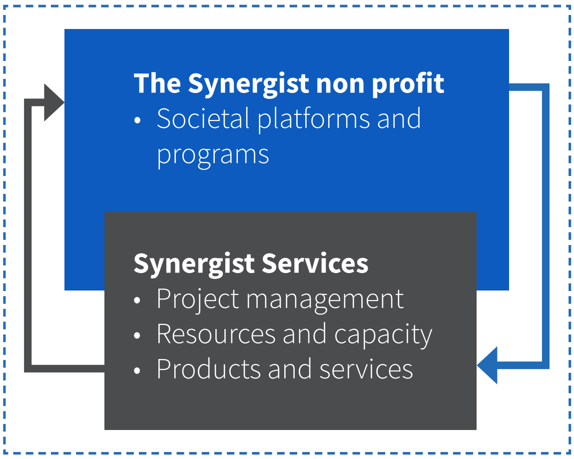
PREGNANCY & MEDICINE INITIATIVE
prescribing change, expecting more

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

Share4Rare

The Synergist sustainability model:

- The Synergist Services consolidates finances at the end of year and gives a rebate back to nonprofit
- Rebate makes the actual operational costs lower than market price



The Synergist non profit
- Societal platforms and programs

Synergist Services
- Project management
- Resources and capacity
- Products and services

- The Synergist nonprofit hires capacity needed to advance societal programmes
- Capacity and resources are billed according to market price
- Shared services and economies of scale

PATIENT FOCUSED
MEDICINES DEVELOPMENT

Patient Focused Medicines Development

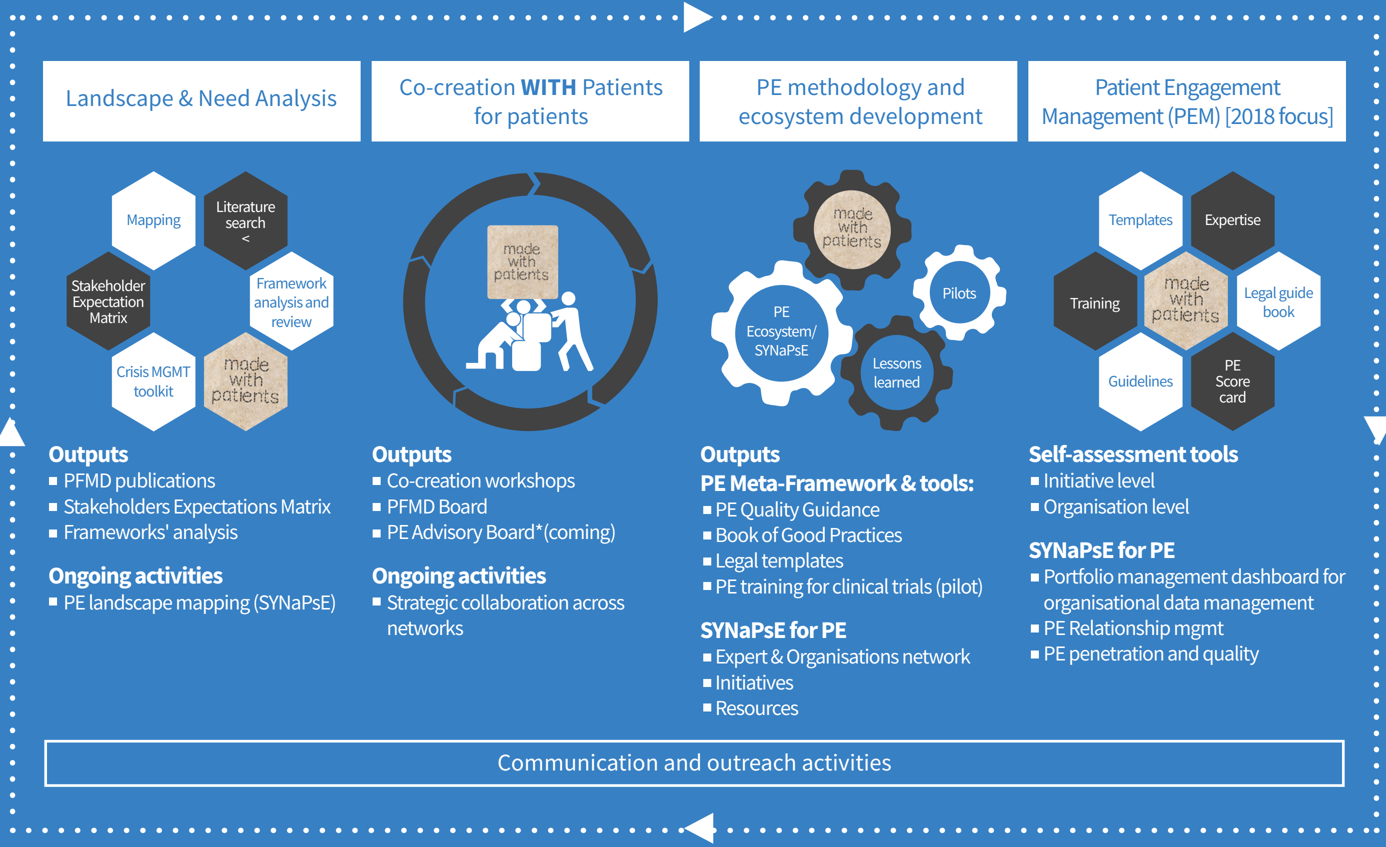
REPORT

2017 has been an amazing year for PFMD and patient engagement (PE). PFMD is an open collective platform, taking a systematic approach to making PE happen by gathering all existing practices, models, frameworks and insights and co-creating solutions with patients. More than ever, we are synergising a fast-moving environment, blurring boundaries, building on positive trends, and addressing gaps in PE.

It is a privilege to be the catalyst for hundreds of change-makers, supporters, committed people and organizations who have invested both in kind and with funding to build an efficient PE ecosystem, and who have helped further our collective goal to enable better outcomes for patients to the benefit of entire communities.

The evolving PE landscape has resulted in an increasing number of PE initiatives around the world, and can also be seen in the growth of initiatives listed in SYNaPSE. To adapt and cater to the changing ecosystem, SYNaPsE has gone from a landscape mapping tool to a comprehensive PE Management tool with a network of relevant experts and organisations, the Pledge to Patients, a resource library - and continues to expand to encompass more functionality for organisations to manage their PE portfolio and activities around the world.

The framework building workstream, in addition to providing an operational model for the PE Meta-framework through five successful multi-stakeholder workshops, has made great progress in coproducing the first set of related PE tools (PE Quality Guidance and Quality Criteria, Book of Good Practices, and Do's and Don'ts to name a few). The Patient Engagement Management (PEM) Suite will include these and additional tools that aim to support and guide stakeholders in setting PE standards internally, and in planning, assessing and recording the impact of their PE efforts.



Landscape & Need Analysis

Outputs
- PFMD publications
- Stakeholders Expectations Matrix
- Frameworks' analysis

Ongoing activities
- PE landscape mapping (SYNaPsE)

Co-creation **WITH** Patients for patients

Outputs
- Co-creation workshops
- PFMD Board
- PE Advisory Board*(coming)

Ongoing activities
- Strategic collaboration across networks

PE methodology and ecosystem development

Outputs

PE Meta-Framework & tools:
- PE Quality Guidance
- Book of Good Practices
- Legal templates
- PE training for clinical trials (pilot)

SYNaPsE for PE
- Expert & Organisations network
- Initiatives
- Resources

Patient Engagement Management (PEM) [2018 focus]

Self-assessment tools
- Initiative level
- Organisation level

SYNaPsE for PE
- Portfolio management dashboard for organisational data management
- PE Relationship mgmt
- PE penetration and quality

Communication and outreach activities

In 2017, PFMD put a great effort into outreach, attending 11 events (staff or members speaking or chairing sessions at eight of them), conducting a Stakeholder Expectations survey with almost 60 respondents from all stakeholder groups, publishing 28 blog posts and videos and 18 guest posts, and reaching over 2.8 million individuals across all PFMD's online communication channels and campaigns.

Find out more about our achievements in 2017 in this report and join PFMD, a global movement dedicated to improving the patient experience.

Nicholas Brooke
Programme Director

Achievements 2017

Membership Growth

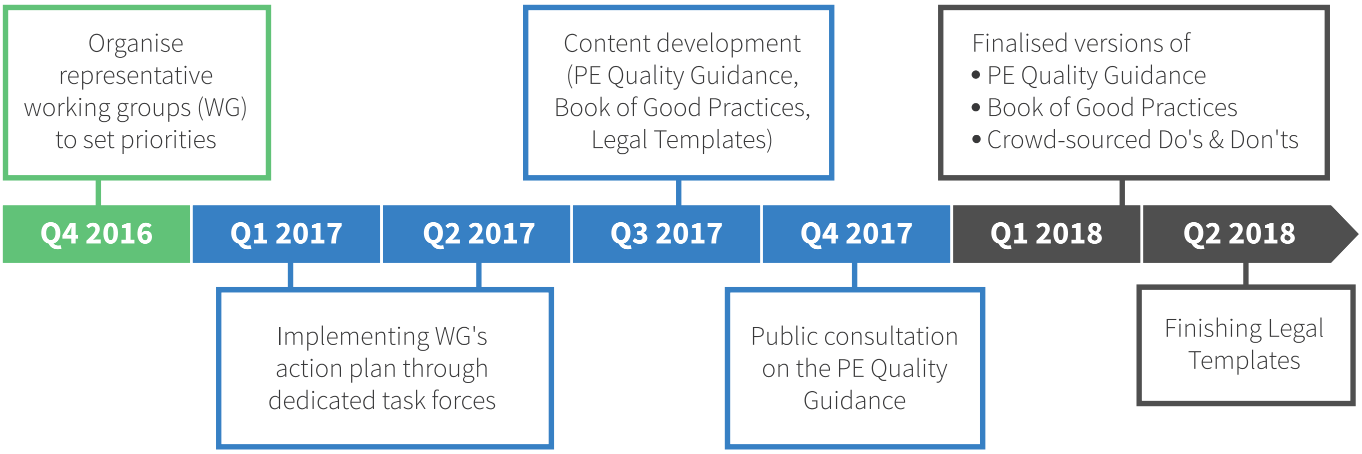
In 2017 we welcomed six new members to the PFMD family:

DIA DEVELOP INNOVATE ADVANCE
NHS National Institute for Health Research
World Alliance of Pituitary Organizations
NOVARTIS
Takeda
INVOLVE

Framework building activities

Despite the growing understanding of the importance of patient engagement from the very early to the latest phases of medicines development, there are no industry-wide standards on how it should be done. Our first working group meetings (held in 2016) aimed to identify key gaps, opportunities and stakeholders to involve, and the next steps to take in order to co-create the Patient Engagement Framework – a guidance and practical toolkit to help all stakeholders, however advanced they are in patient engagement, to do conduct meaningful patient engagement and attain measurable results.

In 2017 we continued this work, moving to more concrete outputs. **5 multi stakeholder groups** and task forces, with **76 experts** representing **51 organisations,** contributed, as well as a committed core team from the most active PFMD contributors.



Q4 2016
Organise representative working groups (WG) to set priorities

Q1 2017
Q2 2017
Implementing WG's action plan through dedicated task forces

Q3 2017
Content development (PE Quality Guidance, Book of Good Practices, Legal Templates)

Q4 2017
Public consultation on the PE Quality Guidance

Q1 2018
Finalised versions of
- PE Quality Guidance
- Book of Good Practices
- Crowd-sourced Do's & Don'ts

Q2 2018
Finishing Legal Templates

Concrete outputs in development:

- **Patient engagement quality guidance**. A tool to help determine why, how and when to involve and engage with patients from each stakeholder perspective
- A **Book of Good Practices** to help showcase the value of patient input
- A template to use in planning and assessing patient engagement activities
- A selection of quick wins - the "Do's and Don'ts" in patient engagement activities

Public consultation results

In order to support the framework development efforts, we launched a public consultation targeted at all stakeholders, with any level of patient engagement experience, giving them the opportunity to comment and contribute to the *Patient Engagement Quality Guidance* tool.

Results

21.589 reach

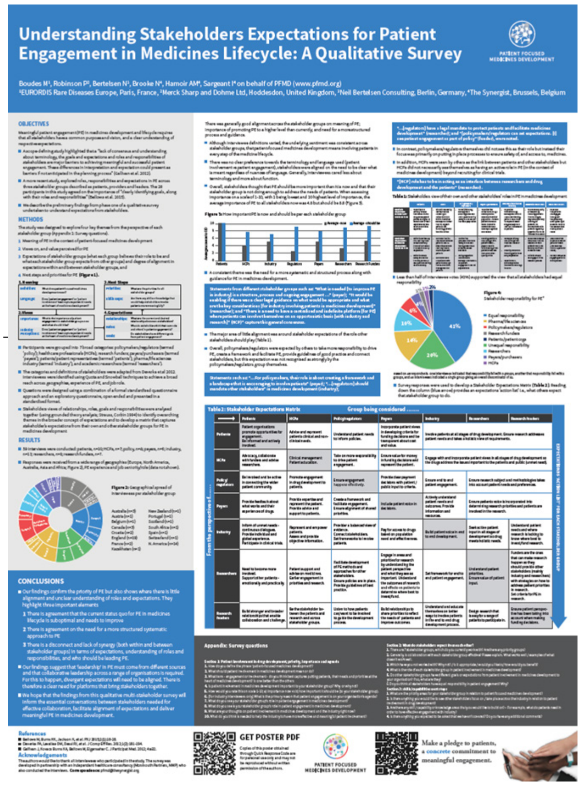
40.259 press release reach

851 website visits

68 Number of answers **(74% completion rate)**

Stakeholder Expectations Matrix

Meaningful patient engagement requires all stakeholders to have a common purpose, vision, and a clear understanding of their respective expectations. That is why in 2017 we launched a major effort to map these expectations.



Understanding Stakeholders Expectations for Patient Engagement in Medicines Lifecycle: A Qualitative Survey

Boudes M[1], Robinson P[2], Bertelsen N[3], Brooke N[4], Hamoir AM[4], Sargeant I[4] on behalf of PFMD (www.pfmd.org)
[1]EURORDIS Rare Diseases Europe, Paris, France, [2]Merck Sharp and Dohme Ltd, Hoddesdon, United Kingdom, [3]Neil Bertelsen Consulting, Berlin, Germany, [4]The Synergist, Brussels, Belgium

Achievements

- **59 in-depth interviews** with representatives from **7 stakeholder groups** (patients, HCPs, policy makers, payers, industry, researchers & research funders)
- **Preliminary analysis presented as a poster at the 20th International Society for Pharmacoeconomics and Outcomes Research (ISPOR)** Conference (November 2017, Glasgow, UK). This provides a 2017 peer-reviewed citation for this first report of the Matrix (Boudes M, et al. Value in Health 2017;20:A563. Poster PHP1).

Synapse

a network for patient engagement

SYNaPsE, your **tool for meaningful patient engagement**, has achieved impressive exponential growth! With **248 initiatives**, **183 organisations** and **707 users**, SYNaPsE is becoming the go to place for all PE experts and enthusiasts.

248 INITIATIVES	**183** ORGANIZATIONS	**847** EXPERTS	**37** RESOURCES

The main features launched in 2017:

- An **experts network**. Now any patient engagement expert or enthusiast can build a profile, promote their work and achievements and connect with a community of like-minded people.
- A **resource library**. Adding various resources (reports, publications, videos etc) to enrich a personal or organisation's profile is now possible.
- Features to improve **usability**: a new way to upload initiatives, admin layers for better control of shared content and a personal dashboard for an easy activity overview.
- **Bookmarking** feature: the ability to save initiatives, organisations and experts that you would like to follow so you are always up to date on the patient engagement news that interests you.

Although SYNaPsE's main focus for 2017 was improved usability and development of new and useful products (initiatives search engine, organisation repository, experts network & resource library), we always strive to grow its usability. We therefore ran a dedicated SYNaPsE digital campaign, put resources into improving customer support and developed offline promotional materials.

Results

68.694
page views in 2017
(520% increase compared to 2016)

24.523
visitors
(2,957% increase compared to 2016)

*SYNaPsE was officially launched for the public in September 2016.

The Pledge to patients

In May 2017, PFMD launched the **individual Pledge to Patients campaign** to contribute to **cultural change** in the healthcare environment. The premise was simple: anyone can make a personal pledge to better **listen, communicate and co-create with patients.** This had to be a real, measurable commitment.

The Pledge to Patients was integrated with SYNaPse, so that contributors would both make a commitment to patients and become part of the biggest online community for patient engagement, enabling them to provide progress updates and inspire others. The campaign will continue in 2018 with an increased focus on reaching all stakeholders involved in the medicines development lifecycle.

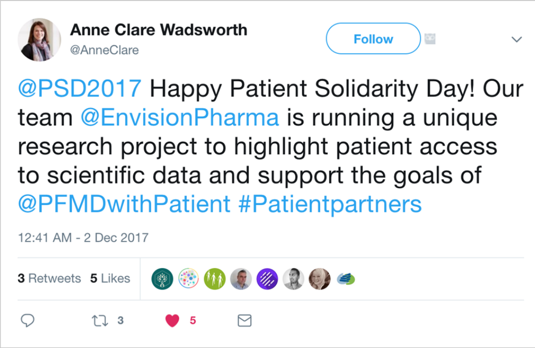
Achievements

2.187.698	**21.353**	**230**	**530**
reach	website visits	Committers	Commitments taken

Project Outreach

A main objective for PFMD outreach in 2017 was to **increase our reach to broader and more diverse audiences**. We managed to achieve a **123% increase** on our overall digital reach compared to 2016. Not only that, but the number of engagements with relevant **audiences increased by 319%**.

In 2017, PFMD was also represented at **11 external conferences,** of which **8 included speaking opportunities**.

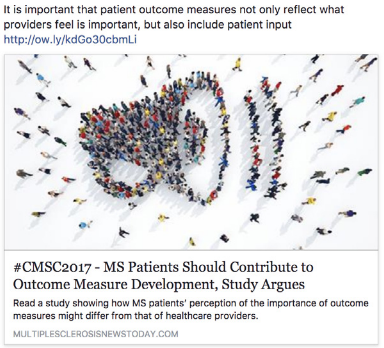


Anne Clare Wadsworth
@AnneClare

@PSD2017 Happy Patient Solidarity Day! Our team @EnvisionPharma is running a unique research project to highlight patient access to scientific data and support the goals of @PFMDwithPatient #Patientpartners

12:41 AM - 2 Dec 2017

3 Retweets 5 Likes



It is important that patient outcome measures not only reflect what providers feel is important, but also include patient input
http://ow.ly/kdGo30cbmLi

#CMSC2017 - MS Patients Should Contribute to Outcome Measure Development, Study Argues

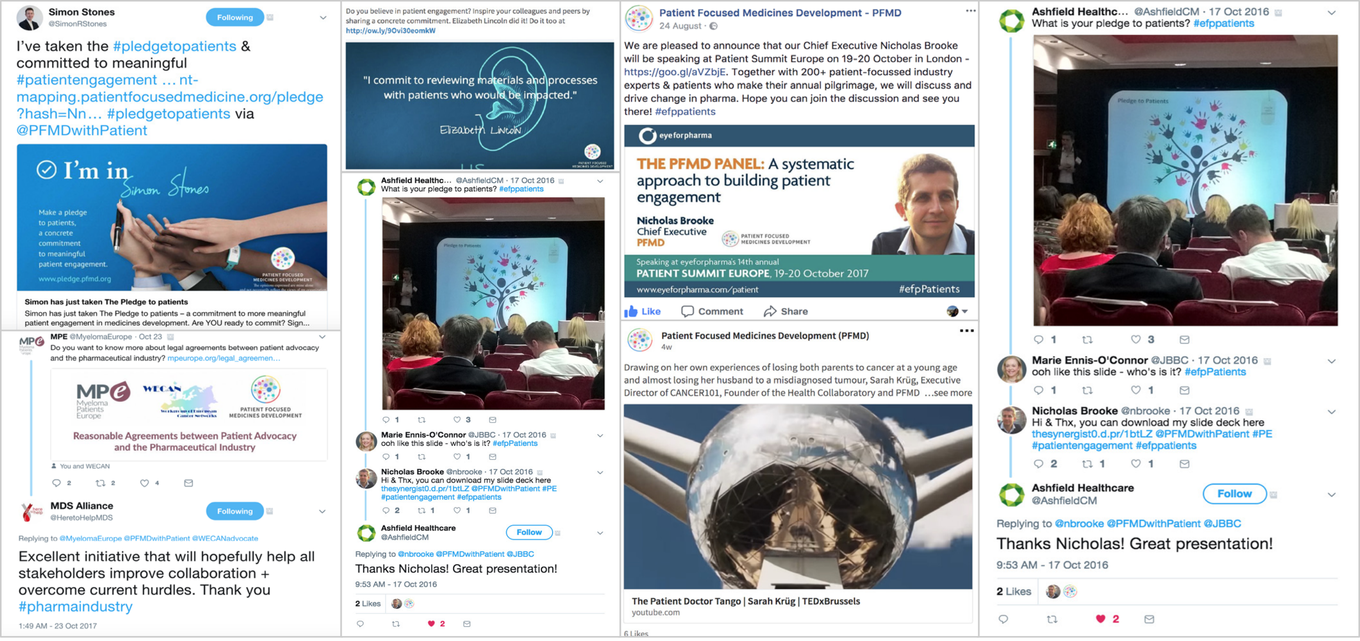
Read a study showing how MS patients' perception of the importance of outcome measures might differ from that of healthcare providers.

MULTIPLESCLEROSISNEWSTODAY.COM

Patient Focused Medicines Development (PFMD)
2w

It is our pleasure to invite you to give feedback on the Patient Engagement Quality Guidance, a practical tool we've co-created with 76 professionals from 51 organisations. ...see more

7 Likes



Simon Stones @SimonRStones Following

I've taken the #pledgetopatients & committed to meaningful #patientengagement … nt-mapping.patientfocusedmedicine.org/pledge?hash=Nn… #pledgetopatients via @PFMDwithPatient

Simon has just taken The Pledge to patients
Simon has just taken The Pledge to patients – a commitment to more meaningful patient engagement in medicines development. Are YOU ready to commit? Sign...

MPE @MyelomaEurope · Oct 23
Do you want to know more about legal agreements between patient advocacy and the pharmaceutical industry? mpeurope.org/legal_agreemen…

You and WECAN
2 2 4

MDS Alliance @HeretoHelpMDS Following
Replying to @MyelomaEurope @PFMDwithPatient @WECANadvocate

Excellent initiative that will hopefully help all stakeholders improve collaboration + overcome current hurdles. Thank you #pharmaindustry

1:49 AM - 23 Oct 2017

Do you believe in patient engagement? Inspire your colleagues and peers by sharing a concrete commitment. Elizabeth Lincoln did it! Do it too at http://ow.ly/9Ovi30eomkW

Ashfield Healthc… @AshfieldCM · 17 Oct 2016
What is your pledge to patients? #efppatients

1 3

Marie Ennis-O'Connor @JBBC · 17 Oct 2016
ooh like this slide - who's is it? #efpPatients

1 1

Nicholas Brooke @nbrooke · 17 Oct 2016
Hi & Thx, you can download my slide deck here thesynergist0.d.pr/1btLZ @PFMDwithPatient #PE #patientengagement #efppatients

2 1 1

Ashfield Healthcare @AshfieldCM Follow
Replying to @nbrooke @PFMDwithPatient @JBBC

Thanks Nicholas! Great presentation!

9:53 AM - 17 Oct 2016

2 Likes

2

Patient Focused Medicines Development - PFMD
24 August ·

We are pleased to announce that our Chief Executive Nicholas Brooke will be speaking at Patient Summit Europe on 19-20 October in London - https://goo.gl/aVZbjE. Together with 200+ patient-focussed industry experts & patients who make their annual pilgrimage, we will discuss and drive change in pharma. Hope you can join the discussion and see you there! #efppatients

Patient Focused Medicines Development (PFMD)
4w

Drawing on her own experiences of losing both parents to cancer at a young age and almost losing her husband to a misdiagnosed tumour, Sarah Krüg, Executive Director of CANCER101, Founder of the Health Collaboratory and PFMD …see more

The Patient Doctor Tango | Sarah Krüg | TEDxBrussels
youtube.com

6 Likes

Ashfield Healthc… @AshfieldCM · 17 Oct 2016
What is your pledge to patients? #efppatients

Pledge to Patients

1 3

Marie Ennis-O'Connor @JBBC · 17 Oct 2016
ooh like this slide - who's is it? #efpPatients

1 1

Nicholas Brooke @nbrooke · 17 Oct 2016
Hi & Thx, you can download my slide deck here thesynergist0.d.pr/1btLZ @PFMDwithPatient #PE #patientengagement #efppatients

2 1 1

Ashfield Healthcare @AshfieldCM Follow
Replying to @nbrooke @PFMDwithPatient @JBBC

Thanks Nicholas! Great presentation!

9:53 AM - 17 Oct 2016

2 Likes

2

Results (as of 30 Nov)

1.970
followers on all of our channels (Twitter, Linkedin and Facebook - new channel opened in 2017)

34.170
engagement on all of our channels (people that commented, liked or shared our activity). **319%** increase compared to 2016

2.894.684
reach of our digital channels (people that saw our activity and updates).

38
blogs published (more than double compared to 2016), out of which 18 were guest posts from members or collaborators.
The blog posts attracted 3,665 views.

Ongoing internal (with exclusive information and updates for our members) and external newsletters, reaching a community of **639** people.

Legal & compliance solutions for patient engagement

The topic of contractual and administrative barriers surfaced in discussions both in the working group sessions and during PFMD's board meetings in 2016. The Legal and Compliance Hurdles task force came together to address the need to lower legal, compliance, administrational and other perceived barriers that hinder collaboration between stakeholders or the involvement and engagement of patients in the medicines development lifecycle.

The objective is to produce guidance to tackling legal and other barriers for all stakeholders who want to work with each other in the medicines development continuum. As an output, the "legal guide" (working name) will also include tools for capacity building, such as an online and interactive guide that explains the different clauses and sections in a template contract in lay language, a selection of alternative clauses and template contracts that can be suggested to the partnership, an interactive description of the usual processes for collaboration, a set of recommendations on payment and accessibility issues, and a listing of agencies or stakeholders that can provide assistance on legal questions or barriers (this preliminary plan may change as the project moves forward).

In order to ensure collaboration across stakeholder groups and geographically, and to avoid duplication of efforts, PFMD has joined forces with Myeloma Patients Europe (MPE), along with the Workgroup of European Cancer Patient Advocacy Networks (WECAN), a network of 20 pan-European cancer patient organisations, on their project: “Reasonable agreements between patient advocacy and the pharmaceutical industry”.

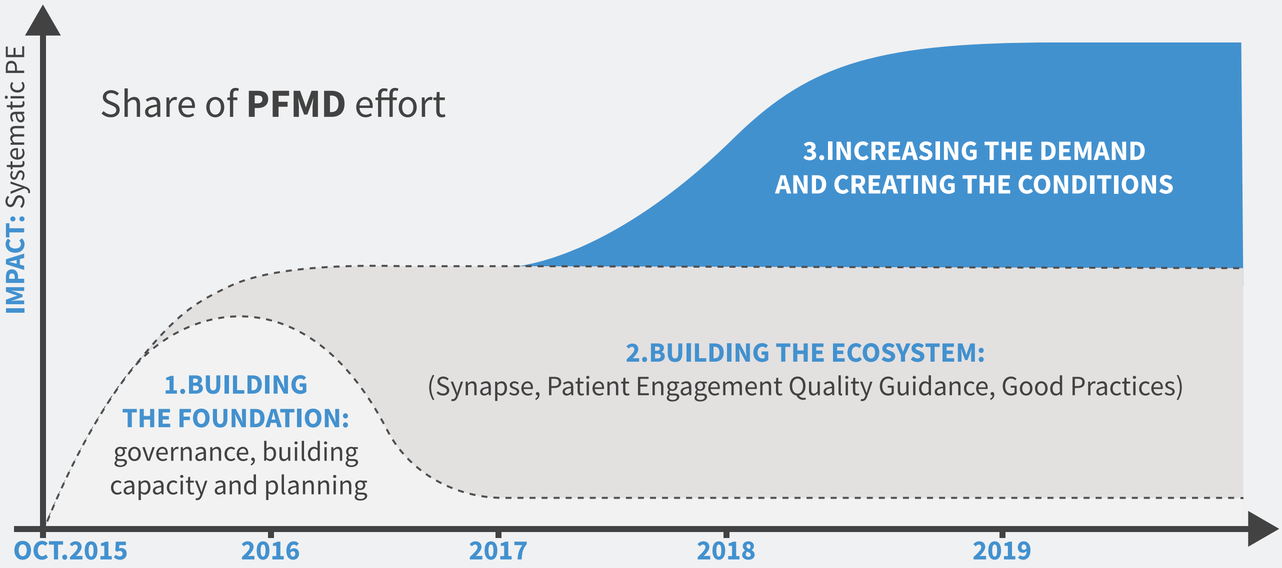
Strategic approach for 2018

The need for PFMD remains present and is even increasing.

While key initiatives including PFMD are gaining maturity and developing better material to support it, we have found a persistent mismatch in expectations between stakeholders, and an absence of leadership in the patient engagement landscape to harmonise and drive patient engagement forward. In this context, PFMD is uniquely and strategically positioned to fulfill both a role of collaborative leadership and drive harmonisation.

The tools and networks we have built, online and offline, together with our global collaborative leadership platform and approach, are defragmenting PE and bringing stakeholders together in full alignment towards achieving our shared objectives for patient engagement.

In 2018, we will focus on extending outreach to individuals who have not embraced PE yet and to build a better understanding of the patient engagement “Why”, “What” and “How”, as well as a better understanding of existing tools and methodologies, whether generated by PFMD or not.



The logical evolution of PFMD activities shows a clear shift in focus from the foundation building to increasing demand. In the first two years of PFMD’s operations, the focus has been to build a strong and trustworthy foundation through building capacity and presence in the patient engagement community, and establishing a robust modus operandi.

We began to build the global patient engagement ecosystem early on with offline activities as well as the mapping tool and gradually growing the breadth of activities and tools to answer the needs identified through our members and dedicated multi-stakeholder working groups.

While keeping a strong emphasis on continuing to build the patient engagement ecosystem in a credible way, PFMD will enhance the focus to increase the demand and create conditions for PE to happen moving forwards.

This broadening of scope will firstly address the identified mismatch of stakeholder expectations and the lack of leadership, secondly reach and influence the early majority, and thirdly mean more efficient dissemination of PE tools and resources out there for maximum impact..

Member & Partner testimonials

I truly believe what we've seen so far is many individual initiative that have really not talked to each other, that sometimes duplicated the work and here with PFMD our ultimate goal is to bring access to patients in a much more efficient way for new medicines. PFMD can bring all these stakeholders together. First of all can map all the initiatives, secondly reach a consensus what the best instruments, the best framework would be, the best tools would be to really create meaningful patient engagement. And third, it can then develop a framework that would be applicable for all stakeholders and would ultimately again lead to much much better medicines to patients.

Tony Hoos
Head of Medical, Amgen Europe

"PFMD is a transatlantic group with a global intent from the start. The mutual respect of stakeholder members and contributors is a fertile ground for co-creating tools we all need to ensure the next horizons of patient involvement in development of new therapies. I'm grateful for what the Synergist brings as experts in convening diverse stakeholders and a vision for meaningful change in the world."

Roslyn Schneider
Global Public Affairs Lead, Pfizer

"PFMD has played such a crucial role for us as a company and for the broader patient community by helping us understand how to connect and engage, and helping us to address the real challenges that we have. This way we will be able to achieve our mutual desired end goal of incorporating patients into our work, into our thinking so that we're ultimately designing and developing the solutions of greatest value for patients. PFMD is really taking the lead for all of us to be able to open that conversation, to share the work that we're doing, to make those important connections and strengthen our connections as a community. So that we ultimately can make a difference and do what's right for patients and improvement of their care."

Rebecca Vermeulen
Head of Product Development Medical Affairs,
Roche Pharmaceuticals

The 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 Programme,
GSK

Luther Clark
Deputy Chief Patient Officer,
Global Director, Scientific
Medical And Patient Perspective
(SMPP), MSD/ Merck

Katherine Capperella
Global Patient Engagement
Leader, Janssen

Rebecca Vermeulen
Head Global Medical Liaisons
And Communications, Roche

Elisa Ferrer
Patient Engagement Manager,
EURORDIS

Kelli Collins
Vice President Patient
Engagement, National Kidney
Foundation

Kimberly McCleary
Managing Director,
FasterCures

Lode Dewulf
Consultant,
Permanent Guest

Paula Wray
Senior Public Involvement
Manager, NIHR INVOLVE

The Executive Team consists of

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Chief Executive Officer,
National Health Council

Jan Geissler
Director, EUPATI

Tony Hoos
Head Of Medical, Europe,
AMGEN

The PFMD Team consists of

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Executive Director

Helena Harnik
Operational Director

Chi Pakarinen
Project Manager

Roxana Radu
Communication Coordinator

Anne-Marie Hamoir
Head Of Membership And Project Management

Natalia Sharamandzhieva
Project Coordinator

Bernadette Hendrickx
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Ify Sargeant
Editor In Chief

Geoffroy Ryckaert
Head Of IT

Laila Deeb
Web Developer

Break Dengue

Break Dengue

REPORT

Over the last four years Break Dengue, together with its partners, has tackled important issues including disinformation, a lack of a sense of urgency, and uncoordinated efforts in the fight against dengue. As we begin 2018, Break Dengue is reflecting on a year of growth.

We have welcomed new partners and collaborators such as Janssen and the Skoll Foundation, taken our strategy and tools to the field in countries including Colombia and Brazil, and been recognised for our innovative efforts to combat dengue.

We look forward to working together in the exciting year ahead. Together we can Break Dengue!

Aaron Hoyles
Programme Manager

Achievements 2017

Partner growth

In 2017, Break Dengue proudly welcomed Janssen Pharmaceutica, a Johnson & Johnson company, as a partner. In addition to participating in Break Dengue's full agenda of activities, Janssen is a key partner in the eBarometer project.

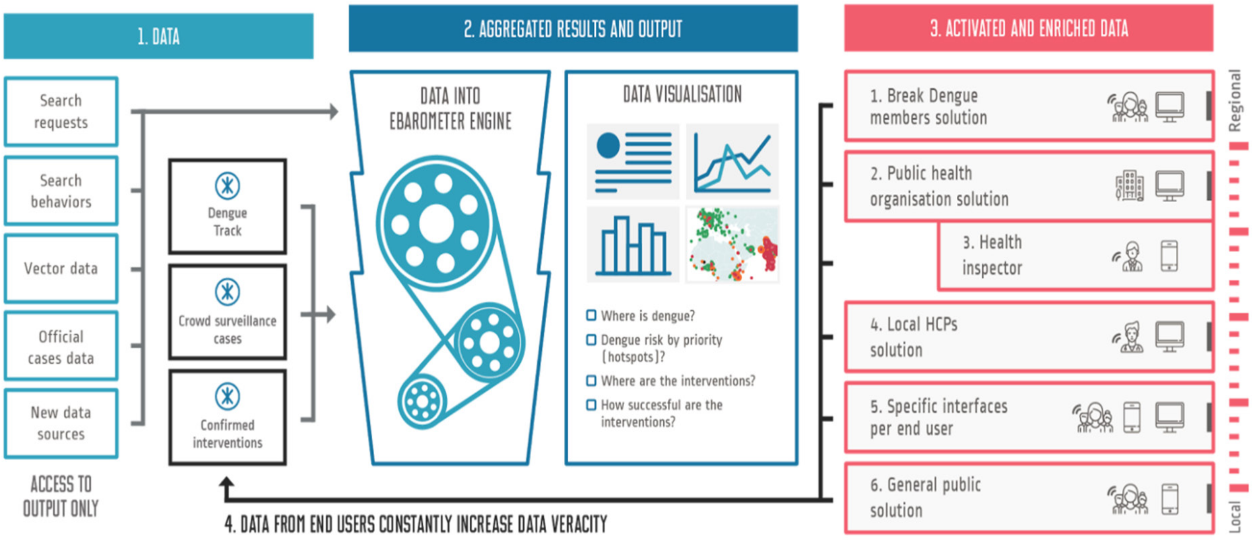
Break Dengue was also excited to begin a partnership with AIESEC, the world's largest youth-run organisation. With AIESEC, Break Dengue is building capacity to engage with local communities through projects on the ground.

Break Dengue also forged a promising new alliance with the Skoll Foundation, which sponsored Break Dengue's participation in Epihack Sri Lanka. Nicholas Brooke, the founder of Break Dengue, attended the 5-day hackathon from November 6-10 2017, with a variety of professionals and dengue experts brought together to hack an open source digital solution to dengue communication and surveillance.

Advancing the eBarometer project

In 2017 Break Dengue advanced the development of a groundbreaking step in dengue surveillance, the Dengue eBarometer. The eBarometer represents one of a number of strategic projects through which Break Dengue acts to lead impactful projects that fight dengue on the ground.

The Dengue eBarometer will combine data and analytics to produce a revolutionary, actionable, vector-borne disease surveillance and alert system. The team building the eBarometer, including Janssen, Harvard Medical School, and Avia GIS, recently came together to plan the next phase of development at our offices in Brussels.



Scientific publications

In 2017 we were honoured to publish, together with our partners at Harvard Medical School, a research paper revealing how search engines can be used to monitor dengue fever outbreaks in underdeveloped countries. The paper was published in PLOS Computational Biology, a peer-reviewed scientific journal and it looks at how big data analytics combing Google searchers with official clinical data from government sources can give a quick and accurate picture of dengue outbreaks.

A WHO Report on eHealth cited Break Dengue in 2017. The report – Global diffusion of eHealth: making universal health coverage achievable – was produced by the WHO's Global Observatory for eHealth, and looks at how governments and organizations around the world are embracing eHealth, big data and information communications technologies to advance global health.

The report explains how Break Dengue has built a coalition of stakeholders to meet the considerable challenge posed by dengue fever. In particular, the authors note that, since its creation in 2013, we have encouraged stakeholders to look at the bigger picture, rather than focusing on single aspects of the challenge such as vector control or vaccine development.

Mobilization campaign performance with emphasis on local-level impact

Break Dengue had the pleasure to launch our awareness and mobilization campaign live, in Cartagena, **Colombia in front of 600 young leaders** and influencers from Latin America. The **"Don't Let Dengue Break You" awareness campaign** puts an emphasis on the people who went "missing" because of dengue - our friends, family members or colleagues whose lives were disrupted because of the disease.

We followed up with an intense online campaign during the remainder of 2017, focusing on communicating about dengue risk and prevention methods to communities most affected by the disease in **South East Asia, South America and Africa**. The campaign reached almost **6 million people from dengue endemic areas.**

In addition to this, we also worked on bringing Break Dengue to local communities by developing a youth-led outreach campaign in Brazilian communities affected by dengue. Our programme, **"Don't let dengue break Brazil"**, will bring youth leaders from throughout Latin America to São Paulo, Santa Maria and Maringá to work on projects designed to raise awareness and a sense of urgency about dengue, teach dengue prevention techniques and mobilise communities against dengue.

Strategic approach for 2018

Break Dengue's 2018 strategy builds upon the programme's success and continues to develop new opportunities for the programme to make an impact.

By leading impactful projects to fight dengue on the ground, Break Dengue is entering communities affected by dengue, such as those in Brazil. Meanwhile, the programme will continue to foster innovation and drive results with projects that use collective impact to develop and deploy solutions to dengue, such as the eBarometer.

Continuing to strengthen and activate the dengue ecosystem continues to be a key strategic focus of the programme. Break Dengue will engage with our network and inspire them to join the fight against dengue using platforms such as Dengue Lab to build and nurture a sustainable ecosystem that allows diverse groups to connect, share and collaborate.

Break Dengue will also continue to use its well-established editorial and digital platforms to educate and mobilize the general public against dengue. By educating the public on dengue, its risks, and dengue solutions, Break Dengue will communicate the disease burden and build a sense of urgency. Our work aims to activate communities and stakeholders to contribute to dengue prevention.

Finally, Break Dengue's leadership will continue to strengthen the programme's foundation and enabling capacity building. This is accomplished with a strong governance structure, diversified and sustainable funding and cultivating a diverse membership.

Member & Partner testimonials

"…the collaboration Break Dengue facilitated has proved beneficial and has advanced my project's goals…"

Dr. Aileen Chang
Asst. Prof. Of Medicine, George Washington University,
Colombia Dengue Prize Winner

"Collaborative approaches have the greatest potential to make an impact in reducing the burden of dengue worldwide. In this regard, Break Dengue has done a great job at getting involved in basic scientific research, fostering partnerships between academic and private institutions, and reaching out to local health authorities and communities that are affected by dengue. The ability to successfully navigate these often-disconnected ecosystems is the strength of Break Dengue. It has been a great experience to be a member and collaborator of Break Dengue."

Mauricio Santillana
Assistant Professor, Harvard Medical School

The 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

Helena Harnik
Operational Director

Aaron Hoyles
Program Manager

Diana Zaharia
Communications Manager

Roxana Radu
Communications Coordinator

Natalia Sharamandzhieva
Project Coordinator

Gary Finnegan
Chief Editor, Break Dengue

Motherhood Collective
Impact Programme

Motherhood Collective Impact
REPORT

2017 represented an exciting and important milestone for the Safe Motherhood Collective Impact Programme, as we started to be recognised more widely for our work and impact, including plaudits from the president of Malta and the EU Commissioner.

We also put a new streamlined programme structure in place, welcomed a new partner in Safe Motherhood Week - OpenIDEO - who are bringing valuable design-thinking approach to solving maternal health issues, and were recognised as an Ally Organisation by Women Deliver's Deliver for Good programme.

Maternal health is a topic that a huge number of organisations and initiatives address. As our mission is to solve maternal health issues in an agile and efficient way, without duplicating efforts, we have decided to narrow the focus of our programme in 2018 to gaps and opportunity areas where we are sure we will make a rapid positive impact on maternal health. We will centre on the development of a beta version of the **Synapse for Maternal Health**, a global interactive, searchable platform, to identify existing maternal care initiatives and actors to bring together people and projects, match solutions to resources and solve specific needs.

We will also aim to continue working on strategic projects to deliver real solutions that will directly benefit women going through the pregnancy and motherhood experience, and are exploring several exciting opportunities such as developing better guidelines for medication use during pregnancy and breastfeeding so that women and healthcare professionals can make easier, more informed decisions.

Helena Harnik
Programme Director

Achievements 2017

Alliance Matrix for Measuring Healthcare Systems Performance for Maternal Health endorsed by President of Malta and EU Commissioner

The Alliance for Maternal Health Equality reached an important milestone in 2017 at the Women in Parliaments Global Forum (WIP) Meeting in Malta on Maternal Health and Refugee Women.

Continuing the work we did at the Women Deliver meeting in 2016, and then again within the context of the European Health Gastein Forum, the Alliance presented its Matrix for maternal health assessment and its 5 dimensions: person-centric approach; timeliness and accessibility, equitability; resilience and efficiency; safety, quality and standards. The Matrix's five dimensions and indicators were firmly endorsed by Vytenis Andriukaitis, EU Commissioner for Health and Food Safety, and also the President of Malta H.E. Marie-Louise Coleiro Preca.

Importantly, this endorsement represents a firm acknowledgment of the need for a structured approach to tackling the problem of maternal health equality and helping move policy forward, and was a major opportunity to highlight our work with policy makers.

Safe Motherhood Week 2017

Safe Motherhood Week is an annual event supported by year-long activities and ongoing communications.

The third edition of Safe Motherhood Week (October 2-8) brought together new partners and supporters of the programme and marked the launch of the global #MakeMotherhoodCount initiative.

This year, we furthermore succeeded in:

- Consolidating our online presence
- Launching the Safe Motherhood Week Instagram account
- Conducting a new series of interviews with high-level maternal care ambassadors and luminaries:
    1. Dr Flavia Bustreo (Assistant Director-General for Family, Women's and Children's Health (WHO): "Maternal mortality is a key indicator of a health system's strength"
    2. Dr Julie Gerberding (infectious disease expert and the former director of the U.S. Centers for Disease Control and Prevention (CDC) and administrator of the Agency for Toxic Substances and Disease Registry (ATSDR)): "People don't know that mothers die giving birth in Ireland or other Western European countries"
    3. SocialGoodMoms (a network of +3000 mother bloggers who currently span twenty countries) "Europe is tackling its own maternal health issues. Here's why. #MakeMotherhoodCount"
    4. Launching the "#OneThing" campaign around improving universal access to maternal health on International Women's Day, receiving fantastic support from international platforms such as TEDxWomen and Microsoft Global Health .

European Maternal Health Policy Landscape Analysis

Maternal health goes beyond health itself. When focusing on the issue we must avoid thinking in silos and take a holistic view, considering the broader picture (education, vulnerable groups, chronic conditions, quality of life, social determinants).

There are regulations, declarations, rights, laws, strategies and a myriad of scientific evidence on this topic. But what is lacking is a systematic approach and translating discussions and policy drafts into action.

Over the past year, together with our partners and members of the Alliance for Maternal Health Equality, we have increasingly identified the need for an integrated EU-National policy approach in all our activities. With this in mind, during 2017 we worked to identify the gaps in policy across countries, by conducting a first maternal health landscape analysis from a policy perspective, to enable us to build a programme that responds to concrete needs of maternal health systems in Europe.

Our pro bono partner White & Case successfully delivered the first part of the analysis which focuses on the rights of women to receive maternal (pre-pregnancy, prenatal, and postnatal) healthcare within the European Union and the corresponding requirements imposed on EU Member States to provide maternal healthcare, resulting from EU law and the European Convention on Human Rights (“ECHR”). White & Case is a global law firm and a signatory to the UN Global Compact, the world’s largest voluntary corporate sustainability initiative.

The Phase I analysis will be used to measure the extent to which Member States comply with their EU and ECHR law Matrix pillar obligations, and will provide a framework to analyse the extent to which the Matrix pillars are provided for under the law of these Member States.

Together, Phases I (EU & ECHR Legal Analysis) and II (Specific Country Legal Analysis) will provide the legal landscape in respect of maternal health in the Member States selected. The research conducted will provide data for the social science and policy analysis that will be performed in Phase III of the project (Best Practices for wider replication).

First steps towards a robust policy roadmap and strategy at the maternal rights and health policy roundtable

As part of the Alliance for Maternal Health Equality's contribution to Safe Motherhood Awareness Week 2017, the Alliance members and select guests came together in Brussels, Belgium to present, exchange on and unite our respective activities and learnings towards co-creating a shared policy roadmap for the Alliance.

Alliance members EPF (European Parliamentary Forum on Population & Development), UNFPA (United Nations Population Fund) and IOM (International Organisation for Migration) were joined around the table by Doctors of the World, White & Case and Hill & Knowlton. Fatema Das, from Maastricht University and representing MSD for Mothers, presented highlights from her thesis, Barriers, Policy Implications, and Quantification of Access to Antenatal care for Vulnerable Women in Europe.

This was followed by a presentation of research findings for the first phase of a European Maternal Health Policy Landscape analysis (EU & ECHR Legal Analysis) by Irina Trichkovska and Pierre Pecheux of White & Case, who presented their study of existing legal entitlements and rights for women in Europe around maternal health, and several different possible policy approaches that the Alliance could pursue. Finally, Thomas Tindemans, Chairman of Hill+Knowlton shared some first reflections on how to turn advocacy into policy impact. As a conclusion to this meeting, Members agreed to find a common ground and crystallize this into a policy ask with 2-3 priorities that we seek. Once priorities have been redefined by the Alliance, White & Case will determine the appropriate next step for their study, and Hill+Knowlton will participate in defining how we can turn the policy ask into reality and where we can make the biggest impact.

Strategic approach for 2018

Motherhood Collective Impact - Leading co-impact for better systems to solve maternal health issues

In 2017 we brought all our motherhood activities under one strategic programme called Motherhood Collective Impact (MCI). MCI is a not-for-profit partnership that aims to address the most challenging issues in maternal health by taking a novel, co-impact and systems-based approach. The Motherhood Collective Impact programme aims to accelerate co-impact in maternal health by bringing all actors together within an interconnected ecosystem, facilitating collaboration, creating and matching solutions with resources to bring these solutions to life more quickly.

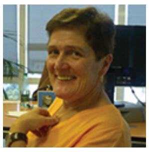
In 2018 we will continue to achieve our mission through six priority areas:

1. Reinforce a robust and agile leadership structure
2. Visualise and grow the maternal health "ecosystem" of stakeholders and initiatives to facilitate diverse collaboration across organisation types, topics and geographies
3. Promote culture change and increase demand for better maternal care through advocacy and awareness campaigns
4. Make policy impact
5. Generate compelling real world evidence that maternal care is still an unfinished agenda
6. Deliver real solutions for women

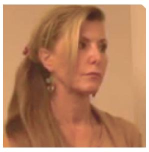
Membership & Partners

The Motherhood Collective Impact Program Team

The Motherhood Collective Impact Board consists of:


Bernadette Hendrickx
Senior Scientific Adviser


Lode Dewulf
Senior Adviser


Roumyana Petrova -Benedict
IOM Senior Regional Migration Health
Manager For Europe And Central Asia


Neil Datta
Executive Director At EPF


Irene Donadio
Advocacy Officer At IPPF


Dr France Donnay
Consultant, Women's Health,
Bill & Melinda Gates Foundation

The Motherhood Collective Impact Team consists of:


Nicholas Brooke
Executive Director


Helena Harnik
Operational Director


Diana Zaharia
Communications Manager


Danielle Barron
Chief Editor, Motherhood
Projects

Building our co-impact portfolio by joining public-private partnerships

2017 brought new opportunities for our team to bring The Synergist's skills and expertise to two European public private partnerships, Share4Rare and IMI PARADIGM, both of which will accelerate progress towards a better patient experience through systemic innovation.

Our involvement in these partnerships represent a slightly different role for us as a catalyst. We were invited to bring meaningful engagement, co-creation and agility to large consortiums, both of which aim to improve patient outcomes and experience in a digital age. Additionally, we bring important expertise in "collaborative leadership" and engagement strategies with stakeholders and end-users. For The Synergist, this is an opportunity to complement and diversify participation on our projects, reach new spheres and environments, and most importantly increase our overall impact and refine our co-impact model.

We feel incredibly privileged to be involved and we are dedicated to delivering impact.

Nicholas Brooke
The Synergist CEO

Share4Rare

Project and partners description

Share4Rare is a new collective awareness platform for patients, caregivers, researchers and other stakeholders involved in the growing health challenge of Rare Diseases. Based on a socially innovative approach and building on citizen science and collective intelligence, the platform will engage and connect all relevant stakeholders. The purpose? To improve the quality of life, the disease management and the collection of scientific knowledge and data on rare diseases. The platform will integrate three important pillars: Education, Sharing and Research.

The project will pilot the platform in two groups of pediatric rare diseases: neuromuscular disorders and rare tumors, but will eventually expand to other rare disease as well.

Project objectives

- To co-design and incubate a collaboration-friendly, sustainable and scalable ecosystem for the rare disease community
- To increase awareness about the specificities of rare diseases at the European level and improve social recognition
- To enhance and gather exchanges of experience between patients, researchers and general practitioners in the field of rare diseases
- To reduce the isolation between patients and families, and between general practitioners and researchers, caused by the limited number of patients that can exist in one country
- To develop registries where patients, researchers and general practitioners can contribute, use and re-use patient reported or clinical data for the benefit of the rare diseases community

The Synergist role

The Synergist will bring its co-creation expertise to this project and help develop and formalise a robust governance to foster collaboration and co-creation with the end user.

Moreover, The Synergist will bring its expertise in developing digital tools for societal change by:
- Organizing three co-development workshops where the end users will be able to co-create the platform, its principles and functionality.
- Implementing a robust captology plan, to attract and retain users on the platform. This will be done using best-in-class communication efforts for user acquisition, as well as a collaboration model involving other partners to increase conversion and user uptake.

IMI PARADIGM

Project and partners description

We are pleased that PARADIGM (Patients Active in Research and Dialogues for an Improved Generation of Medicine) has been approved for the EU-funded Innovative Medicines Initiative, which funds health research and innovation in Europe. PARADIGM will provide a unique framework that enables structured, effective, meaningful, ethical, innovative, and sustainable patient engagement (PE) and demonstrates the 'return on the engagement' for all players.

This 30-month project aims to tackle the fragmented landscape in patient engagement (PE) by co-creating tools to systematise how we do PE. The project will focus specifically on three decision-making points:
1) research priority setting;
2) design of clinical trials; and
3) early dialogues with regulators and HTA bodies.

Project objectives

PARADIGM's approach will ensure maximum synergies with other PE initiatives and relevant international players in the field to share, stimulate buy-in and acceptance. PFMD supports the mission by an innovative collaborative approach that not only gives input during the project scope, but also provides an avenue of dissemination for the project outputs, which increases their sustainability and adoption-rate.

PARADIGM's objectives are to
- Increase the understanding of **stakeholders' needs**, preferences and expectations (taking into account also the underrepresented and vulnerable populations),
- Develop metrics with validated tools to demonstrate the impact of PE practices
- Strengthen systems-readiness towards PE, to enable the dissemination and adoption of practices through concrete and workable solutions and recommendations on capabilities, processes and rules of engagement
- Develop a sustainability roadmap to optimise PE at key decision-making points, demonstrating the inherent link between patient education, patient engagement and truly valuable innovation

The Synergist role

The Synergist has a major role in this 30-month project that commences in March 2018. Our participation in PARADIGM can be seen as a natural extension for PFMD. We will bring our expertise in fostering global alliances through an organised, collaborative and neutral environment that enhances co-creation with a shared purpose and collaborative leadership. Together with our agile approach and expertise in impactful digital communication, we will support PARADIGM's objectives to deliver the much needed framework and tools for PE. This will in turn feed back to PFMD SYNaPsE, strengthening PFMD's mission to achieve systematically implemented PE across all stakeholders, in all phases of medicines development.

www. TheSynergist.org