



PATIENT FOCUSED  
MEDICINES DEVELOPMENT



# **SYNaPsE** SYNergising Patient Engagement

Patient Engagement Global Landscape Mapping,  
Resources and Networking Tool developed by  
Patient Focused Medicines Development  
(PFMD: [PENetwork.org](http://PENetwork.org))

# Building a collaborative ecosystem for patient engagement

## Introduction

There is growing consensus amongst health stakeholders that meaningful patient engagement (PE) is key to improving drug development and providing solutions that achieve both clinical and patient-desired outcomes. Consequently, there is an encouraging and increasing number of PE initiatives that aim to integrate the patient voice in medicines development specifically, and in the healthcare arena generally. What is required is a consistent approach and a meta-framework for PE. A recent survey across stakeholder groups ([Boudes M, et al. Value in Health 2017;20\(9\): A653](#); [Boudes M, et al. Health Expectations. 2018;1-11](#)) highlights the need to bring together the many components and valuable efforts already in existence, leveraging multi-stakeholder collaboration to address gaps, to co-create a framework and guidance for PE based on experience, learnings and consensus on good practice. This work is ongoing and an update on progress and next steps has been reported ([A dedicated team, one objective: better patient engagement](#)). Of note, a co-created [PE Quality Guidance \(PEQG\)](#) tool relevant to all stakeholders engaged in PE across all stages of medicines life-cycle is now available for use.

Despite the substantial increase in PE initiatives, until now there has been no efficient mechanism for accessing information on what PE activities are ongoing or planned and to identify challenges encountered and lessons learned. A previous White Paper “[Collaborative Patient Engagement: Mapping the Global Landscape](#)”, published by Patient Focused Medicines Development (PFMD; [www.pfmd.org](#)<sup>1</sup>) in 2016, described our vision for a tool that would connect disparate but complementary PE efforts. Here we provide an update on delivery of that vision through SYNAPsE, a PE global landscape mapping, resources and networking tool. We also describe ongoing enhancements to SYNAPsE to make it a comprehensive Patient Engagement Management Suite linking PE activity with co-created [PE quality guidance, quality criteria](#) and actionable [examples of good practice](#). It is an integral part of a larger endeavour to build a connected and global PE ecosystem – a connection that is an essential step in co-creation of a meta-framework to deliver more integrated PE.

## SYNaPsE from vision to reality

SYNaPsE is an online, dynamic user-populated platform that categorizes and ‘maps’ existing initiatives, people, organizations and frameworks to provide a global overview of the PE landscape and a ‘Who’s Who’ of PE. Importantly, the platform provides a means of gathering and analysing data where there may be no documentation publicly available. A key feature of SYNAPsE is that information about each initiative is entered by those directly involved – rather than relying on desk research alone – providing granularity and a greater opportunity to understand PE efforts, including their successes and limitations.

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<sup>1</sup>Established in 2015, Patient Focused Medicines Development (PFMD) is an independent global coalition that aims to improve global health by co-designing the future of healthcare for patients WITH patients. PFMD has from inception been formed as an equal collaboration among its members which includes patient groups, patients, the pharmaceutical industry and regulators. PFMD brings together initiatives and good practices that integrate the voice of the patient throughout the lifecycle of medicines. The aim is to drive the co-creation and implementation of an effective, globally standardized meta-framework for PE to embed patients’ needs and priorities at the heart of medicines development.

SYNaPsE was developed in a step-wise approach. It is continuously reviewed and refined based on user needs and feedback to incorporate updates and requested features. Early population of SYNaPsE was based on: incorporation of known PE initiatives; an extensive literature search covering formal and non-formal publications, journal articles, conference proceedings and reports, and personal communication; and in-depth interviews with stakeholders identified as having developed or delivered PE activities, or providing guidance on partnering with patients. Preliminary data was validated by cross-checking content with organisations involved in each activity. SYNaPsE was then further developed into an active tool to allow user-population and capture of quality data using predefined standards. This provides consistency in depiction and ensures that the information collected across various initiatives is credible, consistent and up to date.

## SYNaPsE structure and products

SYNaPsE incorporates **4 integrated products**: a search engine to explore the global PE initiatives landscape; an experts' network to identify and showcase experience and connect with others active in PE; an organisation repository to discover what other organisations are doing; and a resource library (**Figure 1**). Currently (as of 13 June 2018), SYNaPsE includes **233 initiatives**, **219 organisations**, **961 experts** and **75 associated resources**.

**Figure 1: SYNaPsE structure and products**



# Searching in SYNaPsE

Using the search functionality, users can find initiatives, experts, organisation and resources most relevant for their planned or ongoing PE activities. Meta-tags and toggle filters allow users to conduct general searches, for example using the search term ‘technology assessment’ within the initiatives section will identify all initiatives that focus or incorporate that term. Advanced search with filters can be used to generate more specific results (**Table 1**). Advanced search filters can also be used within the organisations and experts section to specify type of organisation and geography. Search result items have accompanying interactive icons that represent individual subcategories – this provides a visual overview for each result. The [resource library](#) is also searchable and contains documents related to specific initiatives or relevant to general PE.

**Table 1: Searching for initiatives in SYNaPsE**

Filter	Use to specify subcategories
<b>Geography</b>	Global; regional; national; continent; country
<b>Primary focus</b>	Research; education; organisation/system development; access; policy; care delivery; gap analysis
<b>Stage in medicine lifecycle</b>	Pre-discovery; preclinical; clinical; regulatory review and approval; post approval surveillance; evidence communication
<b>Patient expertise</b>	Newly-diagnosed non-expert patient; in treatment non-expert patient; completed treatment non-expert patient; patient advocate affiliated with an organization; patient expert not affiliated with an advocacy organization; caregiver; other
<b>Patient experience</b>	Prevention; newly diagnosed; treatment; clinical trial; long-term management; other
<b>Timeline</b>	Date entered by user
<b>Type of initiative</b>	Involving patients in PE; providing guidance for PE
<b>Type of organisation</b>	Patient advocacy; academic medical centre/hospital/practice; pharmaceutical, biotech, medical device company; regulatory body; private-public partnership; think-tank; insurance company; government; start up; other
<b>Patient partnership</b>	Inform; consult; involve; co-design
<b>Medical scope</b>	Disease area specific; therapeutic area specific; more than 1 therapeutic area; across all conditions

# Reports and analysis

Two types of reports are available in SYNaPsE: automatically generated reports that are available to all and include all the initiatives within SYNaPsE, and tailored reports available to registered users. Automatically-generated public reports provide a comprehensive overview of the PE landscape. These reports include landscape radar maps which have been developed to depict the global PE landscape through different perspectives. This allows users to view the landscape according to their interest and by: [geographical region](#); [medical scope](#); [timeline](#); [patient matrix](#); and [medicine lifecycle](#). Each data point in the maps is interactive, allowing the user to view a summary of all initiatives and/or to drill down to see full details of specific initiatives within the data point. The range of reports available and a description of each radar map is summarised in **Table 2**.

**Table 2: SYNaPsE public reports**

Global report description	Radar map example																																								
<p><b>Geographical region</b> Provides a snapshot of the landscape based on geographical location. The analysis includes breakdowns at local and regional level, as well as an overview taking into consideration the primary focus of the initiative.</p>	<p><b>Initiatives Repartition by Focus and Geo</b></p> <table border="1"> <thead> <tr> <th>Geographic Scope</th> <th>Research</th> <th>Education</th> <th>Organization / System Development</th> <th>Access</th> <th>Policy</th> <th>Care Delivery</th> <th>Gap analysis</th> </tr> </thead> <tbody> <tr> <td>Global (worldwide coverage)</td> <td>18</td> <td>7</td> <td>8</td> <td>4</td> <td>1</td> <td>1</td> <td>1</td> </tr> <tr> <td>Regional (Not country-specific)</td> <td>18</td> <td>3</td> <td>9</td> <td>0</td> <td>0</td> <td>0</td> <td>1</td> </tr> <tr> <td>National (country-specific)</td> <td>9</td> <td>6</td> <td>0</td> <td>0</td> <td>0</td> <td>0</td> <td>2</td> </tr> </tbody> </table> <p><small>Based on 87 initiatives that completed the updated questionnaire.</small></p> <p><b>65 national initiatives</b></p> <p><small>Depiction of number of initiatives by national geographic scope</small></p>	Geographic Scope	Research	Education	Organization / System Development	Access	Policy	Care Delivery	Gap analysis	Global (worldwide coverage)	18	7	8	4	1	1	1	Regional (Not country-specific)	18	3	9	0	0	0	1	National (country-specific)	9	6	0	0	0	0	2								
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**Timeline**

Provides a snapshot of the landscape based on the maturity range of the initiatives, as well as their primary focus.

**Maturity range by primary focus**



Based on 125 initiatives that completed first version of the questionnaire.

Switch v1 v2

**Maturity timeline**



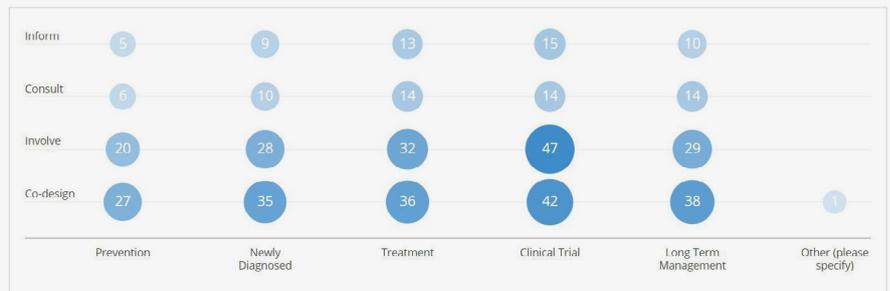
**Patient matrix**

There are different types of patients partnering in the research to care continuum and variations in skills or expertise can affect the level of patient involvement. Understanding and mapping this patient diversity can allow us to capture trends, identify gaps, and define good practices. The Patient Expertise Matrix categorizes each initiative by type of patient involved and the associated level of involvement or partnership. The Patient Experience Lifecycle Matrix has been developed to map initiatives based on phase across the care journey, type of patient involvement, and sector.

**Patient Expertise**



**Patient Experience**



**Medicine lifecycle**

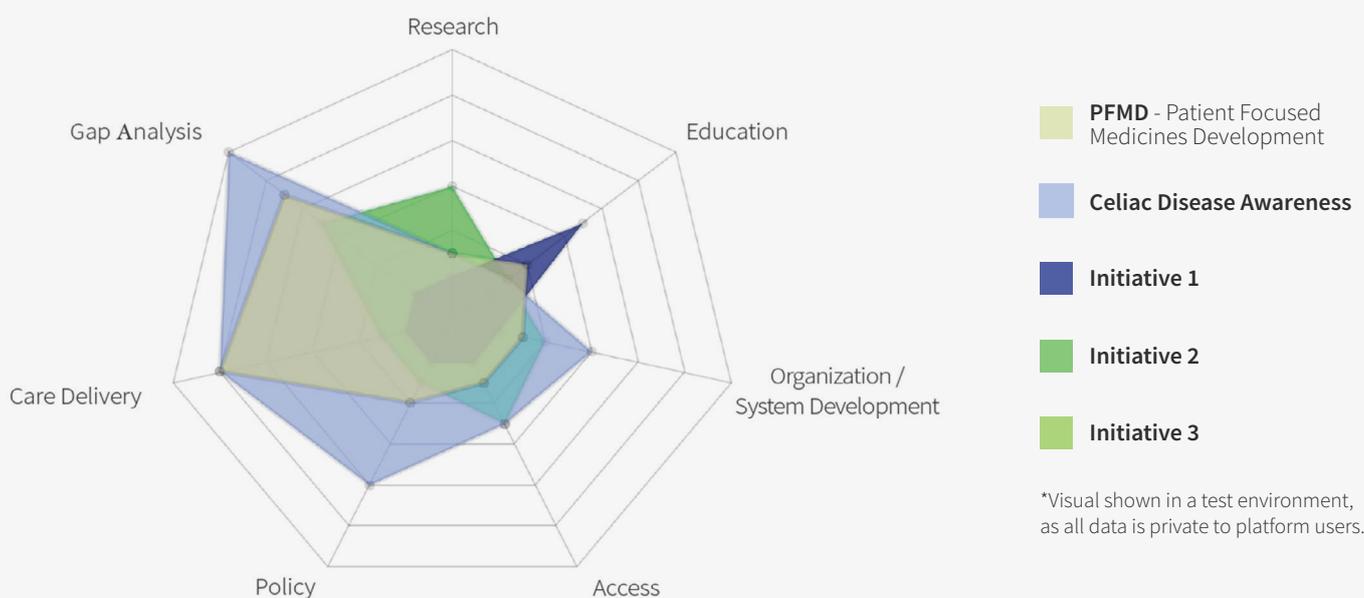
Some initiatives are aligned with a particular phase in the medicine lifecycle, such as drug discovery or clinical trials, while others span several phases. The Partnership by Medicines Lifecycle Matrix maps the levels of involvement or partnership against the corresponding phase (or phases) of the medicine lifecycle.

**Partnership by Medicine lifecycle**



All users are encouraged to register and enter their own PE initiatives, resources and expert profile on SYNAPSE to make the PE platform as comprehensive as possible. Registered users have access to unique reports with visual mapping snapshots that show where each of their initiatives ‘fits’ within the PE landscape. Reports can also be analysed to identify areas of strength and areas for improvement of PE efforts overall, and to assess projects on an individual basis. Addition of a Key Performance Indicator (KPI) analysis function is planned which will provide the user with another way of evaluating their PE activities. Registered user reports are not publicly shared – only the registered user has access to the data within the report. An example visual is shown in **Figure 2**.

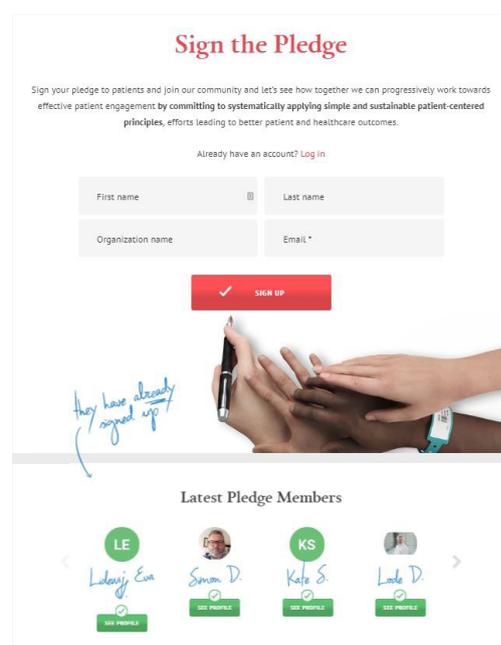
**Figure 2: Example visual from a registered user report**



## Uniting individuals as the backbone of the PE ecosystem

SYNaPsE incorporates [Pledge to Patients](#), a community effort for cultural change. The individual Pledge to Patients unites the PE community through a personal commitment to (1) listen, (2) co-create and (3) communicate with patients (**Figure 3**). Pledge to Patients is a personal promise to make the small changes that add up to a real cultural shift, and has been designed to be simple, meaningful and shareable to inspire others to participate. All Pledge takers automatically have a profile generated for them in SYNAPSE, where they can include additional commitments or share results from ongoing or completed commitments with the community. To date, over **736 Pledges** have been taken and are shared in SYNAPSE. These provide practical and motivating examples of personal, specific, and measurable commitments to the three guiding principles of the Pledge.

**Figure 3: Making a Pledge to Patients**



## Technical details and data privacy

SYNaPsE uses the Symfony framework, MySQL for database management and RabbitMQ as a common platform for messaging between the application components. The search engine is based on Elasticsearch - allowing the user to perform and combine various types of structured and unstructured searches. Ensuring privacy of user-entered information has been an integral and critical element in the design of SYNaPsE.

Users can specify exactly what will be visible, where and when. For example, 'Experts' can choose to be public or private (and can make the same choice for any initiatives they enter onto the system) or even restrict their profile so that only members of their organization can access it. The same user-specified sharing rights apply to organization profiles with the option to invite, add, remove and ignore users and requests to join the organization, as well as full control of the organizations' initiatives and resources.

Organization owners of initiatives can make them available to other organizations (or individual Experts) and decide the level of access or permissions to allow (such as View, Edit) and the role (such as Owner, Partner, Author) in each case. SYNaPsE has been designed to be a fast and agile platform that can be regularly updated to reflect user feedback and requests. It has also been designed to meet the internal and external needs of users for an online platform that facilitates review, alignment and collaboration on PE activities.

## From Mapping and Networking to Patient Engagement Management (PEM)

Since launching in May 2017, SYNaPsE has attracted wide interest and participation from diverse stakeholders. The vision for a uniting online platform for PE has been achieved but the work to encourage all PE 'activists' to get on the PE map and connect with others to foster a PE ecosystem continues. We will also continue to seek user feedback to refine existing functionality and develop new features.

Ongoing enhancements include features to manage relationships with other stakeholders and advanced reports about user's organization activities. Completing the Patient Engagement Management Suite, the co-created Patient Engagement Quality Guidance, Quality Criteria and examples of good practice will be incorporated into SYNaPsE, allowing optimal design of future PE activities and assessment of ongoing or completed ones. SYNaPsE is well placed to become a comprehensive hub for global PE efforts.

# Appendix

## PFMD Membership

PFMD seeks to have a balanced representation of stakeholders to ensure transparency, inclusiveness, diversity and credibility. PFMD welcomes membership from institutions, organizations and enterprises that support a better future for patients.



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Medicine



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MSD

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of Johnson & Johnson

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Sickness  
Support

NOVARTIS

# PFMD Governance

From inception, PFMD has been formed as an equal collaboration among patient groups, patients and pharmaceutical industry. The governance model adopted by PFMD ensures equality and drives collaboration.

