



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)

made with patients

Connecting the patient engagement community across the medicines lifecycle

Health stakeholders agree that meaningful patient engagement (PE) is key to improving drug development and providing solutions that achieve both clinical and patient-desired outcomes. As a result, 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.

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. Connecting the PE community is an essential step towards more meaningful and integrated PE. SYNaPsE is an on-line, 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.

SYNaPsE is a PE global landscape mapping, resources and networking tool that has been developed by Patient Focused Medicines Development (PFMD; www.pfmd.org) as an integral part of a larger effort to build a connected and global PE ecosystem.

SYNaPsE has been developed to gather 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 a greater opportunity to understand PE efforts, including their successes and limitations.

SYNaPsE captures quality data using pre-defined standards to allow for consistency in depiction and to ensure that the information collected across various initiatives is credible, consistent and up to date.

PE initiatives organizations and experts from around the world incorporated into 4 products to deliver better PE



SYNaPsE incorporates 4 integrated products: a search engine to explore the global patient engagement initiatives scene, an experts' network to showcase your experience and connect with others active in PE, an organisation repository to discover what other organisations are doing in the PE field and a resource library.



210 INITIATIVES



749 USERS



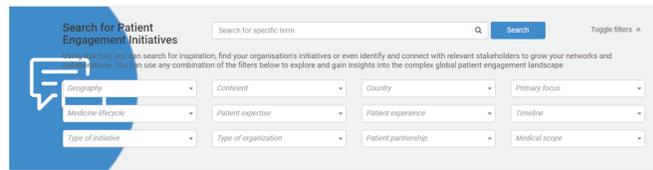
196 ORGANIZATIONS



26 RESOURCES

SYNaPsE: search for PE initiatives, organisations, experts and resources

Using SYNaPsE, you can search for inspiration, find your organisation's initiatives or even identify and connect with relevant stakeholders to grow your networks and collaborations. You can use any combination of intuitive filters to explore and gain insights into the complex global PE landscape.



You can also find organisations and experts active in PE using specific terms or filters to find organisations by type or geographical location. The resource library is home to documents related to specific initiatives or relevant to general PE.

SYNaPsE: reports and analysis

SYNaPsE has automatically generated public reports that provide a comprehensive overview of the PE landscape. The reports include landscape radar maps which have been developed to depict the global PE landscape through different perspectives. The range of reports available is summarised in Figure 1.

Figure 1: SYNaPsE public reports

Global geographical

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.



Global medical scope

Provides a snapshot of the landscape based on medical scope - the medical condition focused on.



Global timeline

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



Global 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.

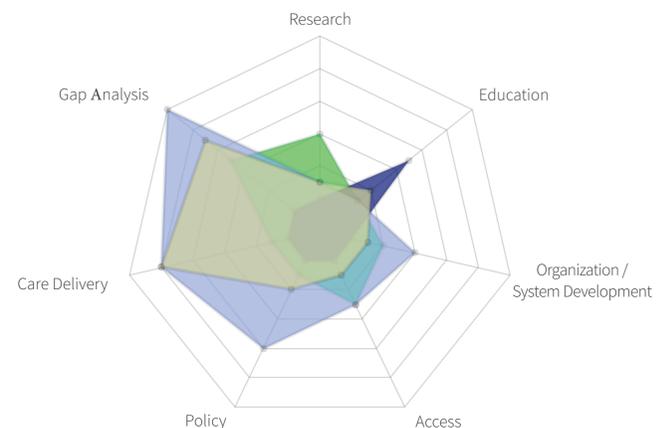


Global medicine lifecycle

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 Patient Engagement and Medicines Lifecycle Matrix maps the levels of involvement or partnership against the corresponding phase (or phases) of the medicine lifecycle.



Registered users have access to unique reports with visual mapping snapshots that show where each of their initiatives 'fits' in the PE landscape. Reports can be analysed to identify areas of strength and areas for improvement of PE efforts overall, and to assess projects on an individual basis.



Legend: PFMD - Patient Focused Medicines Development, Celiac Disease Awareness, Initiative 1, Initiative 2, Initiative 3. *Visual shown in a test environment, as all data is private to platform users.

Almost 200 organisations already feature on SYNaPsE which is continuously reviewed and refined based on user feedback to incorporate updates and new features.



SYNaPsE is an integral part of a larger effort to build a connected and global PE ecosystem

SYNaPsE incorporates Pledge to Patients, a community effort for cultural change. The individual Pledge to Patients unites the whole PE community under a common objective – a personal commitment to work WITH patients, FOR patients. Pledge to Patients is a personal promise to make the small changes that add up to a real cultural shift. It has been designed to be simple, meaningful and shareable to inspire anyone committed to effective and collaborative PE.



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. Our mission is to bring together initiatives and good practices that integrate the voice of the patient throughout the lifecycle of medicines. We aim 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. Find out more at PFMD.org.



SYNaPsE Get on the PE landscape map



Make your Pledge to Patients



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