

Health stakeholders urged to ‘get on the map’ as on-line collection tool to capture global patient engagement goes live

Health stakeholders are being urged to ‘get on the map’ using an on-line collection tool which goes live today (**Sunday 26 June**) and is designed to capture key information from patient engagement (PE) initiatives across the globe.

Data collected through the tool will be used to produce a series of overview ‘maps’ of the PE landscape in the lifecycle of medicines development that will portray the global PE landscape through various perspectives to make them meaningful to diverse stakeholders. The maps will provide a searchable and dynamic ‘who’s who’ of PE (more details and map visuals available from <http://www.diaglobal.org/en/resources/publications/whitepapers/patient-focused-medicine>).

The tool has been developed by Patient Focused Medicines Development (PFMD - www.pfmd.org) – a multinational coalition that aims to embed patients as active partners in the design and development of research and medicines. The collection and mapping initiative is being launched as health stakeholders gather at the DIA 2016 Annual Meeting in Philadelphia.

A unique report with visual mapping snapshots will be generated for each organisation or user that enters data. The report will show where their initiative ‘fits’ in the landscape according to a range of factors including focus area, therapeutic area, geographic scope, degree or spectrum of patient involvement, and level of patient expertise. A key feature of the tool is that information about each initiative will be 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.

Much information on PE is not routinely published but instead is shared in meetings and discussions. As a result, there is a need for a pro-active collection process to gather data where there may be no documentation publicly available. “This is why the new online collection tool has been developed. It will capture quality data using pre-defined standards to allow for consistency in depiction and will also help to ensure that the information collected across various initiatives is credible, consistent, and up to date,” said Nicholas Brooke, PFMD Chief Executive.

“Our end goal is to develop an efficient, measurable and reliable meta-framework for PE that involves patients as partners. But this cannot be achieved without knowing, understanding and learning from the many initiatives that already exist – this is what the mapping project has been designed to achieve. We urge everyone committed to more effective and meaningful PE to access the collection tool and enter their data to make sure their initiatives get on the map,” said Brooke.

For further information

Contact Nicholas Brooke, PFMD Chief Executive (nicholas.brooke@thesynergist.org; mobile +32 (0)2 318 53 64 or visit www.PFMD.org (Interviews can also be arranged)

Notes for editors

- The online collection tool developed by Patient Focused Medicines Development (PFMD) is now open for users and organisations to enter their data and can be accessed at:
<https://involvement-mapping.patientfocusedmedicine.org/register/>
- The collection tool and mapping initiative are described in detail in the PFMD White Paper *“Collaborative Patient Engagement: Mapping the Global Landscape – A first step in co-creating an action-orientated framework for patient engagement”* published on April 26, 2016 and available in the DIA White Paper Library at:
<http://www.diaglobal.org/en/resources/publications/whitepapers/patient-focused-medicine>
- The PFMD group, established in 2015, is an open, independent multinational coalition based on expertise and commitment to develop and drive implementation of PE. It is a non-profit collaboration whose activities are funded by member organizations.
- PFMD is a truly global partnership and a collaborative platform that synergizes efforts to integrate the voice of the patient across the lifecycle of medicines development. Its vision is to improve global health by co-designing the future of health care for patients with patients. PFMD aims to transform the way in which health ecosystem stakeholders understand, engage, and partner with patients globally in the design and development of research and medicines by focusing on unmet patient needs.
- PFMD has developed an organic and inclusive partnership strategy that encourages evaluation and feedback, review and ongoing refinement of their work towards a meta-framework for patient engagement. Visit www.PFMD.org for more information about PFMD.
- The DIA 2016 Annual Meeting takes place from June 26–30, 2016 in Philadelphia and is the largest global interdisciplinary gathering of life sciences professionals (<http://www.diaglobal.org/flagship/dia-2016>).