BACKGROUND

- The value and necessity of engaging patients during the development and lifecycle of medicines is increasingly recognised, and many don’t initiatives are underway or planned.
- Though complementary, these separate activities have resulted in a fragmented patient engagement (PE) landscape. This activity plan is intended to enable systematic, continuous development and implementation of a multi-stakeholder framework for PE, providing direction and guidance for stakeholders, researchers, funders, pharmaceutical companies. 

METHODS

PE Quality Guidance co-creation

- Multi-stakeholder working groups (WSG) and task-forces (TF) were established for Guidance co-creation. Published literature and existing frameworks were reviewed (2011-2017) and a PE mapping and networking platform developed by PFMD was used to identify and build upon existing WSGs and task-forces.

A preliminary PE Quality Guidance tool incorporating PE Quality Guidance was developed by PFMD in an iterative process, through review of published material and landscape analysis to identify current needs, incorporation of participants’ PE experience, identification and prioritise needed actions, and owners retrospectively applying the draft Guidance to their experience as a pressure testing evaluation (Figure 1).

Results: PE Quality Guidance Co-Creation

- Nine WSG/TF Core meetings were held (Nov 2016-June 2018) involving 51 unique participants, representing 35 organisations (including patient leaders, academic researchers, funders, pharmaceutical companies).
- Using the PFMD PE Excellence framework for project development and implementation.

RESULTS: MAPPING AND CONNECTING THE PE LANDSCAPE

- Articles were published on the impact of the period of 2011-2017 PE relevant search criteria (in PubMed and British Medical Journal Open), of which 25 were relevant, and somewhat relevant. An additional 20 resources (including seven case-study frameworks/mooc’s) were included to capture approaches outside of the search.

Multi-stakeholder co-creation of PE Quality Guidance

- WSG/TFs adapted a coherent and connected lens from the literature on PE guidance and frameworks developed by INVOLVE and enriched with the analysis of WSG initiatives collected during the project.

Structure of the PE Quality Guidance

- The PE Quality Guidance is structured to be used either as an aid to planning new PE projects, or to facilitate assessment of ongoing or completed PE projects. It incorporates four components to capture basic background information, quality of PE, outcomes and lessons learned.

- The PE Quality Guidance presents seven PE Quality Criteria (Table 1) to aid assessment of the quality of PE in specific projects.
- The PE Quality Guidance describes how a good PE practice should consider including in its processes, provide a set of principles to improve consistency in PE practice, and enable systematic assessment and communication of project outcomes.

- For each criterion, there is a definition, a rationale and questions for consideration and prioritisation.

Identification of good practice examples for the Book of Good Practice (BGP)

- Examples of good practice were collected through screening of initiatives in PFMD and via TF and PFMD networks. The review and selection process for inclusion in the BGP was anonymous to avoid bias and was undertaken by a multi-stakeholder PE Meta-Framework Core Team.

RESULTS: RESULTS: RESULTS: RESULTS: PUBLIC CONSULTATION ON DRAFT PE QUALITY GUIDANCE

- A public online, survey-based consultation on the draft PE Quality Guidance was undertaken from 20 November 2017 to 1 January 2018. To gather wider input from a broad range of stakeholders.

- Consultation was invited via the PFMD website and across stakeholder groups via WG, TF and PFMD networks; and through advertising (235,889 reach, media 462,991 reach) and a social media campaign. Feedback from the public consultation and from a separate focus group was used to refine the final PE Quality Guidance.

Identification of good practice examples for the Book of Good Practice (BGP)

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Table 1: Overview of the PE Quality Guidance

<table>
<thead>
<tr>
<th>PE Quality Guidance</th>
<th>Description</th>
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<tbody>
<tr>
<td>1. Shared purpose</td>
<td>Identify and agree on the project’s purpose and outcomes that all stakeholders support and agree on, ensuring meaningful engagement of stakeholders and keeping projects on track.</td>
</tr>
<tr>
<td>2. Respect and responsibility</td>
<td>Ensure that the project is conducted with respect and responsibility, including in its processes; provide a set of principles to improve consistency in PE practice, and enable systematic assessment and communication of project outcomes.</td>
</tr>
<tr>
<td>3. Implementation and sustainability</td>
<td>Ensure that the project is realistic, feasible, and achievable.</td>
</tr>
<tr>
<td>4. Transparency in communication, project management and governance</td>
<td>Ensure that the project is communicated, managed and governed with transparency, involving different stakeholders with different needs in transparent and impactful ways, ensuring different stakeholders are treated differently and therefore the project can be made more accessible for those with different needs.</td>
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Table 2: Using the PE Quality Guidance tool - step-by-step

<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Section 1: Basic Information</td>
<td>Describe which stakeholders the project involves</td>
</tr>
<tr>
<td>Section 2: Quality of PE</td>
<td>Systematically ‘walk through’ each project, identifying and detailing specific tactics or approaches to achieve project aims</td>
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<tr>
<td>Section 3: Results and outcomes</td>
<td>Capture expected or desired outcomes for planned projects</td>
</tr>
<tr>
<td>Section 4: Lessons learned</td>
<td>Capture actual results and details of methods used to collect for planning or ongoing projects</td>
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CONCLUSIONS

- The co-created PE Quality Guidance tool can be used by multiple stakeholder groups and provides a practical tool for stakeholders to be able to improve the quality of PE during planning and development of new projects or assess the quality and impact of ongoing/completed projects. The good practice examples provided will support implementation of PE quality guidance.
- PE is not ‘one size fits all’ and consequently, the PE Quality Guidance is not prescriptive, rather it is based on core principles that can be adapted and applied according to the unique needs of each interaction and project.
- We urge use of, and feedback on, the PE Quality Guidance tool by diverse stakeholders to drive improvements in PE and allow for continuous refinement of the tool.
- The PE Quality Guidance is not an isolated tool. It is part of a wider and ongoing effort to synergise PE with other frameworks for more effective, systematic and measurable PE through co-creation and implementation of a multi-stakeholder framework.

Figure 5: Roadmap to the PE meta-framework

REFERENCES


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EXPLORING SYNAPSE

Patient engagement initiatives, organisations, experts and resources from around the world in one place.