

Reporting and Dissemination of Patient Engagement Activities

Guidance for Reporting and Dissemination of Patient Engagement Activities

Background/Rationale for the document

The complete and reliable reporting and dissemination of all patient engagement (PE) activities is essential to ensure transparency and enable continuous broad learning for all relevant stakeholders undertaking PE. Nevertheless, this is often a neglected area and there is less awareness about its relevance and value among those involved in PE. It is still often the case that information about how a PE activity was planned and carried out, its results and impact, and the lessons learned are not available or easily accessible in the public domain. When some of this information exists, it often lacks these important details.

There is a need for practical guidance and support to help organisations involved in PE to develop adequate reporting and dissemination plans so that the important outcomes and learnings from PE activities are more readily available in the public domain for the benefit of all stakeholders.

Objective of the tool

The “Guidance for Reporting and Dissemination of Patient Engagement Activities” was developed to support organisations participating in PE activities in more effective and timely planning, reporting and disseminating of information about the PE activities they had been involved in.

The tool includes guidance principles, a checklist and a template that can be used in combination with an organisations’ existing documentation.

Summary of the content

This tool recognises and builds upon the work of other relevant initiatives on the topic of reporting and dissemination of PE. However, this content is specific to PE in medicines development. It consists of three elements:

- Guiding principles covering themes such as (i) the dissemination strategy, process and planning, (ii) accessibility, style and format of outputs, (iii) translation into other languages (iv) and involvement of patient populations in reporting and dissemination of PE activities.
- An accompanying checklist to help users in the planning phases, summarising the key considerations and principles to follow.
- A template to be used to promote consistent and detailed PE reporting, which includes the core elements (or minimum criteria) to be included in the reporting materials. An example of how the template could be completed is provided. In addition, there is also signposting information to resources from key stakeholder groups.

Key message

The reporting and dissemination of PE activities in the public domain in a timely, consistent and accessible manner is a crucial element in the evolution of PE in medicines development, yet it is not always appropriately addressed. Patients and patient organisations should be invited to and be supported in taking part in the reporting and dissemination of the PE activities where they have been involved.

Methodology

The identification of several gaps in patient engagement (PE) practices and process emerged from the report of PARADIGM work package (WP) 2. A prioritization exercise of gaps by WP2 at the patient engagement open forum (PEOF) in September 2019

highlighted the overarching gap of a lack of reporting and dissemination of PE practices as one to address with the creation of a new guidance and tool. This theme was subsequently explored during a multi-stakeholder workshop by work package 4 at the PEOF. A working group consisting of patient organisations, industry and academia developed this tool during January-May 2020. The guidance and checklist have been developed through desk research and internal and external consortium consultation rounds and a workshop in April 2020. The template has been developed through mapping key themes and sections from several internal pharmaceutical company reporting templates, European Patients' Academy on Therapeutic Innovation (EUPATI) and Patient Focused Medicines Development (PFMD) quality guidance 'case study' style templates, and the short form of the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) template for the scientific publication of patient engagement and patient and public involvement activities. Exemplar wording under each section within the template is anonymized and aggregated text from real PE activities from a variety of stakeholders.

Contributors

<p>Main authors</p> <p>Stuart Faulkner (Oxford University) Ana Diaz (Alzheimer Europe) Lynne Van Poelgeest (EFGCP) Laiba Husain (Oxford University) Kay Warner (GSK) Apostolos Kalogiannis (EATG)</p>	
<p>Contributors</p> <p>Stuart Faulkner (Oxford University) Ana Diaz (Alzheimer Europe) Lynne Van Poelgeest (EFGCP) Laiba Husain (Oxford University) Kay Warner (GSK) Apostolos Kalogiannis (EATG)</p>	
<p>Coordination</p> <p>Karina Huberman (EATG) Wolf See (Bayer) Ingrid Klingmann (EFGCP)</p>	<p>Editorial committee</p> <p>Stuart Faulkner (Oxford University) Michaela Dinboeck (Novartis)</p>

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