

Enhanced EUPATI Industry Guide

Enhancement of the EUPATI industry guidance

Background/Rationale for the documents

During the PARADIGM project further expansion of specific sections of the EUPATI Guidance for Patient Involvement in Medicines Research and Development (R&D); Guidance for Pharmaceutical Industry-Led Medicines R&D guidance were required.

The working practices section required further emphasis to provide more detail on how an engagement could be defined with specific actions and to describe what should happen during pre-engagement planning and discussions to ensure mutually beneficial interactions with adequate preparation.

The considerations for events and hospitality required further emphasis to provide more detail on the level of attention needed when arranging patient engagement activities to ensure patients have the best experience.

Objective of the tools

The suggested working practices document provides recommendations with a checklist designed to help organisers planning patient engagement activities and addresses the PARADIGM defined recommendations on the required capabilities for patient engagement.

The events and hospitality checklist is designed to help individuals responsible for coordinating and planning patient engagement activities consider specific patient needs for travel, meeting venues, accommodation and associated elements. It is written for general application across all different scenarios and aims to be simple to follow by all stakeholders involved.

Summary of the content

The two checklists have been designed as practical tools which may be used during pre- engagement planning of patient engagement activities.

The suggested working practices checklist defines specific actions that may be appropriate to the activity and can aid discussions to ensure mutually beneficial interactions with adequate preparation. Organisers can use the rightmost column to include comments addressing considerations such as: “What is the activity?”, “who/what will it affect?”, “what impact will it have?”, “What is the benefit to the patient/community in participating?” and self-assess the quality of their preparedness and identify areas for improvement.

The events and hospitality checklist defines high level considerations for events and hospitality and is not intended to be an exhaustive list.

Key message

The tools presented here as an enhancement of the EUPATI guidance for patient engagement in industry led R&D, give the detailed steps to follow which were purposely not addressed in the original guidance document. However, the guidance document should be read in conjunction with these recommendations. Advice given in the suggested working practices tool is not intended to be exhaustive or applicable at all times. Judgement is needed to decide whether or not a recommendation can, should or must be followed.

Methodology

During the PARADIGM project it was identified that further expansion of specific sections of the EUPATI Guidance for Patient Involvement in Medicines Research and Development (R&D); Guidance for Pharmaceutical Industry-Led Medicines R&D were required.

Following initial discussion during a break-out session at the

PARADIGM workshop in March 2019, an authoring group was formed within work package 4 (WP4) partners that was balanced in terms of stakeholder representation and expertise. Discussions were led by the three original guidance authors. An analysis by this group determined that focus be given to two specific areas.

The working practices section required further emphasis to provide more detail on how an engagement could be defined with specific actions and to describe what should happen during pre-engagement planning and discussions to ensure mutually beneficial interactions with adequate preparation. The considerations for events and hospitality required further emphasis to provide more detail on the level of attention needed when arranging patient engagement activities to ensure patients have the best experience.

The authoring group met routinely until November 2019 to agree on content and relevant reference materials, the outcome was the first draft of both enhanced guidance documents. The main authors collaborated with PARADIGM partners to progress the documents. In March 2020 a further draft of the enhanced guidance documents were submitted for consultation within the PARADIGM consortium. In June 2020 the two enhanced guidance documents were submitted to external consultation and discussed during the Patient Engagement Open Forum session on July 9th.

All feedback received throughout the consultation was addressed and consolidated. This was supported by the editorial team who worked to ensure consistency across the outputs.

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Download the guidance

- PARADIGM EUPATI Suggested Working Practices
- PARADIGM EUPATI Suggested Working Practices Checklist
- PARADIGM EUPATI Events and Hospitality
- PARADIGM EUPATI Events and Hospitality Checklist

