



PART TWO: CREATING FUTURE PATIENT ENGAGEMENT TOOLS

Objectives:

The participants will bring their collective expertise to influence and inform the construction of new tools which will shape the future of patient engagement, based on previously presented evidence of gaps in Part One. By the end of the session, they will be aware of recently developed materials, and collaboratively have arrived at the direction for future co-creation of the next generation of patient engagement tools. They will also have increased their understanding of priorities and material needed for patient engagement .

Description:

The purpose of this session is to enable patient representatives, industry, academia, regulators and other stakeholders to work together to inform the development of a new set of patient engagement tools. Their input will ensure the appropriateness, format and relevance of the tools following gap analysis research to identify material not currently available. Participants will learn about new tools recently developed by Work Package 4 in response to earlier PARADIGM research and then have an opportunity to inform and influence the next set of developments. They will also have an opportunity to meet and learn from the PARADIGM partners and other patients and stakeholders experienced in patient engagement and the creation of tools to support its role in medicines development.

This session will begin with a brief (30 minutes) presentation of the results of work to date from work package 4 of PARADIGM, based on previously presented research undertaken in work packages 1 and 2.

These outcomes include draft guidance documents on a number of key issues on patient engagement; Community Advisory Boards, Conflict of Interest issues and a Code of Conduct for patient engagement. Although already in draft form, the opportunity will be presented for participants to comment further on these tools through an online consultation. Work to enhance the EUPATI Guidance for Patient Involvement in Industry-led Medicines R&D, published in 'frontiers of Medicine' in October 2018, will also be discussed.

This opening section will be primarily informational, giving participants an overview of new patient engagement tools already in production for PARADIGM. It will also enable them to provide input to the following interactive part of the session. This background information will be used in conjunction with the identification and prioritisation of gaps in current patient engagement materials presented in Part One (Session 3) on the first day to inform the discussions in the rest of the session.

The second part of the session will consist of group work, followed by discussion and feedback in the larger group. It will act as a consultation on appropriate inclusions for a new set of patient engagement tools, for which the need has been identified by the gap analysis. Participants will begin by forming smaller break-out groups, which will support active participation in discussions. The groups will discuss a prioritised list of missing tools, with each group asked to consider key elements for their development. These will cover the format that each tool should have; what the key objective of each tool should be;



and what key messages each tool should convey.

Participants will discuss this in the small groups for 45 minutes. Finally, they will come together again in a plenary round-up to share their results and discuss their recommendations for the future tools.