

PATIENT ENGAGEMENT OPEN FORUM - DAY 2 WORKSHOPS

It is now recognized that patient engagement is a major asset in clinical development, by making trials co-created with patients more acceptable, accessible and therefore more attractive to participate-in. This collaboration generates more consistent trials, improves trial recruitment rates, and speeds up the medicine development process which can lead to faster filings towards regulatory bodies and higher rates of approvals (a program co-created with patients has a 20% chance higher of obtaining Marketing Authorization¹). Despite this recently measured success, R&D global activity is still facing major increases in difficulty and costs, and too few programs of research succeed in reaching the clinical development stage or go on to fail early on. These wasted resources result in a heavier burden on the entire healthcare system, with an increase in the price of the few drugs reaching the market, and extremely long waiting times for patients with urgent medical needs.

This combined with the already measurable and reported benefits of involving and co-creating with patients during clinical trials should inspire stakeholders to collaborate earlier in the medicines lifecycle. Research papers and guidance on this topic often refer to patient involvement 'across the medicines development continuum', however, in practice there are only a few examples of meaningful partnership working between patients and those delivering research throughout discovery and early clinical phases of development.

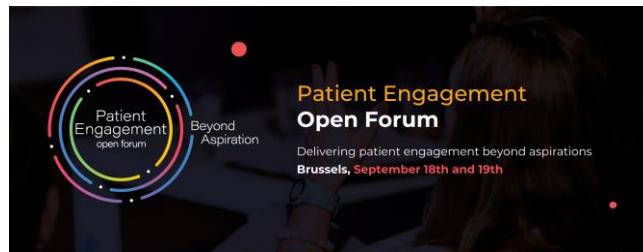
WORKSHOP 3 - THE ROLE OF PATIENTS IN CO-DESIGNING PLAIN LANGUAGE SUMMARIES TO MAXIMISE THE IMPACT AND UNDERSTANDING OF RESEARCH RESULTS

There is a growing need and expectation for plain-language versions of research results that are accessible to patients and the public. This expectation does not come only from the patient community - the new European regulation for Clinical Trials⁴ (that will come into effect in 2020 will make lay summaries of clinical trial results mandatory at the end of any research initiative. However, there is a wealth of other research results, disseminated in medical publications and congress presentations, that falls outside the remit of the EU-mandated clinical trial lay summaries.

Plain language summaries of publications and congress presentations are required to ensure that research findings are accessible to everyone. In addition, there is evidence that improving health literacy can improve health outcomes - plain language summaries are a key approach to addressing the needs of patients and the public for accurate, relevant scientific content.

¹ The innovation imperative: the future of drug development, a study conducted by The Economist Intelligence Unit and commissioned by PAREXEL (<https://druginnovation.eiu.com/>)

⁴ EU Clinical Trials Regulation 536/2014 (Article 37) (EU CT Regulation



The goal of this workshop is to discuss why the co-creation of plain language summaries (PLS) of publications in partnership with members of the public is important, and how to better achieve this in the future. In this workshop, you will get to

- give your input on how to identify potential target audiences for PLS and their dissemination,
- review version 1 of the PLS of Publications Toolkit and participate in co-creating version 2, and
- participate in validating the most appropriate dissemination format and avenues for reaching different audiences.

Join this workshop to learn about how PLS can bring value for patients, publishers and pharma, and how to involve the right audiences as your co-creators to maximise your dissemination impact. Your input and the outcomes of this workshop will help us develop and deliver a how-to module with recommendations on how to involve relevant audiences, structure and create the plain language summaries and make them accessible to wider audiences.