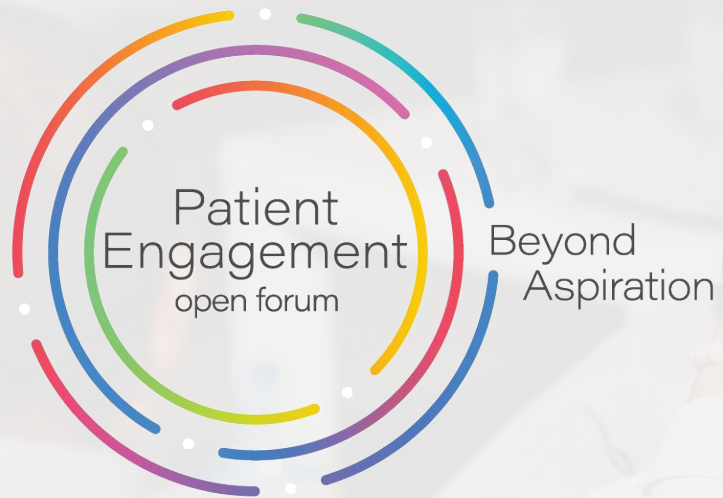


**Patient engagement is
everybody's responsibility.**

**How to reach beyond
the easy targets?**

Patient Engagement Open Forum
19.9.2019



Welcome words

Welcome



Helena Harnik

Programmes Director
The Synergist / PFMD



Camilla Habre

Project Officer
European Patients'
Forum (EPF)



Zsafia Bakonyi

Senior Manager Partnerships
EFPIA



Roxana Radu

Communications Manager
The Synergist / PFMD

Session outcome: share resources & ideas to reach beyond the usual targets in PE

Agenda

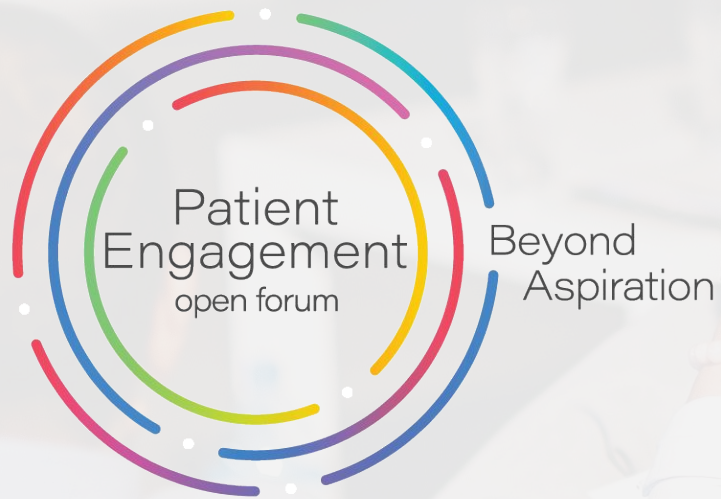
1. Introduction

2. Why this open session?

3. Different perspectives for culture change

4. **Open discussion - what experiences or ideas do you have?**

5. Conclusions and next steps



Intro to patient engagement

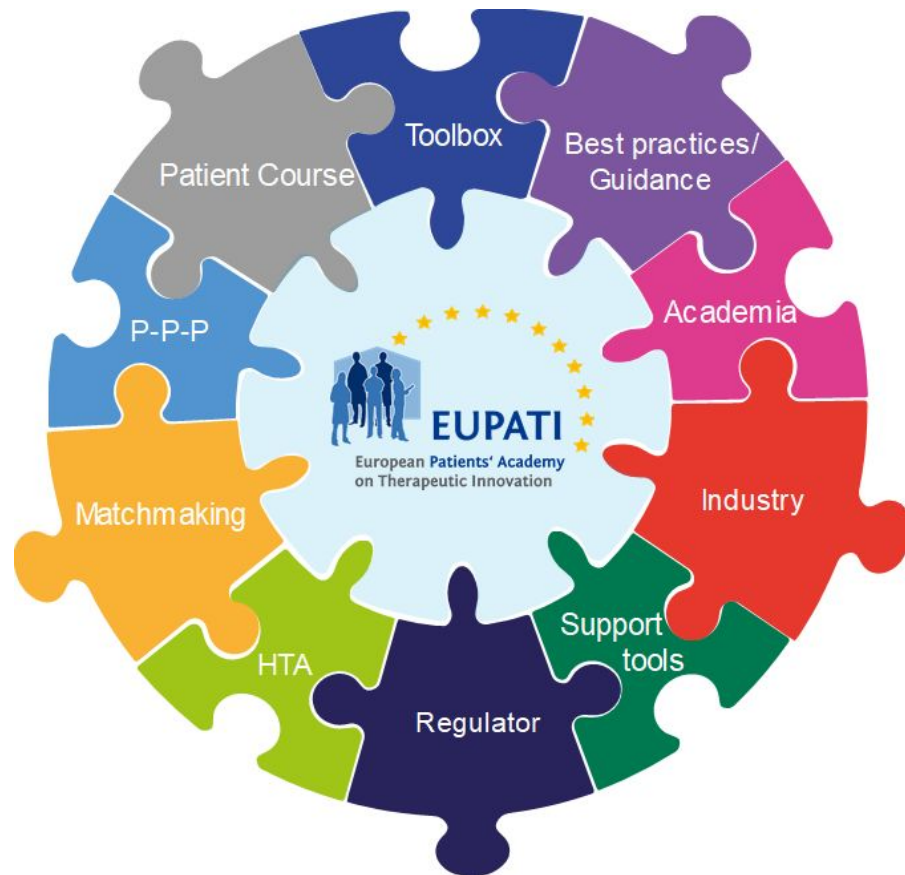
Patient engagement is a journey

- Patient engagement is **effective and active collaboration of patients, patient advocates, patient representatives** and/or carers in the **processes and decisions within the medicine lifecycle**, along with all other relevant stakeholders when appropriate.
- Meaningful patient engagement brings **mutual benefit to the community of medicine developers** (meaning all stakeholders involved from the patients, industry, regulators, HTA bodies to the payers), and requires inputs into decision-making, co-production and dissemination of knowledge.



- European Patients' Academy on Therapeutic Innovation
- PPP established in 2012 with currently +20 partners

www.eupati.eu



IMI PARADIGM

A Distinct Voice In the Patient Engagement Landscape

Mission

Contribute to a sustainable framework that enables meaningful patient engagement (PE) and demonstrates 'return on engagement' for all players



Research and
priority setting



Design of
clinical trials



Early dialogues with
regulators and HTA bodies

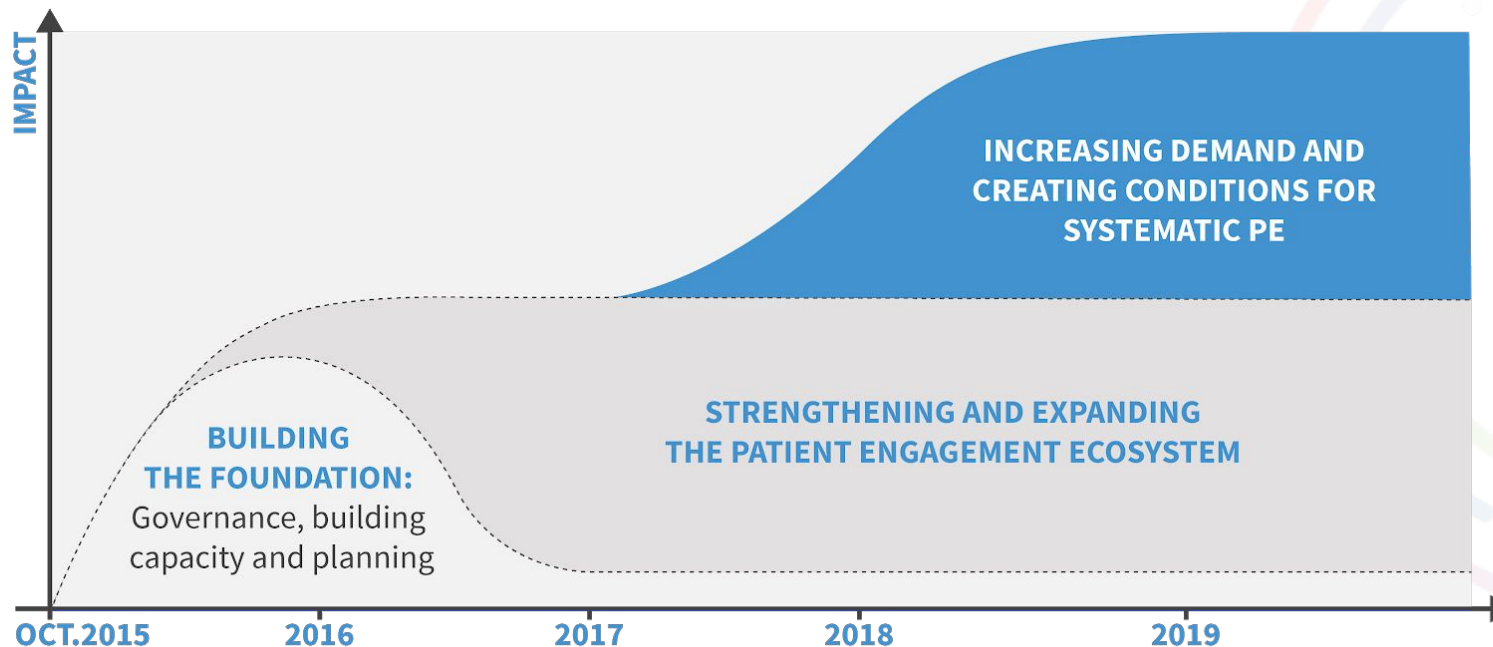


Objectives

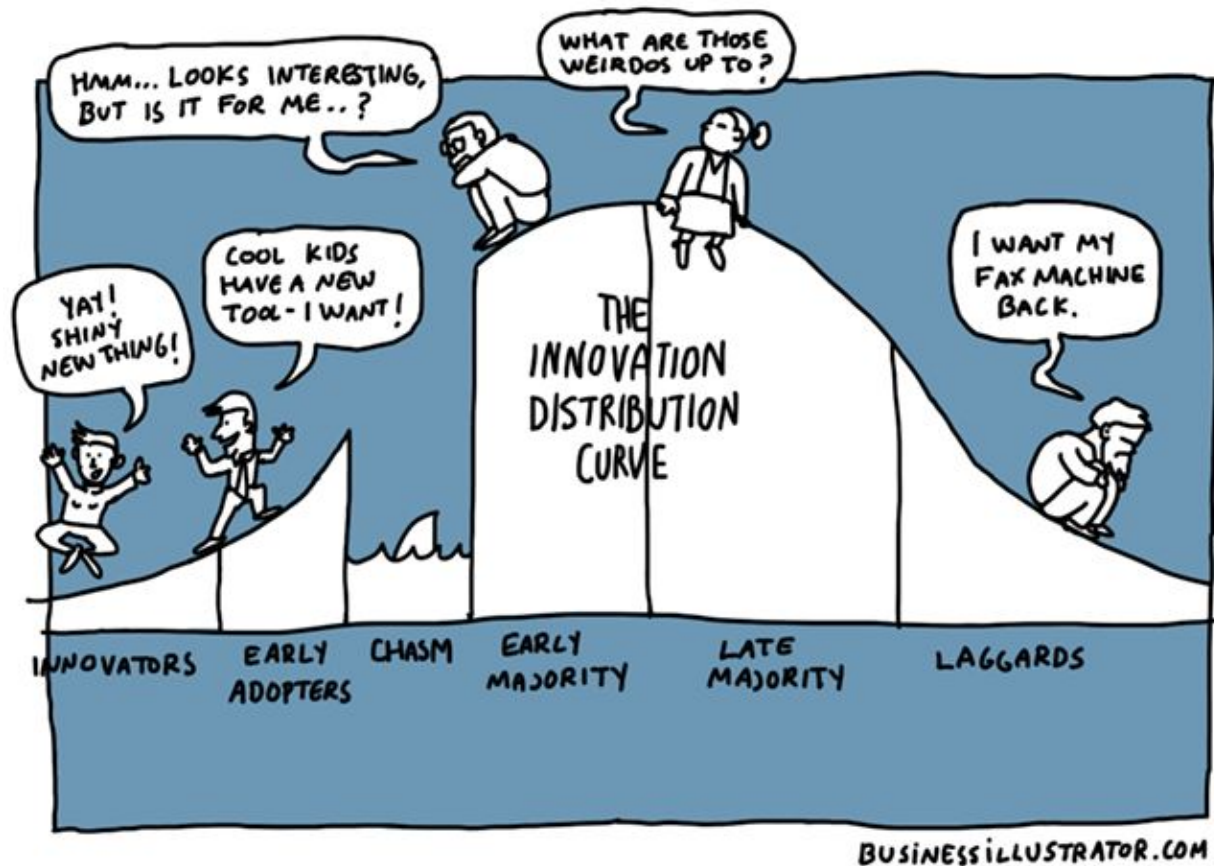
Develop processes and tools for these three points in the medicine lifecycle
Develop a sustainability roadmap for patient engagement

PFMD's Holistic & Integrated Approach Overview

And how we address fragmentation of methodology, tools and capability building

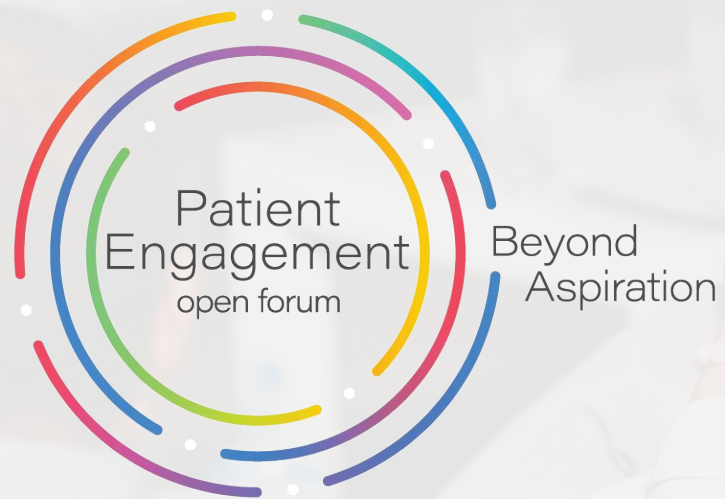


Communication as a powerful tool for culture change



Communication as a powerful tool for culture change

- Defining the expected culture change (internal, external)
- COMMUNICATION
 - Audience mapping
 - Low vs high communication points
 - Influencers
- Leadership example & endorsement
- Systematic follow-up, evaluation & strategy adjustment
- Creating the conditions for change (tools, trainings, ready-made materials etc)
- Sharing of best practices



About this session



Objectives

1

Share experiences: inducing cultural change & communicating about Patient Engagement:

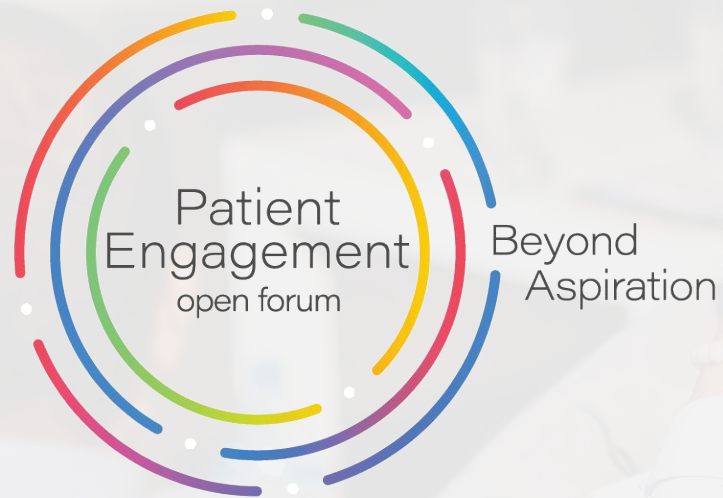
- What were the main challenges?
- How have you approached it?
- What has worked?

2

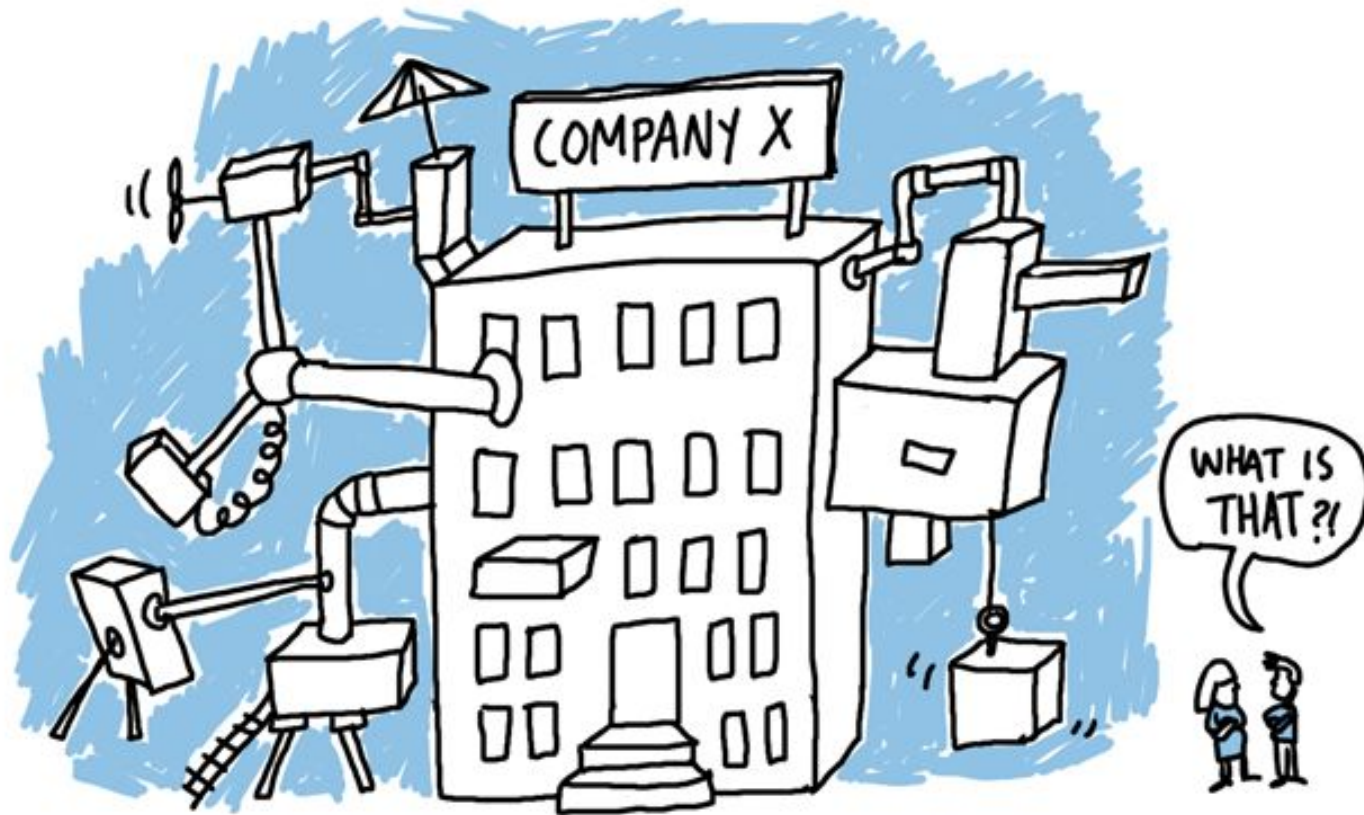
Identify the gaps/need: What kind of tools or information would be useful in making the case for Patient Engagement within your own organisation and beyond?

3

Discuss how can PARADIGM, PFMD and EUPATI address these needs?



Dialogue on the industry perspective



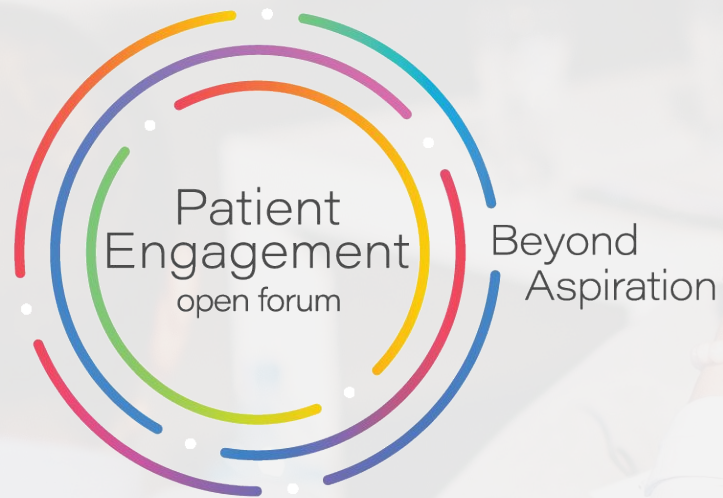
“I want you to find a bold and innovative way to do everything exactly the same way it’s been done for 25 years.”



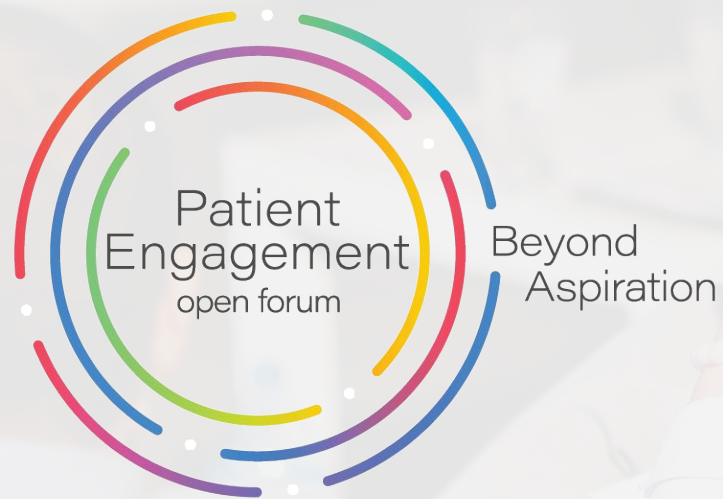
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Communications & Leadership



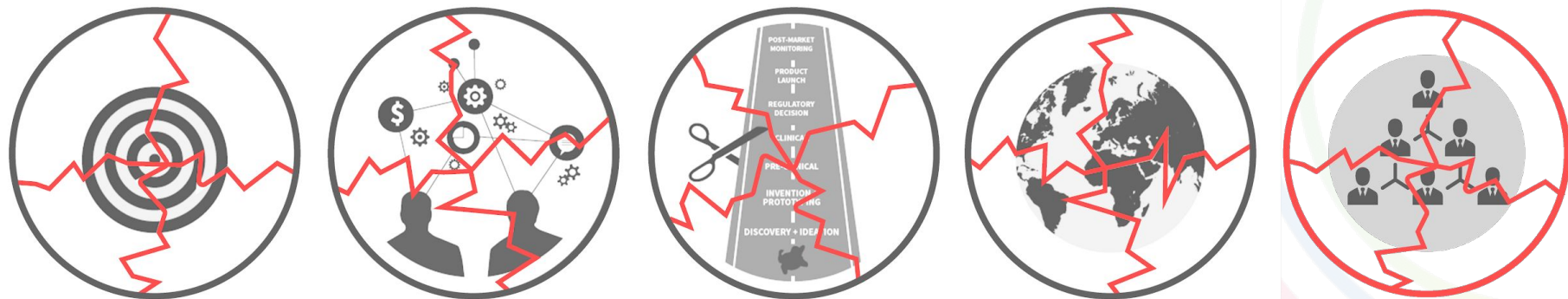


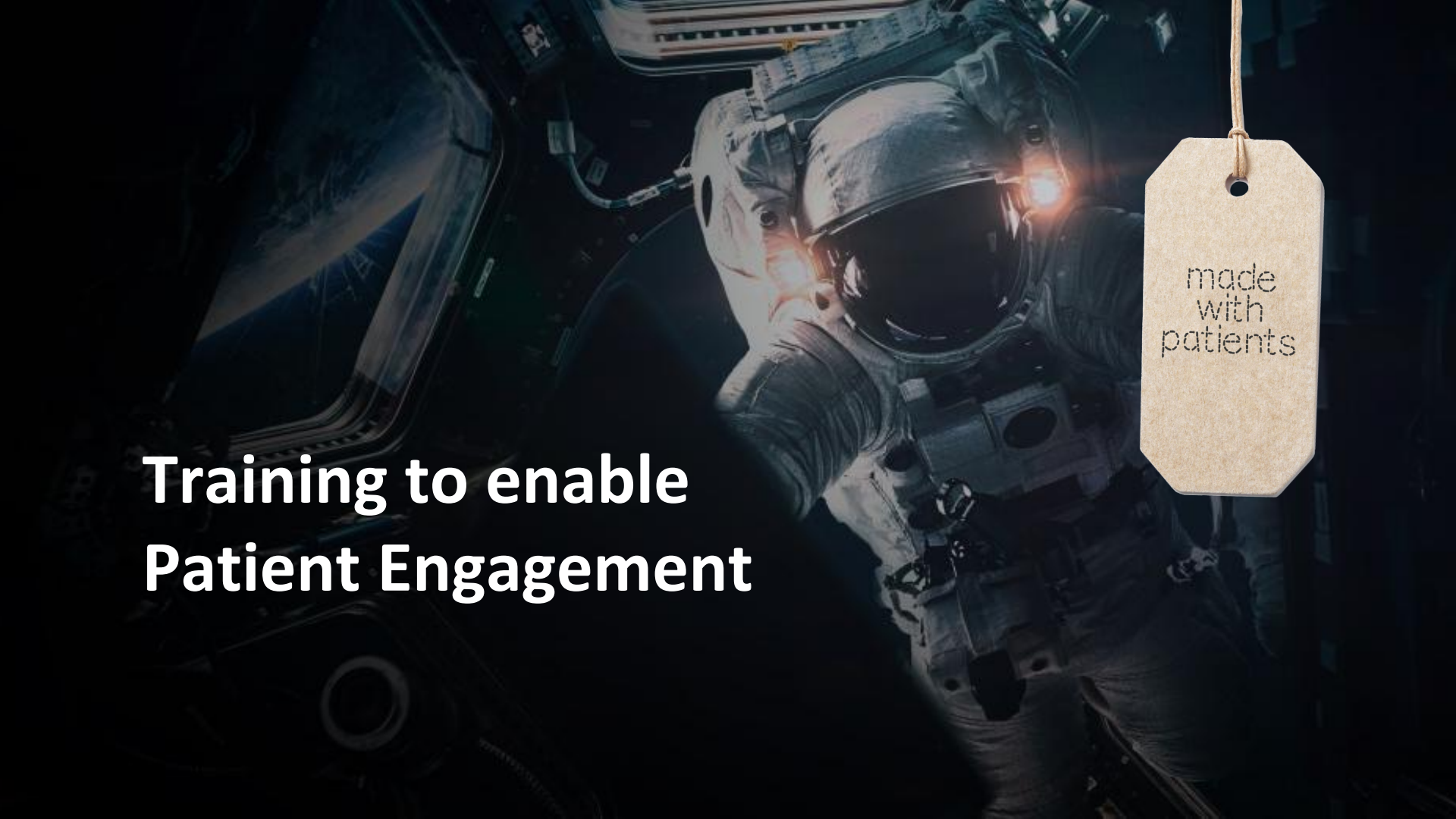
Dialogue on the patient perspective



Systematic change and training

Patient Engagement Landscape Fragmentation



A full-page background image featuring an astronaut in a white spacesuit floating in the dark void of space. The astronaut's helmet is reflective, showing a bright light source. To the right of the astronaut, a small, light-brown, octagonal tag hangs from a thin string. The tag has the text 'made with patients' printed on it in a simple, black, sans-serif font. The overall mood is one of exploration and innovation.

Training to enable Patient Engagement

made
with
patients

Innovative learning opportunities for everyone, co-created with and for

made
with
patients



Industry



Patient advocates



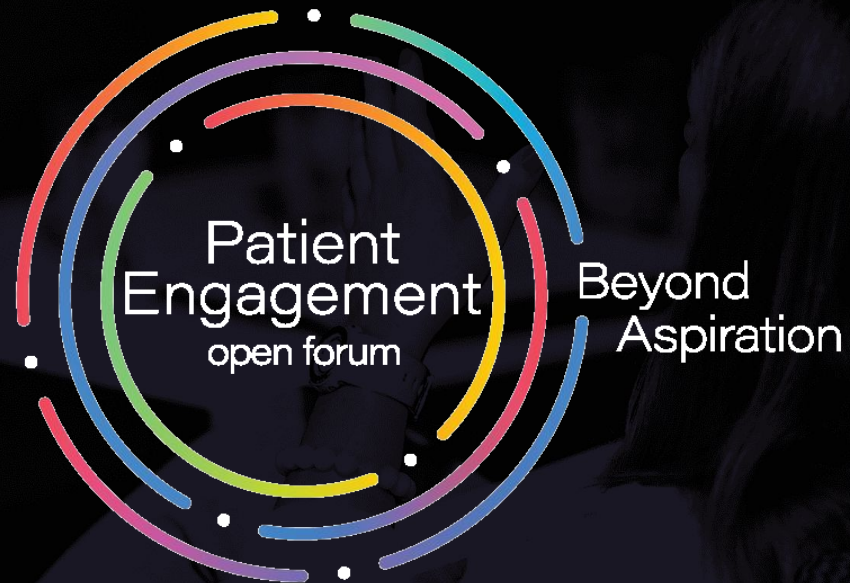
Other stakeholders

(regulatory authorities)

Training is necessary to:

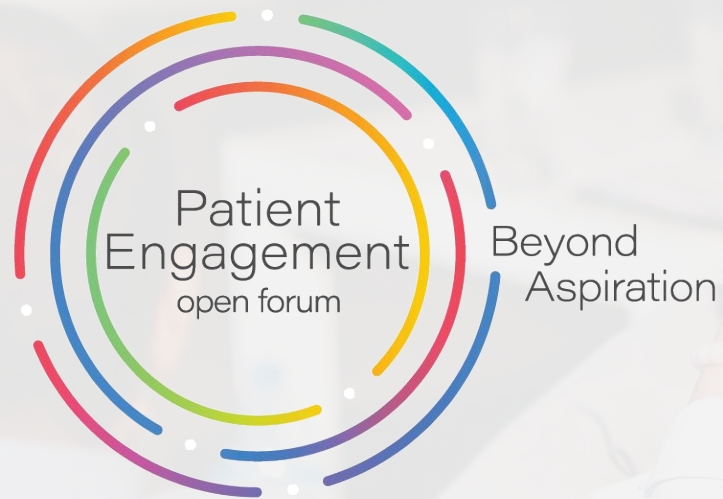
made
with
patients

- ✓ **Provide an introduction** for patient engagement
- ✓ **Support the culture shift** that enables systematic patient engagement
- ✓ **Equip stakeholders with the knowledge and tools** they need to engage with each other



What successful campaigns can you share with us?

What other activities/ initiatives/ communication efforts can be effective in reaching more people than the usual patient engagement officers?



Highlights & next steps