
# Flash sessions

*Sustainability roadmap*

*Legal agreements explained*

*PE in Central and Eastern Europe*

PARADIGM
Patients Active in Research and Dialogues for an Improved Generation of Medicines

PATIENT FOCUSED MEDICINES DEVELOPMENT

EUPATI
European Patients' Academy on Therapeutic Innovation

# What is the Patient Engagement Open Forum

A series of virtual events (in 2020) where we will work together, in a multi-stakeholder context, **to turn patient engagement into reality**.

The Forum aims to provide **a holistic perspective** of patient engagement, the **landscape and actors**, and **foster collaboration** and **co-creation** while **breaking down fragmentation** that are often present in patient engagement work.

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Patient Engagement open forum Into Reality

# Agenda

## June 25th

**PEOF2020 opening plenary (PARADIGM, PFMD and EUPATI)**

**Parallel sessions:**

- Patient Engagement tools session #1 (consultation organised by PARADIGM)
- Patient engagement within MedTech (panel organised by EUPATI)
- Patient experience in regulatory processes (workshop organised by PFMD)

## June 26th

**Parallel sessions:**

- How to engage patients in the early phases? (workshop organised by PFMD)
- Patient engagement in co-creating plain language summaries (workshop organised by PFMD)
- National Health Council Patient Engagement Fair-Market Value Calculator Toolbox (organised by NHC)

## July 9th

**Parallel sessions:**

- Patient Engagement tools session #2 (consultation organised by PARADIGM)
- Flash presentations
  1. Sustainability roadmap for the patient engagement ecosystem
  2. Patient engagement agreements explained
  3. Patient engagement in medicines R&D in the CEE region
- Motherhood should not be a fight – better safety information on medicines use during pregnancy and breastfeeding, with patients for patients. (Workshop organised by IMI-Conception)

## September 10th

**Plenary session**

- PARADIGM Patient Engagement Toolbox (webinar organised by PARADIGM)
- Patient Engagement Monitoring and Evaluation Framework (workshop organised by PARADIGM)

## September 24th

**Parallel sessions:**

- How PE can foster access through improved affordability? (webinar organised by EUPATI)
- Patient engagement in clinical trial phase or/and in the regulatory submission phase (workshop organised by PFMD – to be confirmed at a later date)
- From diagnosis to treatment and beyond: personalised medicine – what's in it for patients and how to make it available to patients who could benefit from it? (workshop supported by PFMD)

## October 15th

**Parallel sessions:**

- Patient Engagement and Quality by Design: Co-Developing an Implementation Roadmap for Clinical Trials (organised by CTTI)
- Good Lay Summary Practice, communicating trial results to the general public – How patient engagement can work (organised by EFPIA and EFGCP)

## November 5th

**THEME: Regulatory**

## November 23rd

**Plenary session:**

- PEOF2020 conclusion session

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Patient Engagement open forum Into Reality

# Let’s work together to spread the word

**#PEOF2020**

**@imi-paradigm**

**@eupatients**

**@PFMDwithPatient**

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PATIENT FOCUSED MEDICINES DEVELOPMENT

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Patient Engagement open forum Into Reality

# Agenda

Sustainability roadmap

Legal agreement explained

Patient Engagement in Central and Eastern Europe

# PARADIGM

Patients Active in Research and Dialogues
for an Improved Generation of Medicines

# Consortium's mission and objectives

**Mission**

Participate to the co-creation of a sustainable framework allowing systematic, meaningful and ethical patient engagement in medicines R&D

Research and priority setting

Design of clinical trials

Early dialogues with regulators and HTA bodies

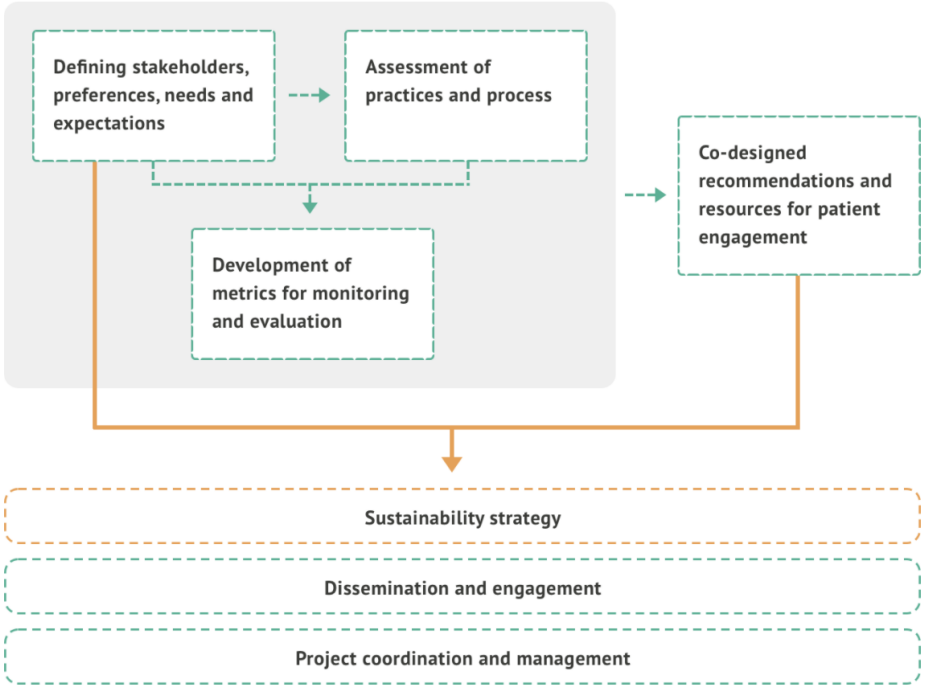
**Objectives**

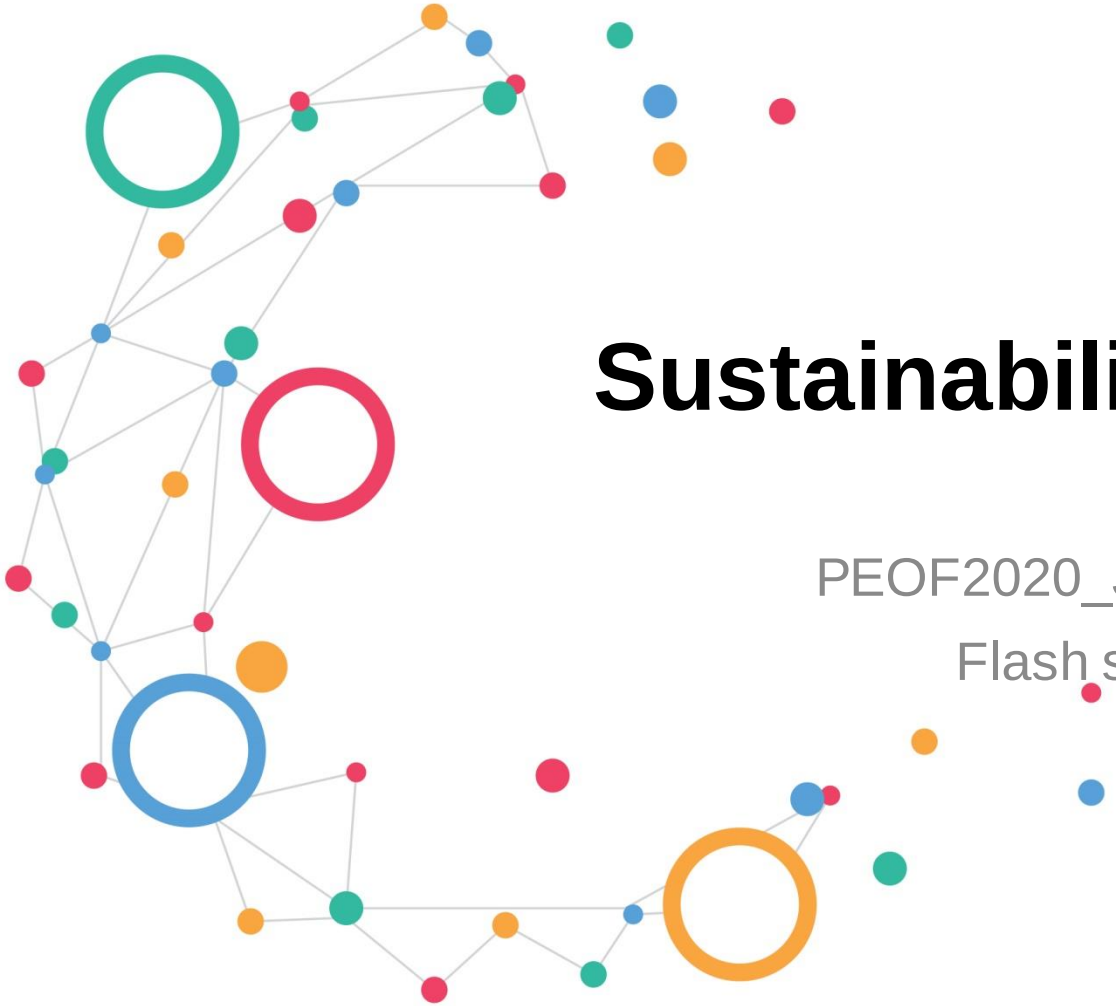
Develop processes and tools for these three points in the medicine lifecycle

Develop a sustainability roadmap for patient engagement

# Consortium members

# A workflow towards specific outputs





# Sustainability roadmap

PEOF2020_July 9th, 2020

Flash session

PARADIGM

Patients Active in Research and Dialogues for an Improved Generation of Medicines

# Who are we?

Concha Mayo

Elisa Ferrer

## Sustainability roadmap core group

…with the invaluable input from the whole consortium and the PARADIGM International Liaison Group

## What is your stakeholder group?

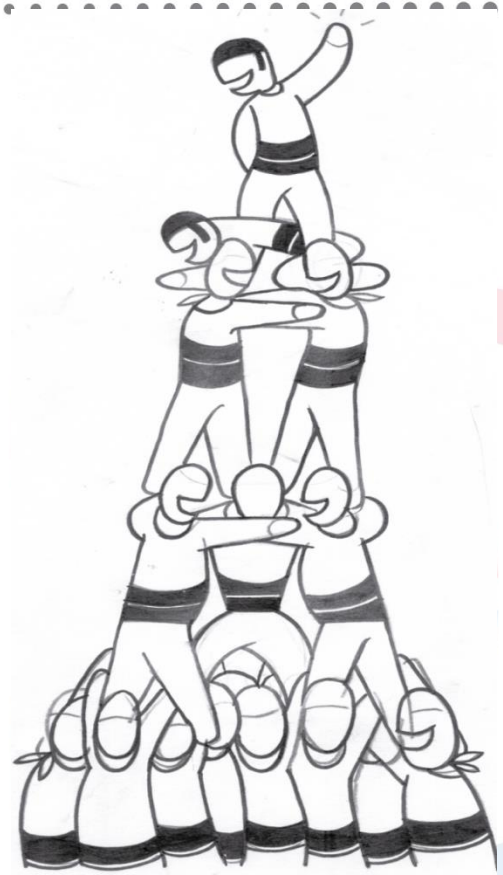
# Patient engagement is a collective work

# Our community

- Patients and patient organisations
- Medicines developers
- Academia

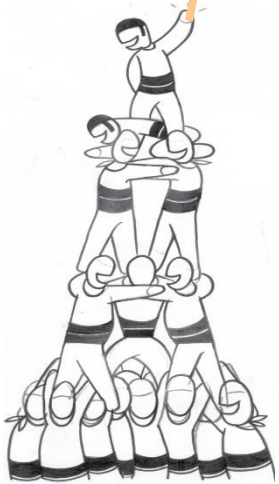
- Regulatory authorities
- Health Technology Assessment (HTA) bodies
- Competent authorities on pricing and reimbursement
- Policymakers

- Public research funders



# This is our VISION

**Meaningful and sustainable patient engament in medicines research and development for better health outcomes.**



# Sustainability strategy

- To ensure the long term use of the resources for patient engagement co-created by PARADIGM
- To achieve system-wide sustained patient engagement in the healthcare ecosystem through changes in the culture, processes and resources, across stakeholder groups and organisations
- To develop a sustainability roadmap to support optimal patient engagement in key decision-making points across medicines research and development

# How did we get here?

2018

Needs assessment survey

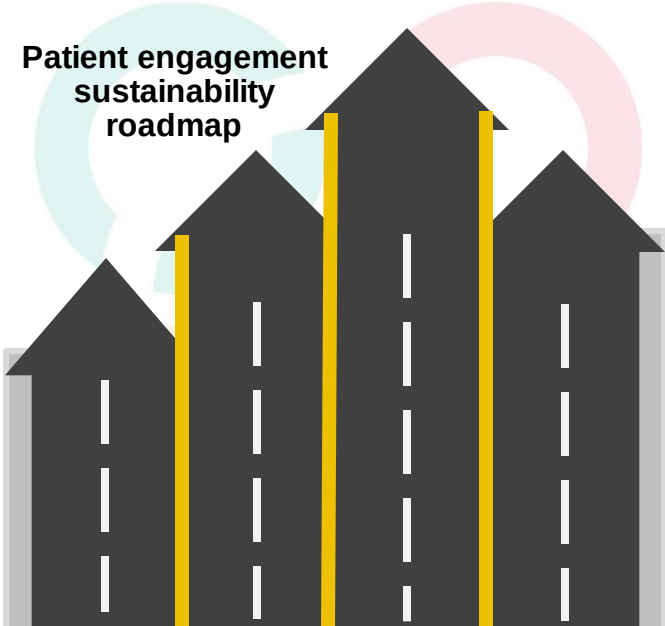
Benchmarking of existing sustainability models

Sustainability scenarios for patient engagement

Sustainability of key PARADIGM assets

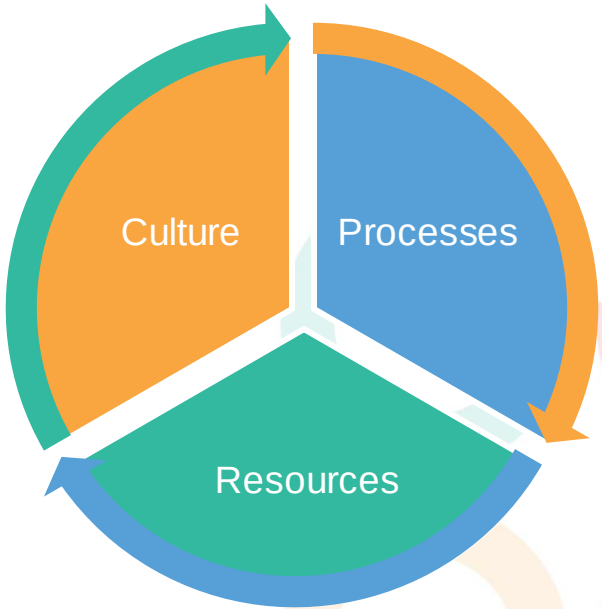
2020

Patient engagement sustainability roadmap



# Sustained patient engagement is fundamentally achievable…

**…through defined changes in the culture, processes and resources across stakeholder organisations**



# Relevant sustainability factors

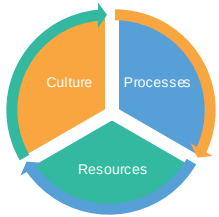
- Transparency (on how decisions are taken, on how things are done)
- Trust-building (ensure everyone is being heard, neutrality, reduce false perceptions)
- Openness, communication (communicate on successes, failures)
- Win – win for all stakeholders (shared purpose)
- Keep consistency with vision and mission

- Flexibility and agility
- Build on existing resources/complementarity
- Clear rules
- Inclusivity
- Change management
- Metrics to show value

- Supportive legal framework
- Financial independence (but not only)
- Compensation for participants

# Sustainability scenarios for patient engagement

- What will drive the practice of patient engagement and make it systematic?
- What will reinforce the uptake of best practices?
- How to finance patient engagement, maintain trust and keep independence?




| | |
|---|---|
| TOP-DOWN SIGNAL | REINFORCED BY PRACTICE |
| ONE-STOP SHOP APPROACH | PE MARKET APPROACH |

# How did we get here?

2018

Needs assessment survey

Benchmarking of existing sustainability models

Sustainability scenarios for patient engagement

Sustainability of key PARADIGM assets

2020

**Patient engagement sustainability roadmap**

Stakeholder consultations PARADIGM patients and industry partners

Informal interviews with regulators and supranational bodies

Patient engagement CEE workshop

Consultation PARADIGM consortium/PILG

## VISION

**Meaningful and sustainable patient engagement in medicines research and development for better health outcomes.**

Knowledge & experience

Language

Cultural

Human Resources

Political

Financial

**CURRENT LANDSCAPE**

**Barriers**

# Our roadmap

**Meaningful and sustainable patient engagement in medicines research and development for better health outcomes.**

## Secure inclusive and diverse patient engagement

END GOAL

Meaningfully involve patients and their representatives

Intermediate Goals

Involve local/regional/national bodies from all stakeholders as drivers for change

## Embed patient engagement in the mind-set, at every step and across organisations

END GOAL

PE recognised as valuable and visible to all stakeholders

Intermediate Goals

Embed PE across the medicines lifecycle, integrated into processes and across functions

Have a common framework for patient engagement

## Ethical, trust-based collaboration among all patient engagement stakeholders in medicines R&D

END GOAL

Include patients as true partners

Intermediate Goals

Identifty the right incentives

Improve societal perception

## Ensure dedicated leadership and operational time, resources and funding for patient engagement

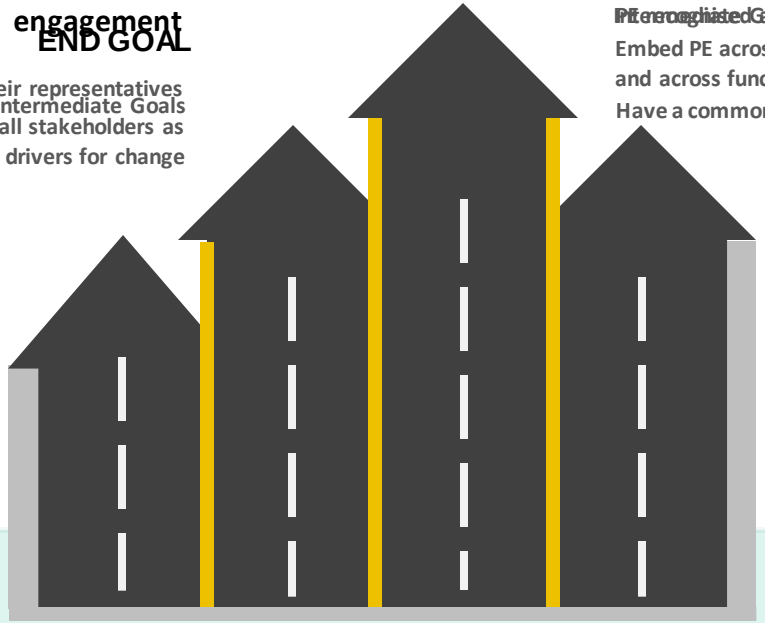
END GOAL

Intermediate Goals

Ensure dedicated time, resources and funding

Ensure PE leadership in all stakeholder organisations

All stakeholders to have the required capabilities for PE



CURRENT LANDSCAPE

**Meaningful and sustainable patient engagement in medicines research and development for better health outcomes.**

## Secure inclusive and diverse patient engagement

Meaningfully involve patients and their representatives

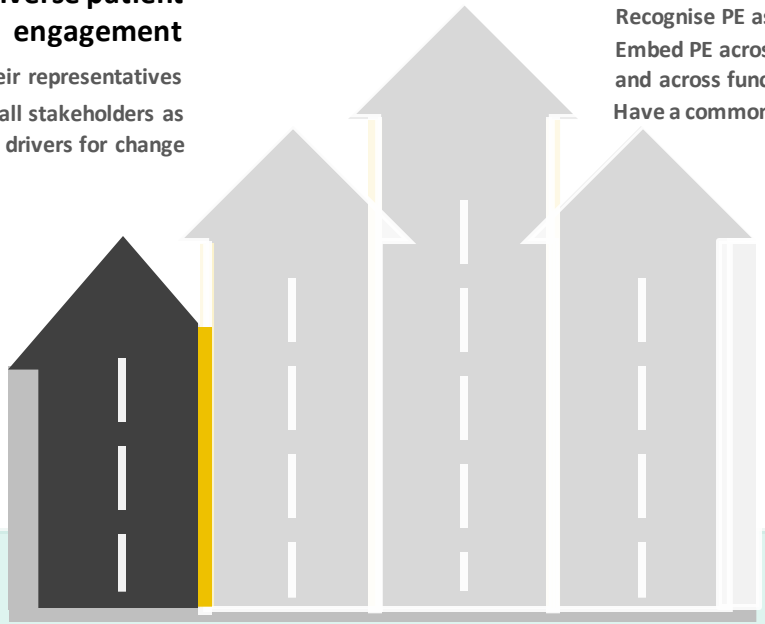
Involve local/regional/national bodies from all stakeholders as drivers for change

## Embed patient engagement in the mind-set, at every step and across organisations

Recognise PE as valuable and visible to all stakeholders

Embed PE across the medicines lifecycle, integrated into processes and across functions

Have a common framework for patient engagement



## Ethical, trust-based collaboration among all patient engagement stakeholders in medicines R&D

Include patients as true partners

Identifty the right incentives

Improve societal perception

## Ensure dedicated leadership and operational time, resources and funding for patient engagement

Ensure dedicated time, resources and funding

Ensure PE leadership in all stakeholder organisations

All stakeholders to have the required capabilities for PE

**CURRENT LANDSCAPE**

**Meaningful and sustainable patient engagement in medicines research and development for better health outcomes.**

**Ethical, trust-based collaboration among all patient engagement stakeholders in medicines R&D**

Include patients as true partners

Identifty the right incentives

Improve societal perception

**CURRENT LANDSCAPE**

**Theme 1. Patients to have a strong, meaningful and coordinated voice for patient engagement**

**ACTIONS**

1. Leverage existing physical/virtual networking platforms for building communities/new partnerships with other patient organisations.
2. Strategic alignment across patient organisations to bring a unified voice into decision-making bodies and policy strategy (sp. in CEE region).
3. Exchange and transfer knowledge between regional and global patient organisations of best practices for defining their strategy and objectives towards patient engagement.
4. Train patients on patient engagement in medicines R&D both in terms of scientific/technical/process knowledge and leadership skills

**Meaningful and sustainable patient engagement in medicines research and development for better health outcomes.**

**Theme 2. Patients' voice in the structure of every relevant decision-making body & stakeholder organisation**

**Ethical, trust-based collaboration among all patient engagement stakeholders in medicines R&D**

**Include patients as true partners**

Identifty the right incentives

Improve societal perception

**CURRENT LANDSCAPE**

**ACTIONS**

1. Identify relevant development milestones in the decision-making processes to embed patient engagement practices and appropriate indicators to monitor progress.
2. Demonstrate the commitment of the organisation's executive leadership and build or augment patient engagement capacity. Incorporation of the patients' voice is easier when such capacity and a receptive culture are present.
3. Use integrated PE resources to build internal capacity, listen to advocacy campaigns from organisations promoting PE and build alliances with private and public institutions that already work with evolving and established processes of PE.

# TOOLS TO CARRY OUT THE ACTIONS

## PATIENT ENGAGEMENT INTEGRATED RESOURCES

### PARADIGM TOOLBOX

- MONITORING & EVALUATION FRAMEWORK
- RECOMMENDATIONS CAPABILITIES PE
- CODE OF CONDUCT
- CONFLICT OF INTEREST
- COMMUNITY ADVISORY BOARDS
- ENHANCED EUPATI GUIDANCE
- LEGAL TOOLKIT
- TOOLKIT HTA EARLY DIALOGUES
- IDENTIFICATION OF THE RIGHT MATCH FOR PE

### OTHER SOURCES

- PFMD PATIENT ENGAGEMENT MANAGEMENT SUITE
- EUPATI TOOLBOX
- TRANSCELERATE CTTI
- NATIONAL HEALTH COUNCIL PCORI

## TRAINING & EDUCATION

- EUPATI
- EURORDIS OPEN ACADEMY
- EPF CAPACITY BUILDING PROGRAMME
- PFMD PATIENT ENGAGEMENT TRAINING

## MULTI-STAKEHOLDER PLATFORMS

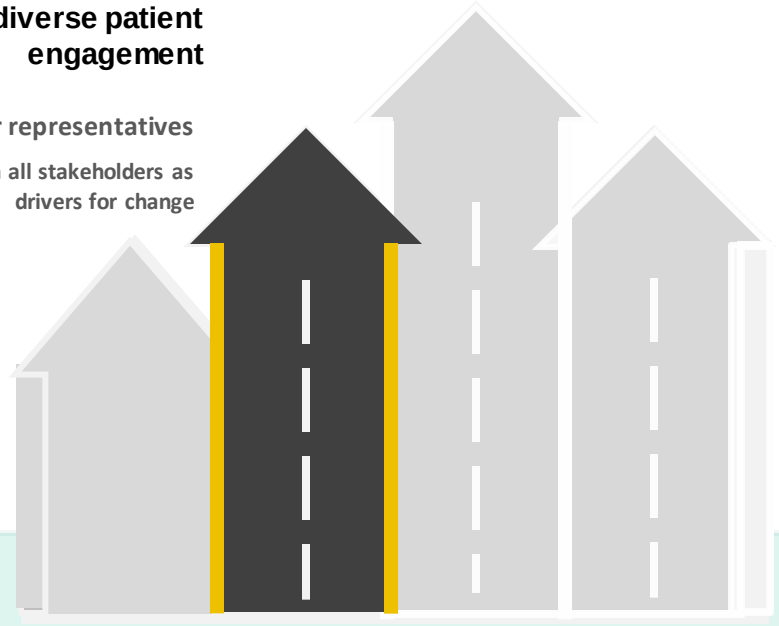
- PUBLIC-PRIVATE CONSORTIA
- REGULATORY, HTA AND PAYERS NETWORKS
- MULTI-STAKEHOLDER NETWORKING PLATFORMS
- PATIENT ENGAGEMENT OPEN FORUM

**Meaningful and sustainable patient engagement in medicines research and development for better health outcomes.**

## Secure inclusive and diverse patient engagement

### Meaningfully involve patients and their representatives

Involve local/regional/national bodies from all stakeholders as drivers for change



**CURRENT LANDSCAPE**

**ACTIONS**

1. Use integrated tools and training solutions to facilitate meaningful involvement and increase capabilities
2. Follow recommendations to achieve diversity (geographical, gender, expertise), inclusion of underrepresented groups and vulnerable populations
3. Monitor changing attitudes to the value of patient engagement

**PATIENT ENGAGEMENT INTEGRATED RESOURCES**

**TRAINING & EDUCATION**

**MONITORING & EVALUATION FRAMEWORK**

**Meaningful and sustainable patient engagement in medicines research and development for better health outcomes.**

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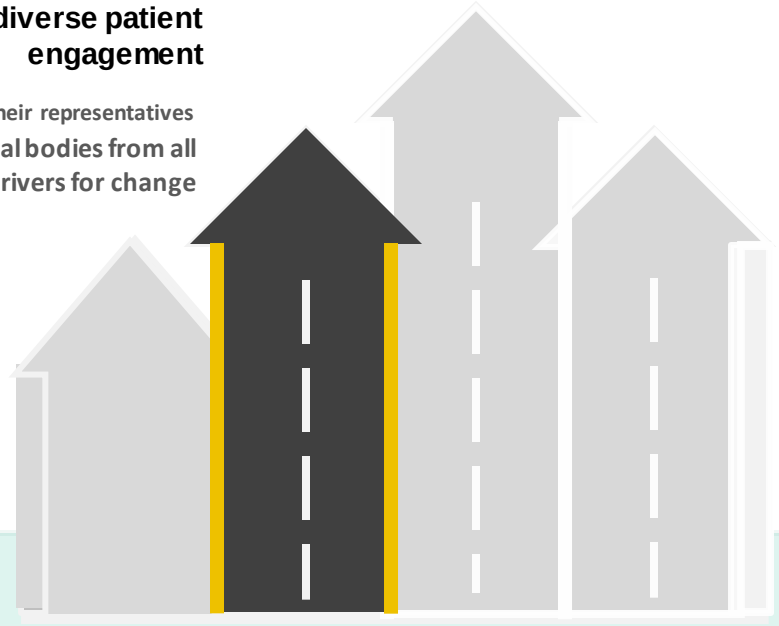


**CURRENT LANDSCAPE**

**ACTIONS**

1. Role for local/regional/national stakeholder group organisations to act as fora for discussion and/or decision-making, and align on strategies and best practices for patient engagement

2. Promote local, national and international alliances between stakeholders, networks, projects, initiatives to avoid fragmentation and duplication. Disseminate, share, and adopt good practices of patient engagement.

MULTI-STAKEHOLDER NETWORKING PLATFORMS

REGULATORY/ HTA/PAYER NETWORKS

**Meaningful and sustainable patient engagement in medicines research and development for better health outcomes.**

## Secure inclusive and diverse patient engagement

Meaningfully involve patients and their representatives

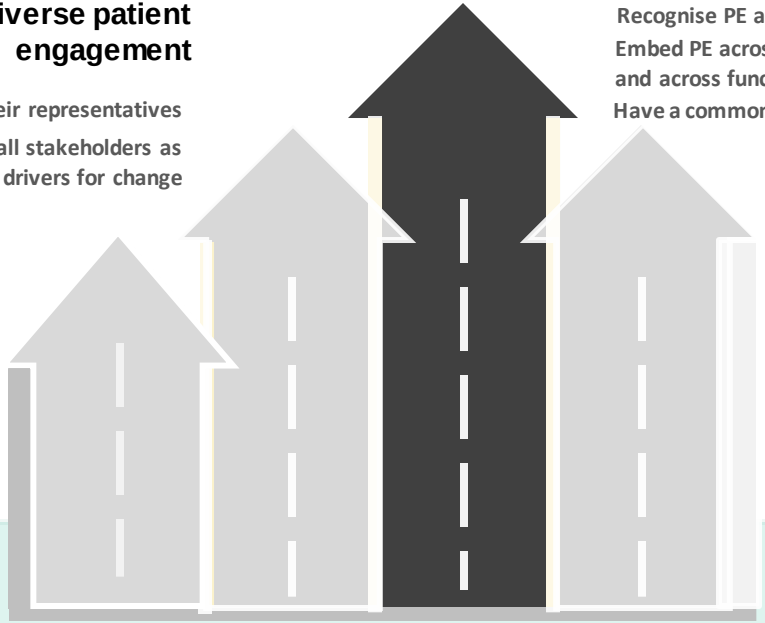
Involve local/regional/national bodies from all stakeholders as drivers for change

## Embed patient engagement in the mind-set, at every step and across organisations

Recognise PE as valuable and visible to all stakeholders

Embed PE across the medicines lifecycle, integrated into processes and across functions

Have a common framework for patient engagement

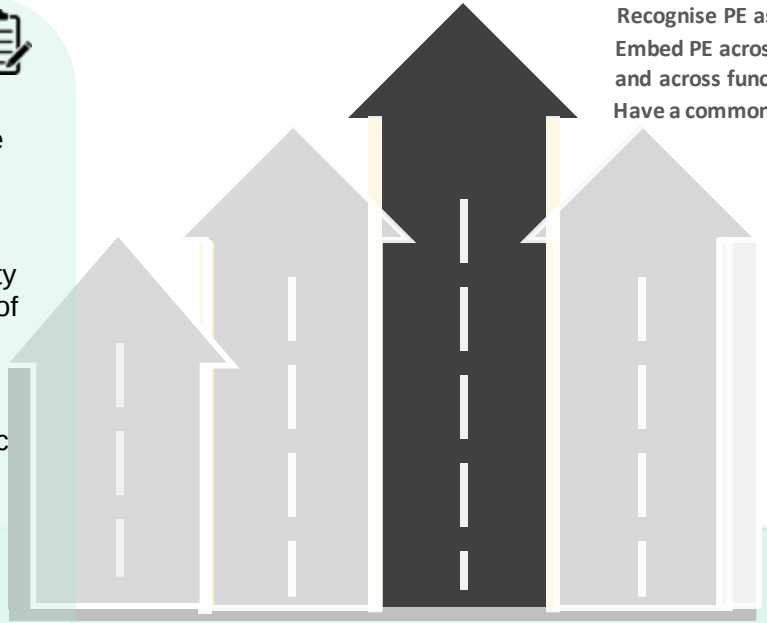


**CURRENT LANDSCAPE**

**Meaningful and sustainable patient engagement in medicines research and development for better health outcomes.**

## ACTIONS

1. Use metrics to demonstrate the impact and value of PE activities
2. Actions to grow a community convinced about the value of patient engagement
3. Actions for organisations to become truly patient-centric following structured and systematic processes
4. Promote guidelines that define what type of patient engagement data can be submitted as evidence and on how to use it



**CURRENT LANDSCAPE**

## Embed patient engagement in the mind-set, at every step and across organisations

Recognise PE as valuable and visible to all stakeholders

Embed PE across the medicines lifecycle, integrated into processes and across functions

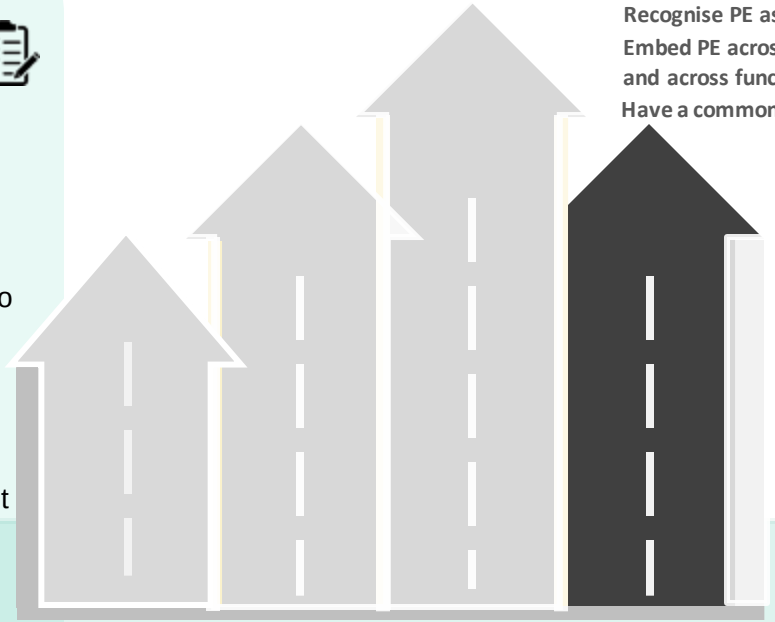
Have a common framework for patient engagement

- MONITORING & EVALUATION FRAMEWORK
- PATIENT ENGAGEMENT INTEGRATED RESOURCES
- TRAINING & EDUCATION

**Meaningful and sustainable patient engagement in medicines research and development for better health outcomes.**

## ACTIONS

1. Analyse the organisation's capabilities to decide whether further develop organisational capacity (i.e. human, financial, organisational) is needed
2. Implement a compensation framework for patients according to fair market value standards and compliant with local laws and regulations.
3. Collect data demonstrating and benchmarking patient engagement value and success in various countries in order to promote patient engagement in countries where it is not well developed.



## Embed patient engagement in the mind-set, at every step and across organisations

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## Ensure dedicated leadership and operational time, resources and funding for patient engagement

Ensure dedicated time, resources and funding

Ensure PE leadership in all stakeholder organisations

All stakeholders to have the required capabilities for PE

## CURRENT LANDSCAPE

RECOMMENDATIONS ON THE CAPABILITIES FOR PE

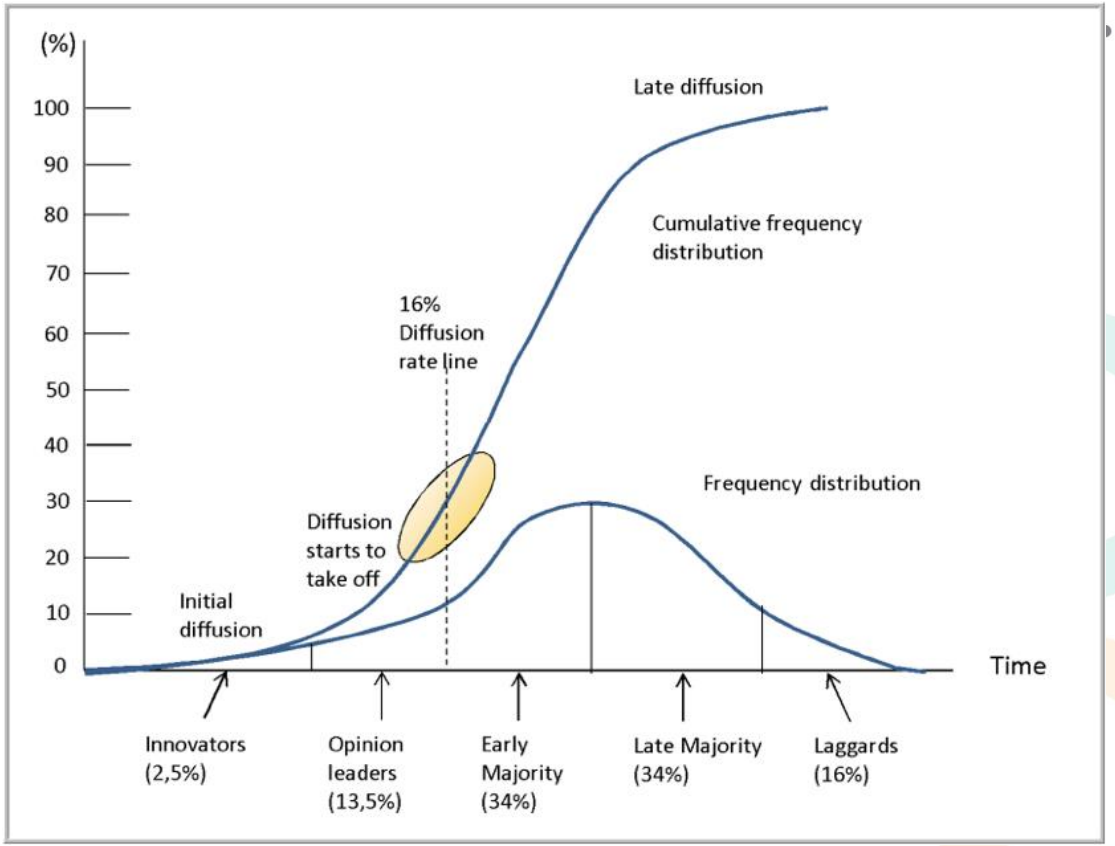
RESOURCES ON FINANCIAL COMPENSATION

TRAINING & EDUCATION

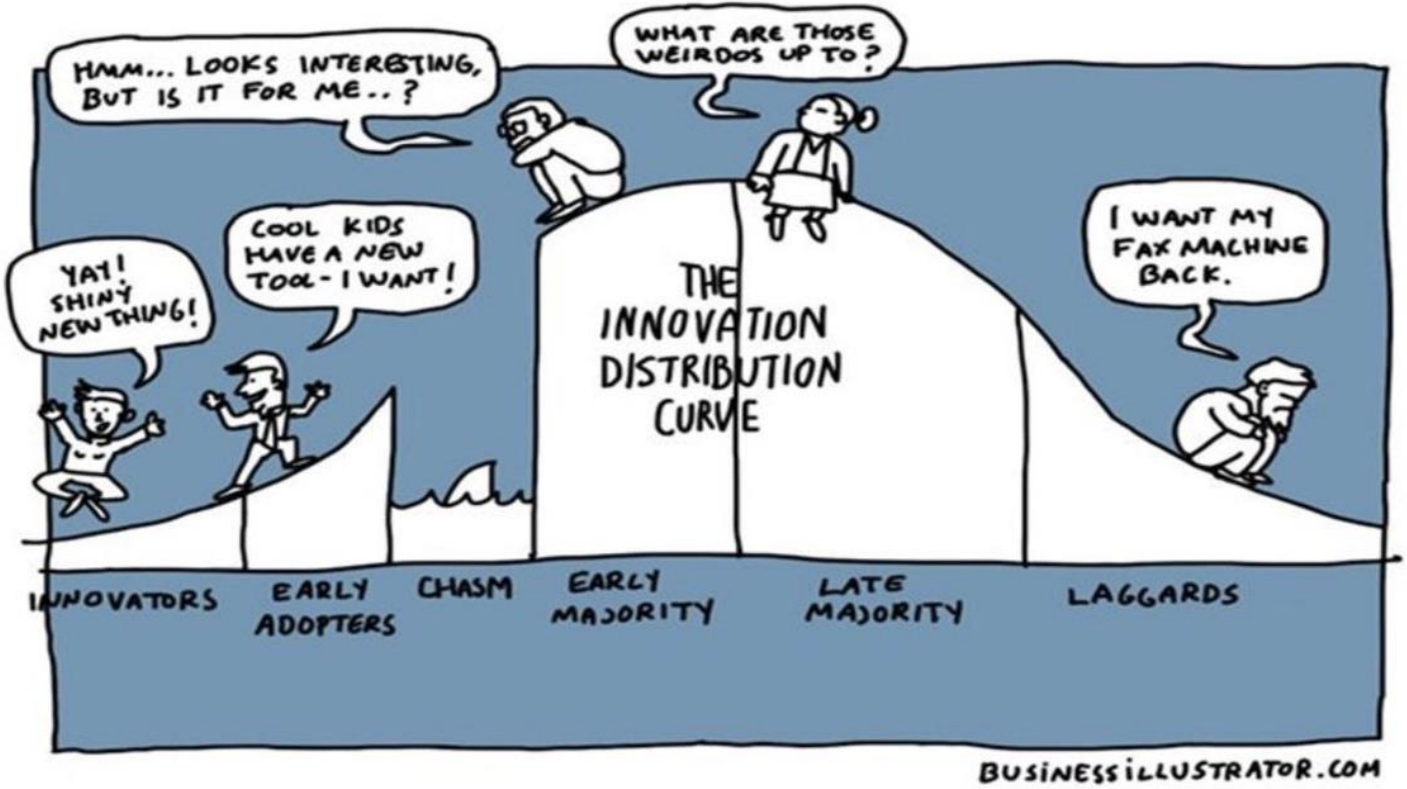
# Limitations

- Roadmap is aspirational
- Roadmap cannot be stress-tested before implementation
- Full implementation of all the elements of the roadmap may not be practical or feasible
- Everyone is responsible for the implementation. Loose collaborations will play a role in taking the strategy forward.
- Many benchmarking mechanisms to measure progress

# Adoption Curve & Critical Mass



# POLL 2 – How do you see yourself?



It’s in our hands

Thank you!

# Legal Agreements Explained

PEOF2020_July 9th, 2020

Flash session

PARADIGM

Patients Active in Research and Dialogues for an Improved Generation of Medicines

# Speakers

**Karen Topaz Druckman**
Board Member
HHT Europe


**Julia Tolley**
Operations Manager
Myeloma Patients
Europe

**Chi Pakarinen**
Programme Manager
The Synergist

# Task force

The Synergist
abpi
EURORDIS RARE DISEASES EUROPE
WECAN
BAYER
SERVIER
EPF European Patients Forum
efpia
UNIVERSITY OF OXFORD
casmi
Alzheimer Europe
EATG European AIDS Treatment Group
EFGCP
HHT europe

# In this session, we will

- Introduce the scope of the work and its background
- Present the outcomes
- Show the prototype of the online tool
- Ask you some questions
- Answer your questions

# Patient Engagement Agreements Explained project

## Where it all started

MPe
Myeloma
Patients
Europe

WECAN
Workgroup of European
Cancer Patient Advocacy Networks

PATIENT FOCUSED
MEDICINES DEVELOPMENT

# Why the reasonable legal agreements project?

- **Collaboration between pharma and patient advocates requires them to sign contracts**
- **The contracts are often too long and difficult to understand, unilateral, disproportionate,** and contain ambiguous clauses or terms that are in conflict with the nature of patient advocacy. They may even put the patient advocate at legal risk

⇒ **WECAN, the Workgroup of 22 pan-European Cancer Patient Advocacy Networks** initiated this project in 2016

# Overall objectives and goals of the project

**Objectives**

- **Improve balance between parties** by establishing model contracts
- **Allowing patient organisations to operate in their role** and purpose while protecting the pharmaceutical companies from reasonable risk
- **Incorporate patient organisation's capacity, legal expertise and experience** on potential consequences in legal contracts
- Better reflect the diversity of relationships in consultancy, advisory, speaker and collaborative roles, which are usually totally different to classical consultancy

**Goals**

- **Provide guiding principles** for reasonable legal agreements
- **Provide template contracts** with simplified terms and language
- **Prevent from unnecessary clauses** (that create unnecessary uncertainty)

# Who was involved?

## Drafting group

WECAN / MPE Myeloma Patients Europe

- Ananda Plate (MPE, project lead)
- Ana Vallejo (MPE)
- Šarunas Narbutas (POLA)
- Gordon Oliver (IBTA)
- Jan Geissler (CMLAN)
- Kathy Oliver (IBTA)

PATIENT FOCUSED MEDICINES DEVELOPMENT

- Nicholas Brooke (PFMD)
- Marc Boutin (NHC)

**Legal experts**

- Jean-Francois Germain (Fieldfisher)
- Imma Barral (University of Barcelona)

**3 pharmaceutical companies' representatives**

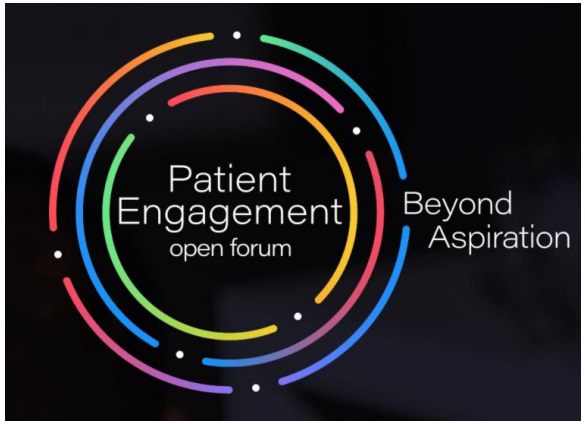
- Andrea Herrmann (Takeda)
- Jordane Fura Cosse (Novartis) – now replaced by Gregor von Arx
- Virginie Vassart (Merck MSD)

## Multi-stakeholder Alignment Workgroup (MSAW)

MSD · Bristol-Myers Squibb · Roche · Novartis · Servier · Celgene · Lymphoma Coalition

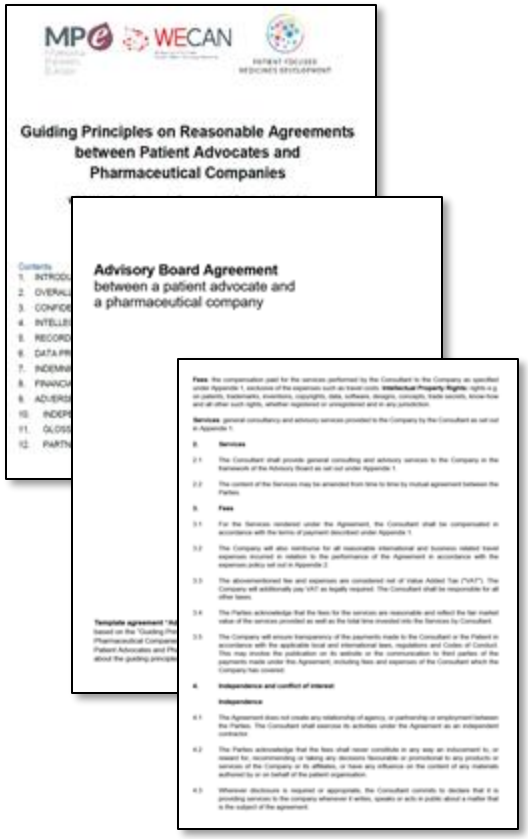
Bayer · Amgen · Pfizer · Janssen · Novo Nordisk · Takeda · National Health Council

# Reasonable Agreements presented at the PEOF2019




- Workshop for testing the Guiding Principles and reference agreements
- Additional needs identified
- Collaboration with PARADIGM starts

# PARADIGM task force - what is the shared purpose?



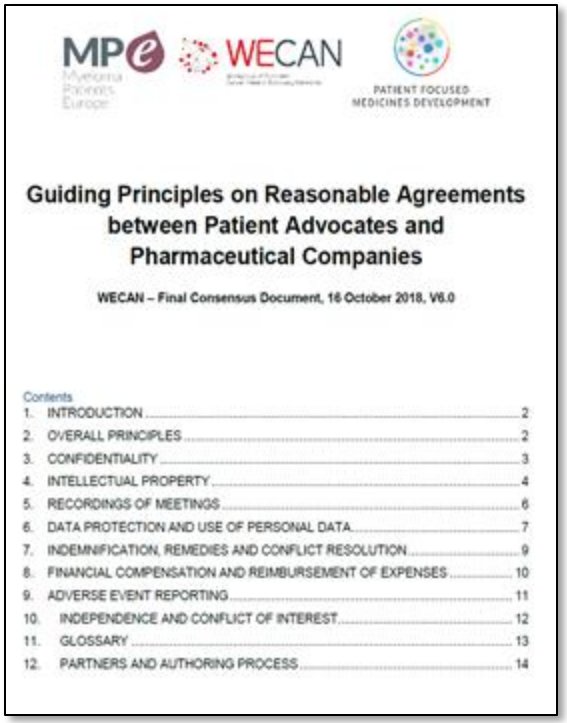

Objective:

- Create a “user guide” for the patient community
- Explain the clauses/ terminology in lay language to increase access, understandability and usability

Scope:

- Introductory part with considerations
- Guiding principles
- 4 reference agreement templates

# Structure and sections of Guiding Principles



MPE Myeloma Patients Europe · WECAN · PATIENT FOCUSED MEDICINES DEVELOPMENT

**Guiding Principles on Reasonable Agreements between Patient Advocates and Pharmaceutical Companies**

WECAN – Final Consensus Document, 16 October 2018, V6.0

Contents



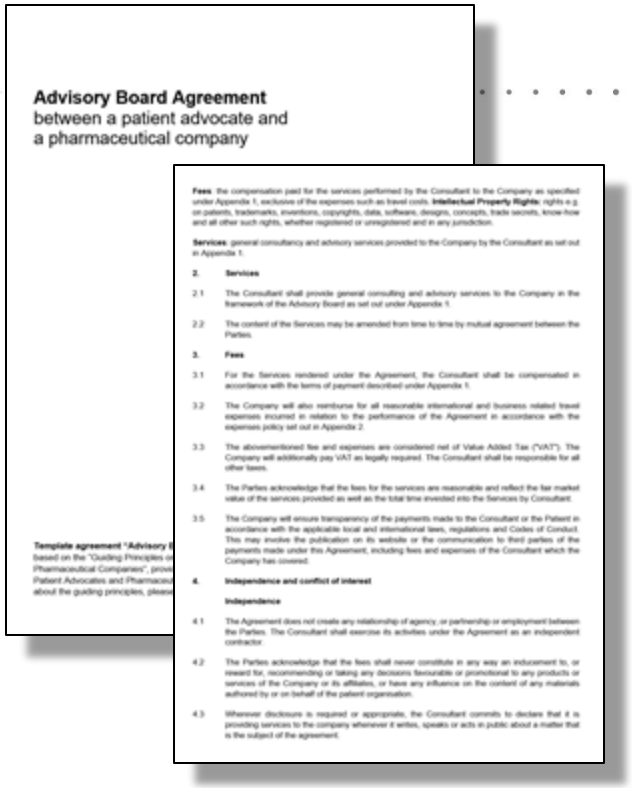
**Guiding Principles document finalized on 16 Oct 2018,**
**Ratified by WECAN on 21 Oct 2018 and PFMD on 25 Oct 2018**

**For download at**

- pfmd.org
- http://www.wecanadvocate.eu/rapp

**All sections have 3 parts:**

1. **Rationale**
2. **Examples**
3. **Guiding principles**




## Reference agreement templates:

- Advisory Board Agreement
- Consultancy Agreement
- Speaker Agreement
- Collaboration Agreement

Download at

- pfmd.org
- http://www.wecanadvocate.eu/rapp

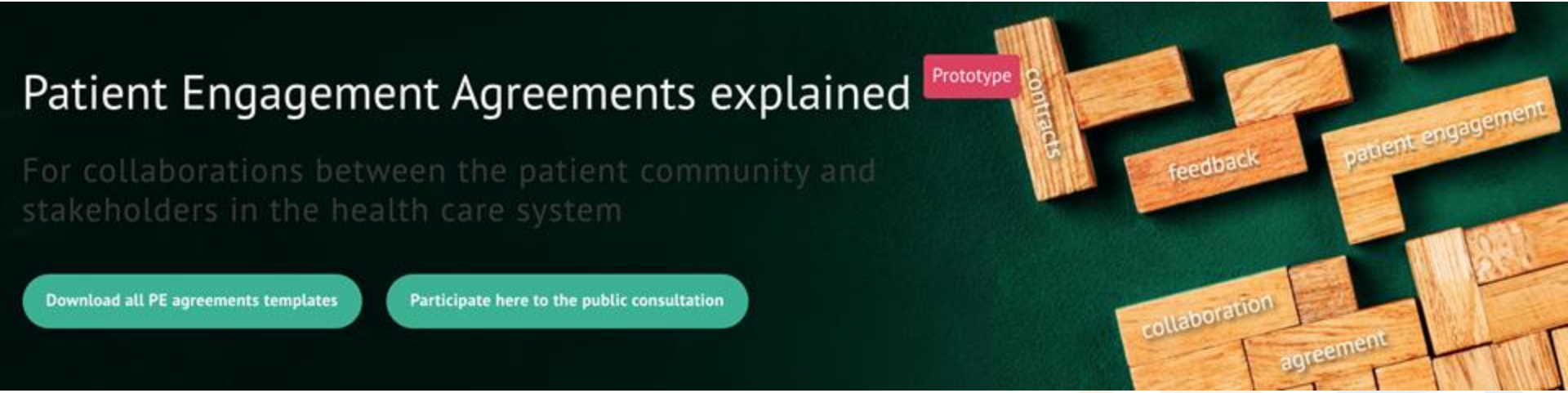
# The purpose of this work is to ultimately

**Empower the patient community**

- Knowledge and understanding
- Appearance of professionalism
- Strength in negotiation

# PE Agreements Explained is...

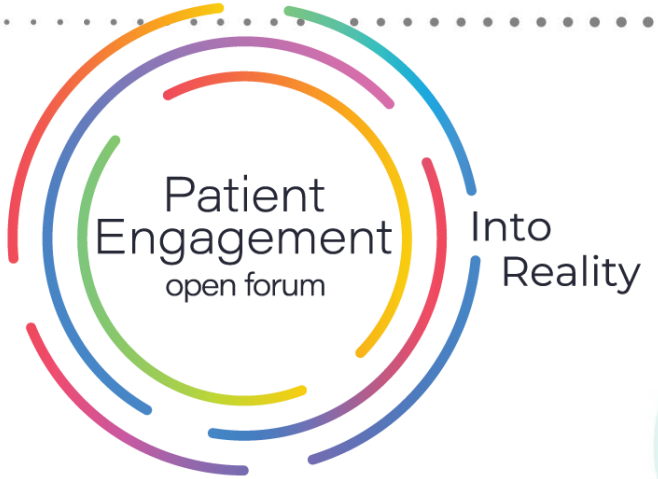
- Reference agreements explained (exportable) with exportable templates
- Easy to navigate online tool with pop-up explanations




In public consultation now - test it and give us your feedback on the usability of the digital tool

# Questions for the audience

# Q&A




# Thank you

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PATIENT FOCUSED MEDICINES DEVELOPMENT

EUPATI
European Patients' Academy on Therapeutic Innovation

# CEE Workshops and the future of PE in the region

PEOF2020_July 9th, 2020

Flash session

PARADIGM

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- Identification of the right match for the right patient engagement activity
- Conflict of interest
- Community Advisory Board
- Enhancing the EUPATI guidance
- Legal toolkit
- Toolkit for HTA bodies to facilitate patient involvement in early dialogues
- Code of conduct
- Guidance to facilitate report and dissemination of PE activities
- Monitoring and Evaluation Framework
- Capacities and capabilities

Sustainability of
the patient engagement ecosystem

# IMI PARADIGM is a European project

but strive to have global impact

**Transferability**

**and**

**Sustainability**

**are key to unlock potential**

# From Gaps to Bridges

The Future of Patient Engagement in Central and Eastern Europe

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AIPM
Innovatív Gyógyszergyártók Egyesülete
Association of Innovative Pharmaceutical Manufacturers

EPF European Patients Forum

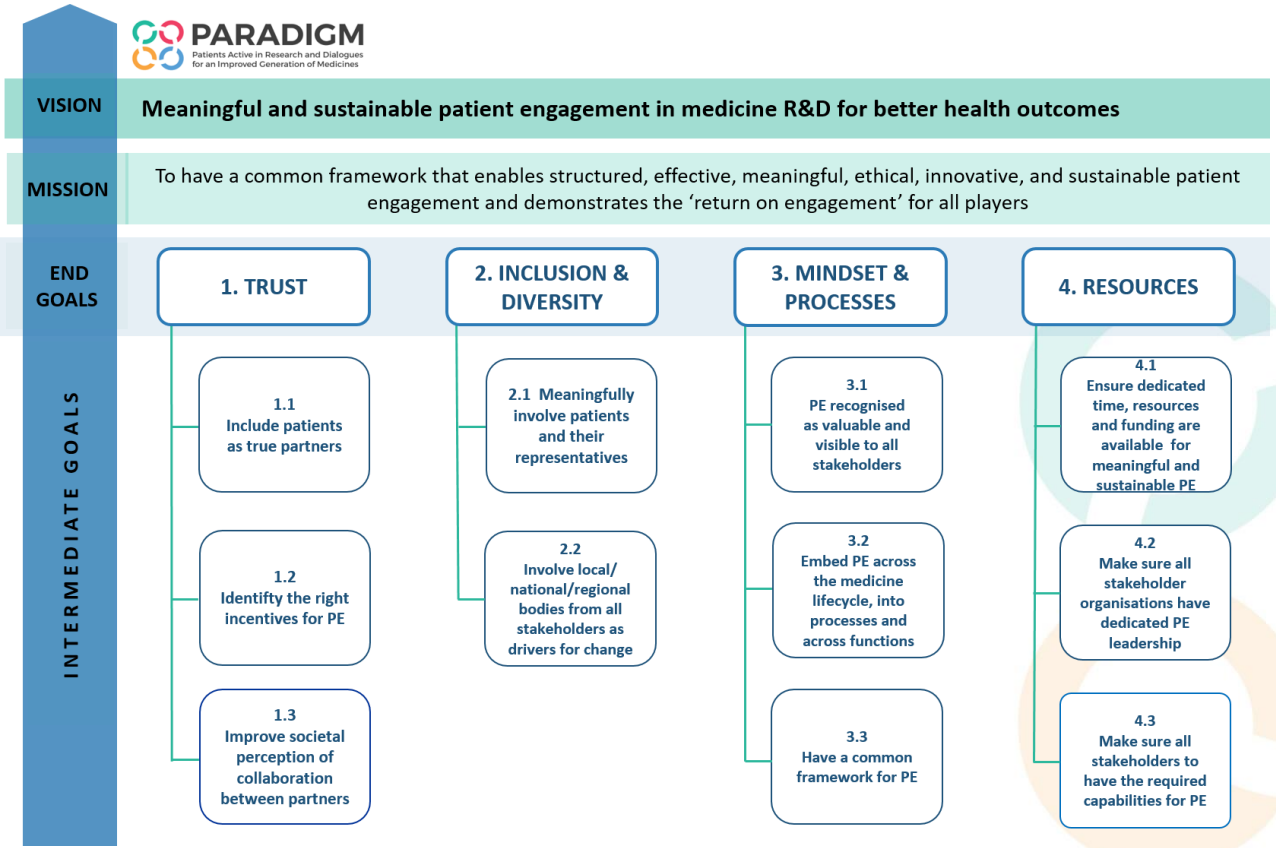
efpia
European Federation of Pharmaceutical Industries and Associations

# Stress test of PARADIGM tools

- **3 transferability workshops**
  - Sustainability of the patient engagement ecosystem
  - Monitoring and Evaluation Framework
  - Capacities and Capabilities

- May 12th, 2020

# Sustainable roadmap



# Capability framework

## Patient engagement capability framework


**Competencies:** Combination of knowledge, skills and behaviours of an individual

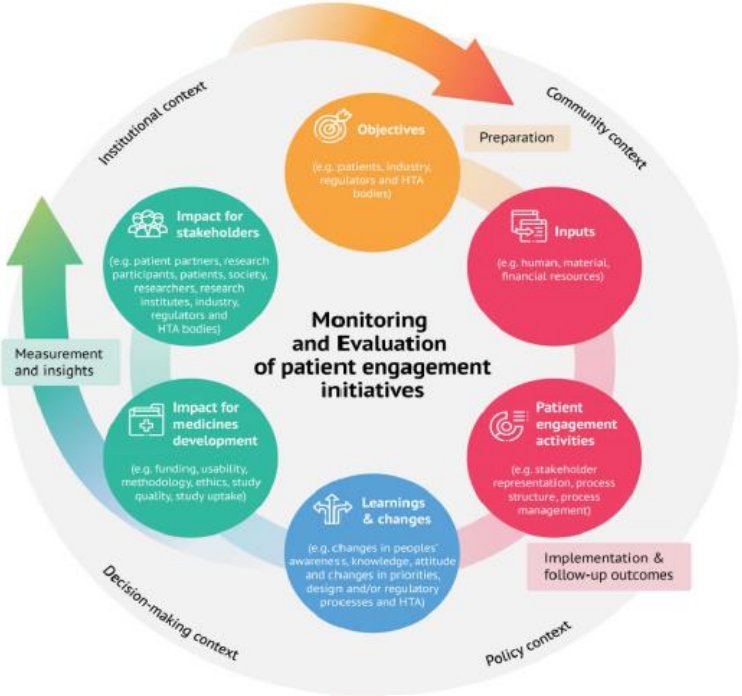
**Processes:** Processes define how things can be done. They can change in accordance with internal policies, regulations, technologies and other influences.

**Tools and systems:** Instruments necessary to perform a specific task, from technological tools to the ability to use certain systems.

**Organisation:** Refers to the organisational structure (functions) of each stakeholder group and also to an organisational culture that enables ethical and meaningful engagement.

# Monitoring and Evaluation Framework

- The framework can help to visualize the **story** of your initiative
- It provides a **map** for monitoring and evaluation
- It provides a set of possible **metrics** per element of the framework

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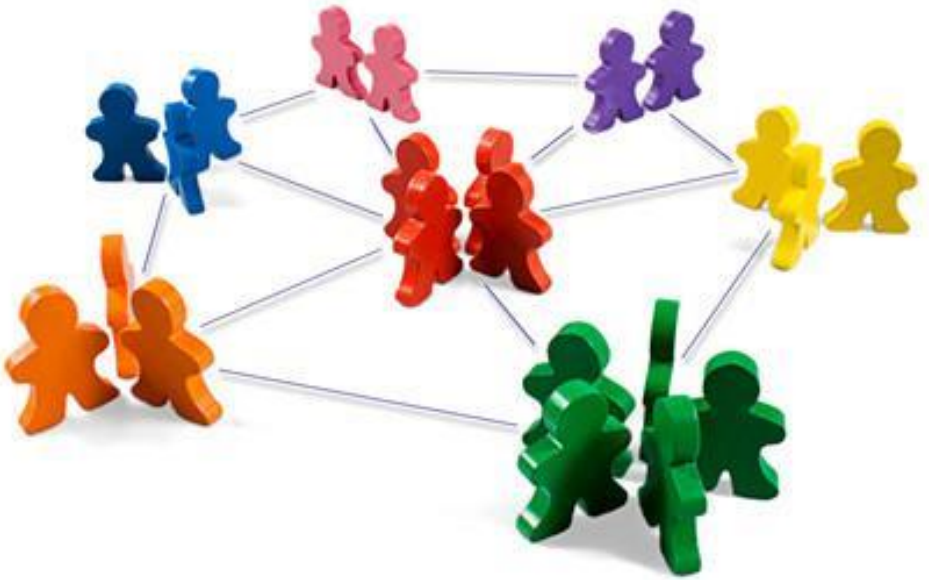
VU VRIJE UNIVERSITEIT AMSTERDAM

# Pre-workshop survey to stimulate thinking and drive discussion

- Political
- Economical
- Socio-cultural
- Technological

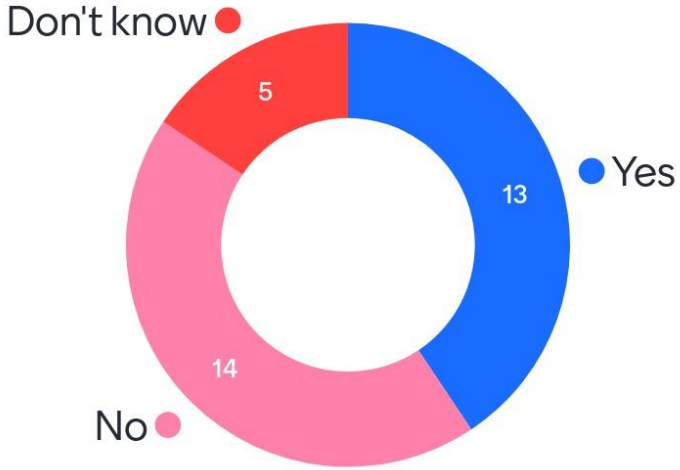


# Workshop participants

- Approx. 80 participants
  - Patients/PO
  - Industry
  - HTA/Regulator
  - NGO’s
  - Academics

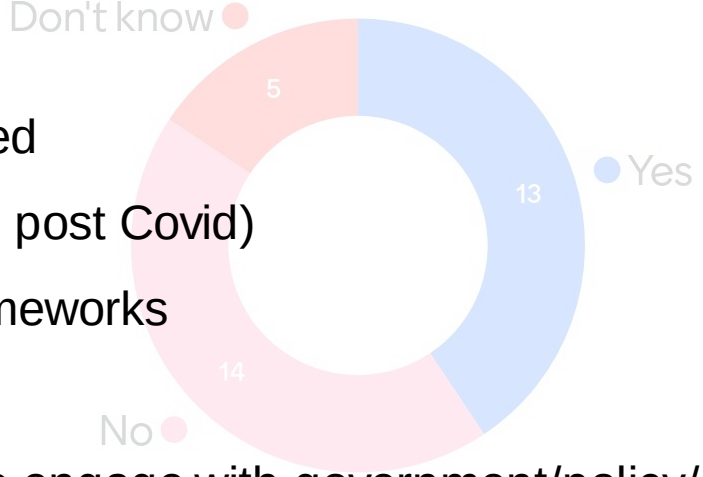
# Political factors

# Does your government encourage or mandate patient engagement in medicines R&D?



# Does your government encourage or mandate patient engagement in medicines R&D?

- Little/no interaction with government/health authorities
  - PO no seat at table
- Not recognised or valued
- Political instability (esp. post Covid)
- Lack of adoption of frameworks

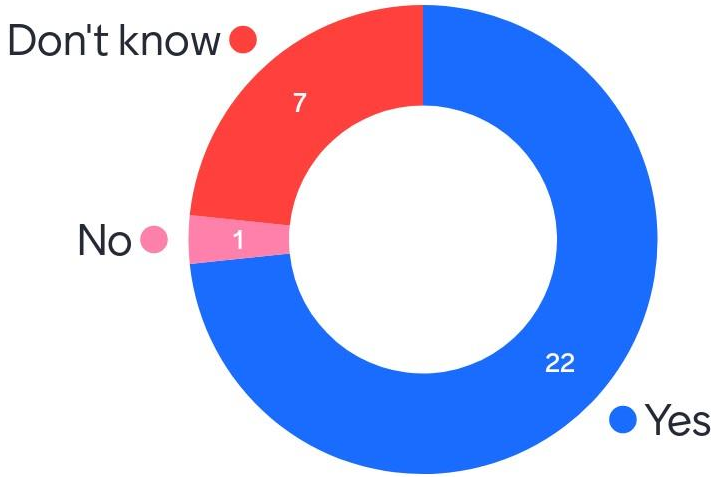




- Improved capabilities to engage with government/policy/strategy
- Improved consolidated patient voice into government.
  - different PO and different priorities

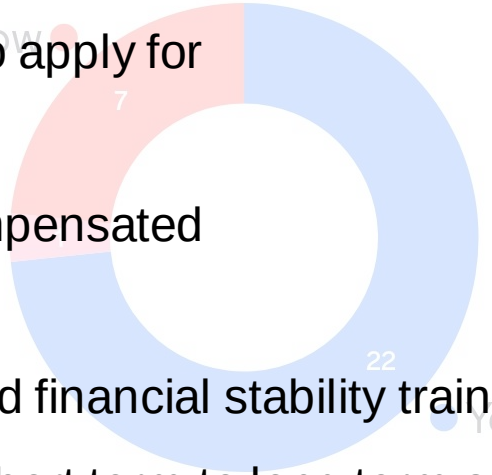
# Economical factors

# Are there any economic challenges emerging that are likely to affect the sustainability of patient engagement in your country?



# Are there any economic challenges emerging that are likely to affect the sustainability of patient engagement in your country?

- PO limited funding
- Lack of funding available to apply for
- Funding not diversified
- Patients not financially compensated

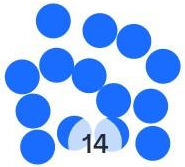



- Need strategic planning and financial stability training/education
- Change management for short term to long term sustainability models
- New cross stakeholder processes needed

# How easy is it in your country to build a skilled workforce with the right capacities and capabilities to sustain patient engagement in medicines R&D?

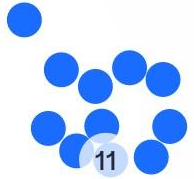
4

Very difficult



14

Difficult



11

Average

1

Easy

0

Very easy

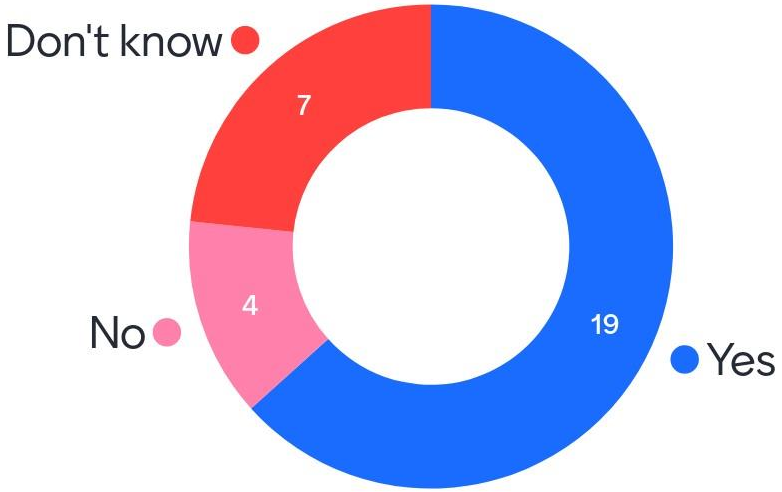
## How easy is it in your country to build a skilled workforce with the right capacities and capabilities to sustain patient engagement in medicines R&D?

- PO resources limited - human and financial
- Sporadic training
- Patient accessibility to fit needs, legal and confidentiality frameworks
- Reach vulnerable/unaffiliated patients – especially HTA
- COI is difficult in federations working across different diseases
- Fair market value needed


- Greater education and medical training –but not professionals
- Knowledge translation, practices and process - “break existing silos”
- Need flexibility, adaptability, affordability in framework- cultural differences

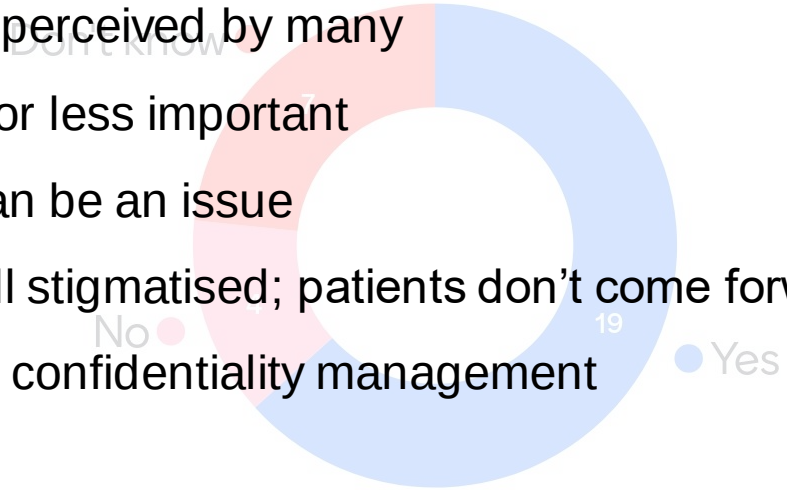
# Socio-cultural factors

# Are there any changes in socio-cultural attitudes or taboos in your country that affect the sustainability of patient engagement in medicines R&D?



# Are there any changes in socio-cultural attitudes or taboos in your country that affect the sustainability of patient engagement in medicines R&D?

- PE and PO poorly perceived by many
- Only as important or less important
- Industry funding can be an issue
- Some diseases still stigmatised; patients don’t come forward
- Transparency, and confidentiality management

# Are there any changes in socio-cultural attitudes or taboos in your country that affect the sustainability of patient engagement in medicines R&D?

New Impact metrics:

- Awareness of PE (visible in media coverage)
- Stakeholder's consideration of the value of patient engagement
- Number of new members of a Patients/PO cited as authors/contributors in research articles


As an objective:

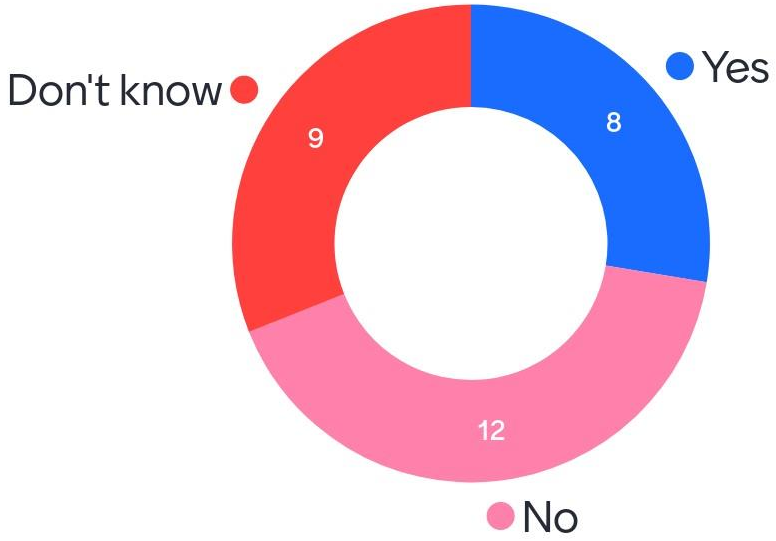
- ‘Clear, transparent and right procedures to involve POs’

Contextual factors:

- Trust and capacity
- Societal view towards PE

# Technological factors

# Do easily accessible technology infrastructures exist in your country to help organize and support patient engagement in medicines R&D?



# Do easily accessible technology infrastructures exist in your country to help organize and support patient engagement in medicines R&D?

- Some infrastructures are limited – computer access varies
- Limited cross boarder initiatives
- Some good collaborations but not always known about or have access to


# What's next?

- **Incorporate feedback into frameworks and roadmaps:**
  - New metrics added/amended -capture awareness,value
  - Priority capabilities highlighted – adaptable, affordable, culture
  - Sustainability roadmap - strategy, financial independence, implementing change

- **Possible further CEE event in 2020**
- **Possible further joint event with PEOF – in development**

## Some questions to drive the discussion

# The next PARADIGM session is on September 10th

www.patientengagementopenforum.org

**2 topics**

PARADIGM Patient Engagement Toolbox

Monitoring and Evaluation Framework

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Patient Engagement open forum Into Reality

## Thank you and happy summer!

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