Flash sessions
Sustainability roadmap
Legal agreements explained
PE in Central and Eastern Europe
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.
<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
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<td>June 25th</td>
<td><strong>PEOF2020 opening plenary (PARADIGM, PFMD and EUPATI)</strong></td>
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<td><strong>Parallel sessions:</strong></td>
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<tr>
<td></td>
<td>• Patient Engagement tools session #1 (consultation organised by PARADIGM)</td>
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<td>• Patient engagement within MedTech (panel organised by EUPATI)</td>
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<td>• Patient experience in regulatory processes (workshop organised by PFMD)</td>
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<td>June 26th</td>
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<td></td>
<td>• How to engage patients in the early phases? (workshop organised by PFMD)</td>
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<td>• Patient engagement in co-creating plain language summaries (workshop organised by PFMD)</td>
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<td>• National Health Council Patient Engagement Fair-Market Value Calculator Toolbox (organised by NHC)</td>
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<td>July 9th</td>
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<td>• Patient Engagement tools session #2 (consultation organised by PARADIGM)</td>
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<td>• Flash presentations</td>
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<td>1. Sustainability roadmap for the patient engagement ecosystem</td>
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<td>2. Patient engagement agreements explained</td>
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<td>3. Patient engagement in medicines R&amp;D in the CEE region</td>
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<td>• 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)</td>
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<td>September 10th</td>
<td><strong>Plenary session</strong></td>
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<td>• PARADIGM Patient Engagement Toolbox (webinar organised by PARADIGM)</td>
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<td>• Patient Engagement Monitoring and Evaluation Framework (workshop organised by PARADIGM)</td>
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<td>September 24th</td>
<td><strong>Parallel sessions:</strong></td>
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<tr>
<td></td>
<td>• How PE can foster access through improved affordability? (webinar organised by EUPATI)</td>
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<td>• Patient engagement in clinical trial phase or/and in the regulatory submission phase (workshop organised by PFMD – to be confirmed at a later date)</td>
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<td>• 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)</td>
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<tr>
<td>October 15th</td>
<td><strong>Parallel sessions:</strong></td>
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<td></td>
<td>• Patient Engagement and Quality by Design: Co-Developing an Implementation Roadmap for Clinical Trials (organised by CTTI)</td>
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<td>• Good Lay Summary Practice, communicating trial results to the general public - How patient engagement can work (organised by EFPIA and EFCGP)</td>
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**November 5th**

**Theme:** Regulatory

**November 23rd**

**Plenary session:**
• PEOF2020 conclusion session
Let’s work together to spread the word

#PEOF2020

@imi-paradigm
@eupatients
@PFMDwithPatient
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

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
Who are we?

Sustainability roadmap core group

Concha Mayo  Elisa Ferrer

…and 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 engagement 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

2019
- Sustainability scenarios for patient engagement

2020
- Sustainability of key PARADIGM assets
- 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) | Win – win for all stakeholders (shared purpose) |
| Trust-building (ensure everyone is being heard, neutrality, reduce false perceptions) | Keep consistency with vision and mission |
| Openness, communication (communicate on successes, failures) | |
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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?
How did we get here?

- **2018**
  - Needs assessment survey
  - Benchmarking of existing sustainability models

- **2019**
  - Sustainability scenarios for patient engagement

- **2020**
  - Sustainability of key PARADIGM assets
  - 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
Meaningful and sustainable patient engagement in medicines research and development for better health outcomes.

Our roadmap

Current Landscape

Barriers

Knowledge & experience

Human Resources

Financial

Language

Cultural

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

**Current Landscape**

- Secure inclusive and diverse patient engagement
  - Meaningfully involve patients and their representatives
  - Involve local/regional/national bodies from all stakeholders as drivers for change

- Ethical, trust-based collaboration among all patient engagement stakeholders in medicines R&D
  - Include patients as true partners
  - Identify the right incentives
  - Improve societal perception

**Intermediate Goals**

- Identify the right incentives
- Improve societal perception
- Meaningfully involve patients and their representatives
- Involve local/regional/national bodies from all stakeholders as drivers for change

**End Goal**

- Embed patient engagement in the mind-set, at every step and across organisations
  - Embed PE across the medicines lifecycle, integrated into processes and across functions
  - Have a common framework for patient engagement

- 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
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

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

- Include patients as true partners
- Identify the right incentives
- Improve societal perception

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

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.

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.

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

Include patients as true partners

- Identify the right incentives
- Improve societal perception
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

**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.

Current Landscape

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

- Include patients as true partners
- Identify the right incentives
- Improve societal perception
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

Meanfully involve patients and their representatives
Involve local/regional/national bodies from all stakeholders as drivers for change

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
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. 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.
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.

**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

**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
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.

**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

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

**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
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
HHT Europe
WECAN
Bayer
SERVIER
EPF
efpia
University of Oxford
casmi
Alzheimer Europe
EATG
EF GCP
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
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**

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

[Diagram showing interconnections between various pharmaceutical companies such as MSD, Roche, Novartis, Servier, Cegea, Lympoma Coalition, National Hereditary Council, and others, illustrating the collaboration and alignment efforts.]
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

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
CEE Workshops and the future of PE in the region

PEOF2020_July 9th, 2020
Flash session
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

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

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

- May 12\textsuperscript{th}, 2020
Sustainable roadmap

VISION

Meaningful and sustainable patient engagement in medicine R&D for better health outcomes

MISSION

To have a common framework that enables structured, effective, meaningful, ethical, innovative, and sustainable patient engagement and demonstrates the ‘return on engagement’ for all players

END GOALS

1. TRUST

1.1 Include patients as true partners

2. INCLUSION & DIVERSITY

2.1 Meaningfully involve patients and their representatives

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

3. MINDSET & PROCESSES

3.1 PE recognised as valuable and visible to all stakeholders

3.2 Embed PE across the medicine lifecycle, into processes and across functions

3.3 Have a common framework for PE

4. RESOURCES

4.1 Ensure dedicated time, resources and funding are available for meaningful and sustainable PE

4.2 Make sure all stakeholder organisations have dedicated PE leadership

4.3 Make sure all stakeholders to have the required capabilities for PE

INTERMEDIATE GOALS

1.3 Improve societal perception of collaboration between partners
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
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/policystrategy
- 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?

- Yes: 22
- No: 1
- Don't know: 7
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?
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?

- Yes: 8
- Don't know: 9
- No: 12
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 border initiatives
- Some good collaborations but not always known about or have access to
What’s next?

• Incorporate feedback into frameworks and roadmaps:
  o New metrics added/amended - capture awareness, value
  o Priority capabilities highlighted – adaptable, affordable, culture
  o 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](http://www.patientengagementopenforum.org)

2 topics

- PARADIGM Patient Engagement Toolbox
- Monitoring and Evaluation Framework
Thank you and happy summer!