



Patient engagement and Patient Expert Centre (PEC)

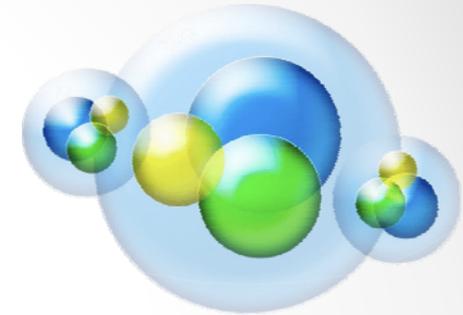
Erik Briers MS PhD

Patient advocate [Belgium]



Patient engagement

Disclosures:



- We are patients
- We need evidence based medicines
- We need evidence based treatments

This presentation contains only personal statements

Patient engagement



What do patient groups think?
At what stage do they engage with the industry?

8% of the 1,218 respondent patient groups engage with companies' drug research/drug discovery, **before clinical trials begin** (2017 was 13%).

14% **engaged in companies' clinical trials** (2017 was 13%).

7% **after clinical trials were completed**

Source: PatientView 2018 (UK)

Patient engagement



How early should patients be involved in research decisions?

Do patients have a say in the marketing authorization process (EU&MS regulatory level)?

Are patients involved in HTA & reimbursement decisions?

Patient engagement



What motivates an educated patient to participate in a clinical trial or wanting to participate in research

- This may be a **last resort** to life? Or an improvement of his/her quality of life?
- Altruism, benefit for future patients...
- Patients don't walk alone...

Clinical trials are the biggest example (not acknowledged) of citizen science! They participate with their own life and take a real risk.

Patient engagement



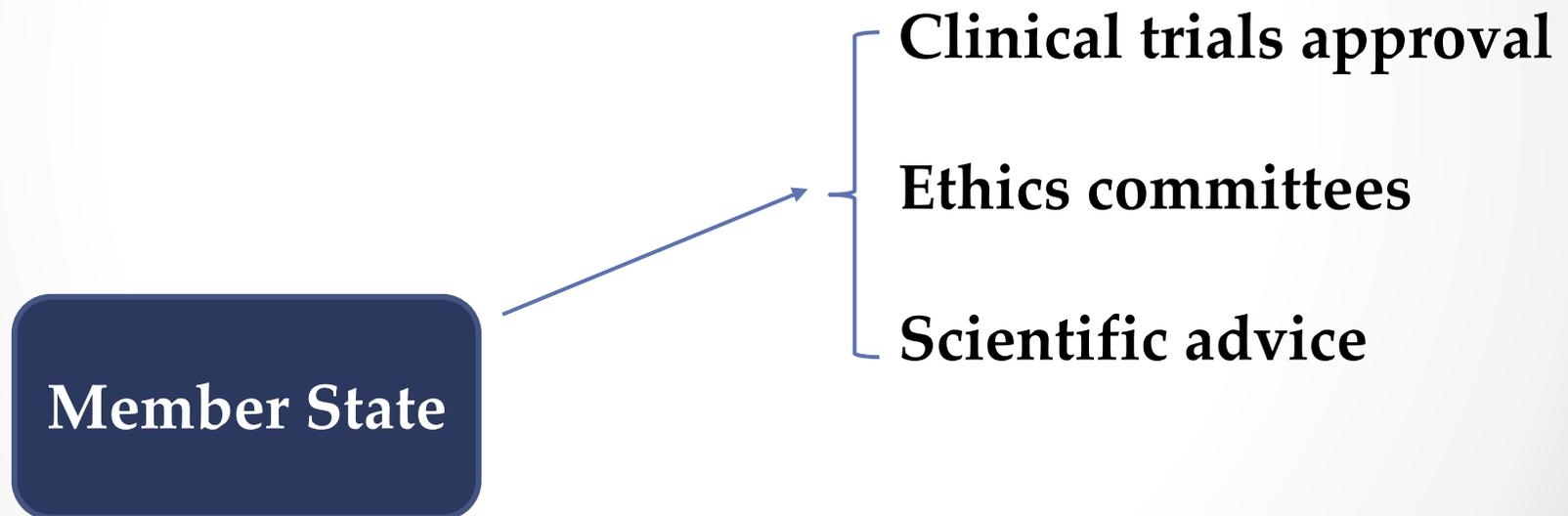
Do patients have a say in the market authorization process? [EU&MS Regulatory]



Patient engagement



Do patients have a say in the market authorization process? [EU&MS Regulatory]



Patient engagement

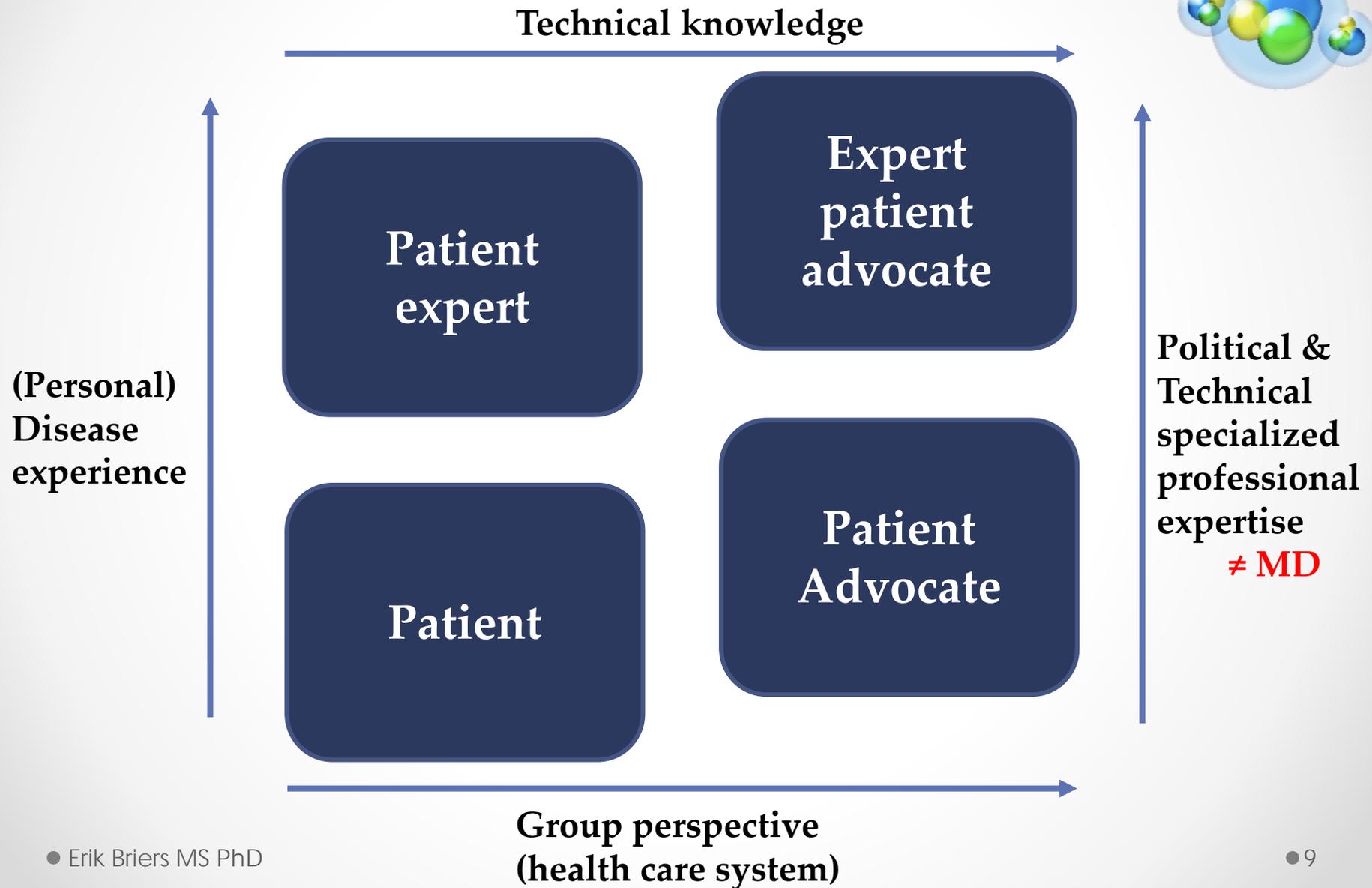


Issues:

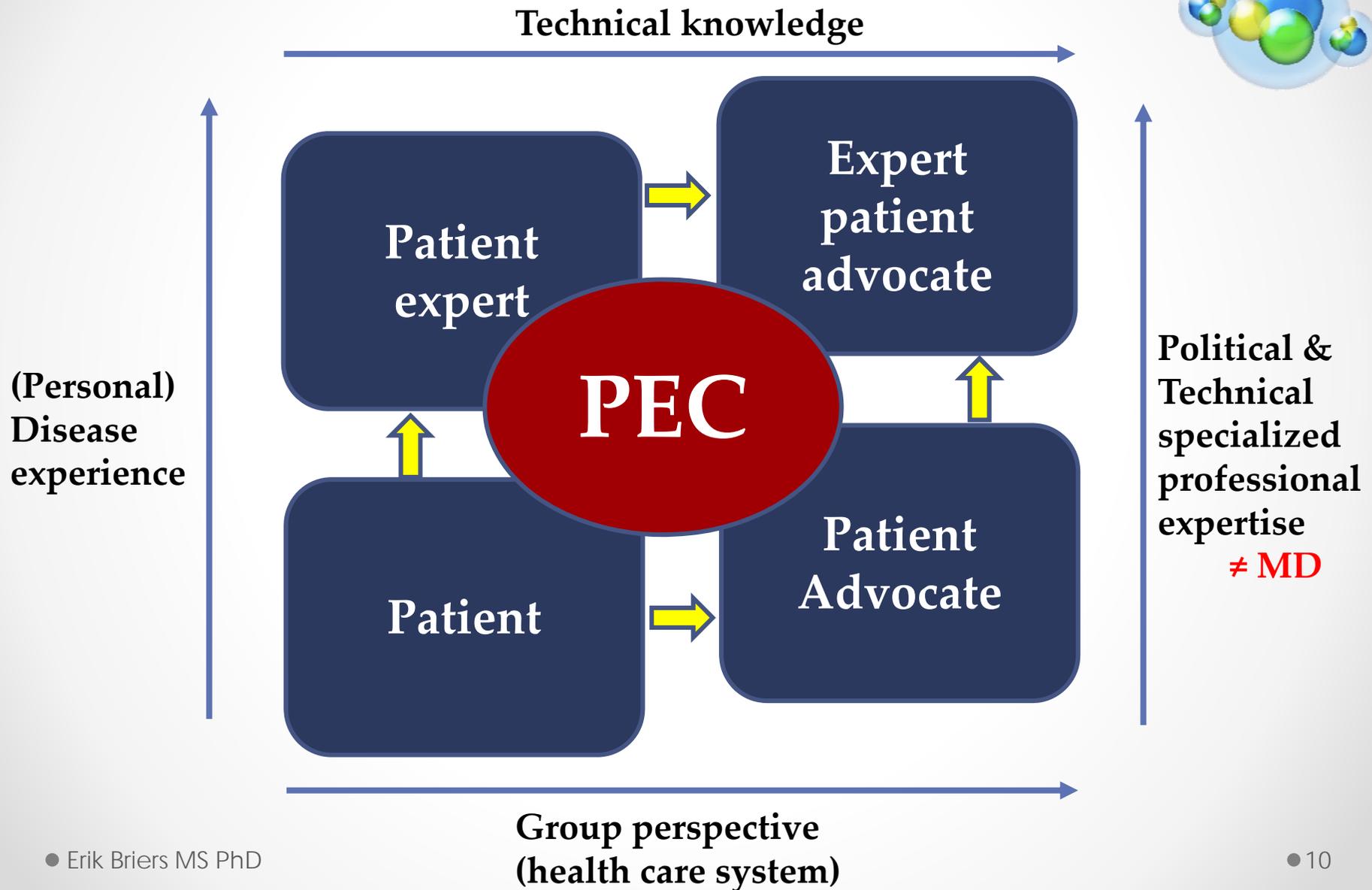
Member State

- Finding expert patients
- For real world patients (not-expert patients), how to offer training for them to be able to participate
- Language barrier, literacy barrier
- Conflict of interest (funding of patient organizations)
- Confidentiality fire wall between patient experts and pharma and between colleagues and confidential info...

Patient engagement



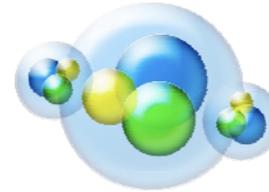
Patient engagement



Patient engagement

Patient expert

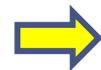
PEC



Expert patient advocate



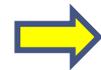
Multi-stakeholder



Patients/patient organizations



Health care professionals



Pharma



Government



Insurers

Patient

Patient Advocate

Patient engagement

Patient expert

PEC



Expert patient advocate

➔ Peer to peer

➔ Regulatory

➔ Regulatory

➔ Co-design / research RCT

➔ Regulatory

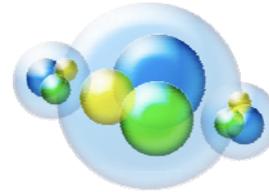
Patient

Patient Advocate

Patient engagement

Patient expert

PEC



Expert patient advocate



Generic training
Social system (Belgium)
Reimbursement
Belgian regulatory
Personal vulnerabilities
How to do “peer to peer”

Patient



Disease specific information

Patient Advocate

Patient engagement

Patient
expert

PEC



Expert
patient
advocate

Save the date!

23 April 2020 - Kick off meeting!

Patient

Patient
Advocate

Patient engagement



European Medicines Agency

2 representatives in the management board

1 representative in the PRAC (pharmacovigilance Risk Assessment Committee)

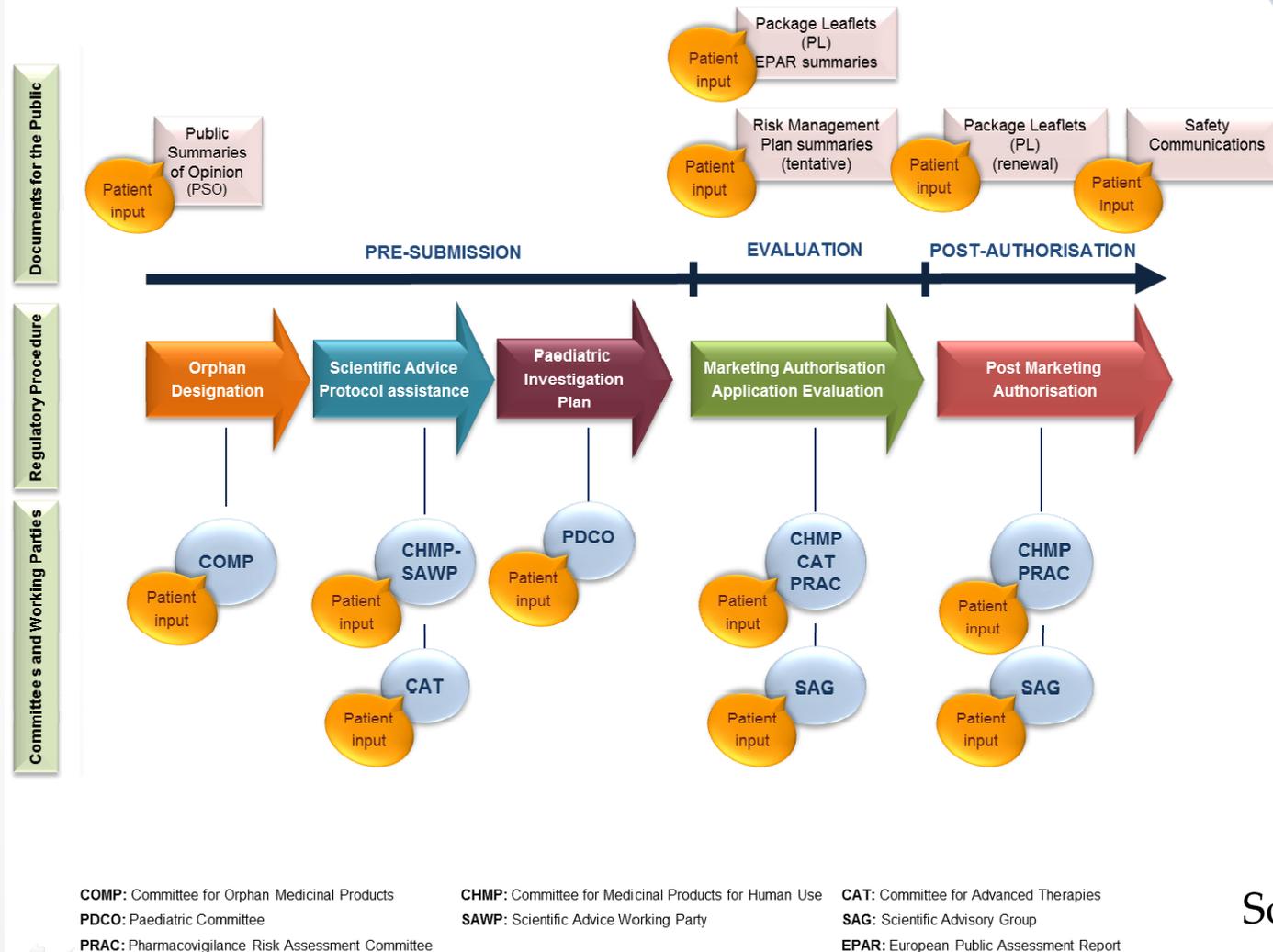
3 representatives in the COMP (committee for Orphan Medicinal Products)

2 representatives in the CAT (Committee for Advanced Therapies)

3 representatives in the PDCO (Paediatric Committee)

Patient engagement

Overview of patient involvement along the medicines lifecycle at EMA



Source EMA

Patient engagement

European Medicines Agency



Issues:

Selection of representatives of patient organizations

Commission may favour professionals

Patient organizations may also favour professionals, they fear not to be “expert” enough

Patient engagement



European Medicines Agency

Issues:

EMA is not **mono-disease** therefore they need

Expert
patient
advocates

and, everybody wants them so they are in short
supply

Patient engagement



PEC

Summary

- 1- Use well-educated patients as a resource
- 2- Involve them in a logical way as early as possible
- 3- Report “to the world” on patient involvement

Save the date!

23 April 2020 - Kick off meeting!

Patient engagement



Thank you for your attention

Questions...

