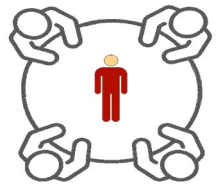
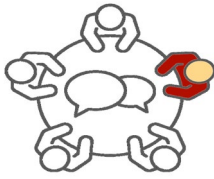


[illegible]

A collage of medical and technology icons and images arranged in a diamond pattern, representing digital health and telemedicine. The central diamond features a doctor in a white coat with a stethoscope, overlaid with a heart icon and a pulse line. Surrounding this are various other diamonds: one with a laptop displaying a red cross, another with a smartphone showing a cross and '24/7', one with a stethoscope and a heart icon, and others with abstract medical symbols like a heart, a pulse line, and a cross. The background is a light blue gradient.

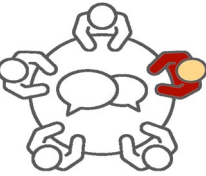


“The patient” synonyms



- **Individual Patient:** Personal experience living with a disease
- **Carer:** Caregivers supporting patients
- **Patient Advocate:** Persons who support a larger population of patients and work toward voicing their concerns
- **Patient Rep.:** Persons who are mandated to represent a patient organization
- **Patient Expert:** Persons who have received training and /or have comprehensive knowledge and experience (accredited or not)



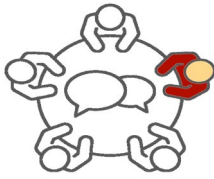


Patient Public Involvement (PPI) in R&D, clinical Research, and across the care continuum

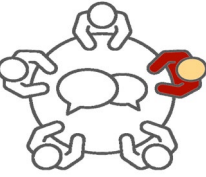




Interchangeable Terminology

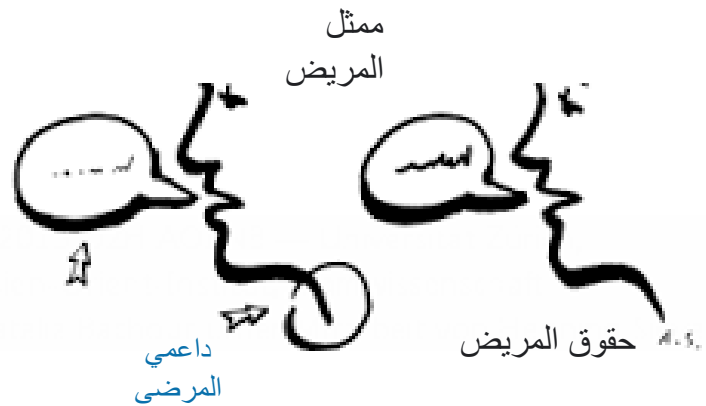


- Patient education
- Patient expert education: requiring training for a specific purpose
- The “expert” patient
- Public education: Health literacy and citizen science
- Patient’s individual education: the ability to obtain, assess and apply
- The “layman”

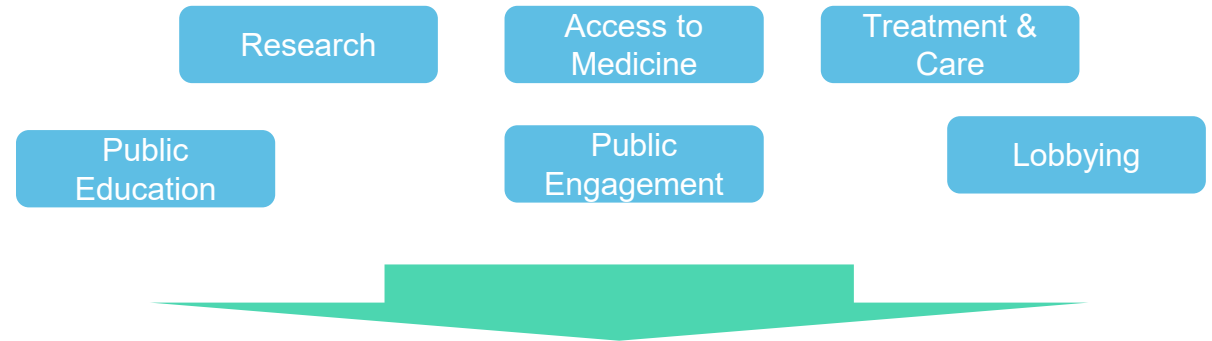


Patient Advocacy:

Are we all referring to the same thing?



Or does it depend on
where we stand / what we're "advocating":



Patient/Public Involvement (PPI) in research and Policy

PUBLIC INVOLVEMENT

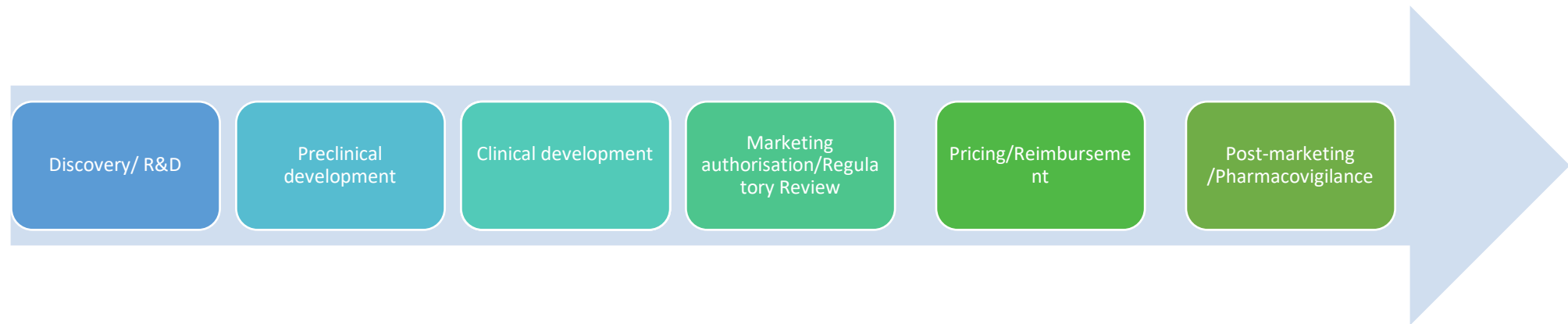
Elevating Health Literacy

Citizen Science

Changes in Legislation
requiring citizen engagement

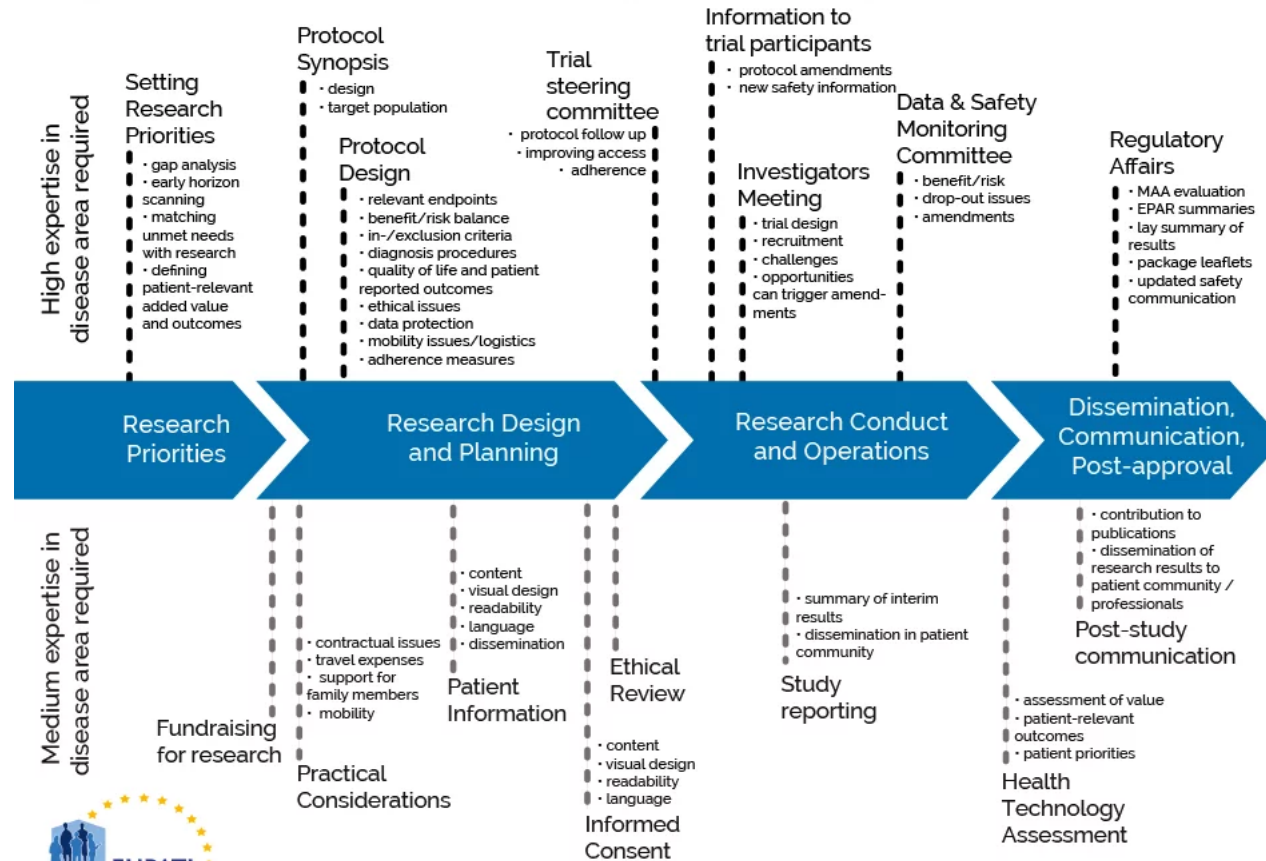
- Voting – animal experimentation
- Electronic medical records
- Data sharing

Patient Public Involvement (PPI) in Medicines R&D, Clinical Research and across the care continuum



Life cycle of Medicines and the value of PPI

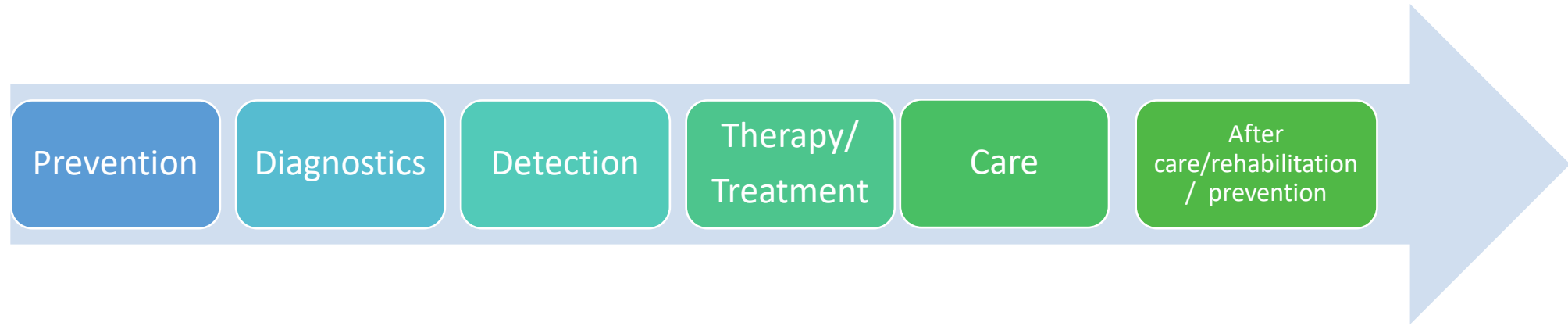
Patient involvement in medicines R&D



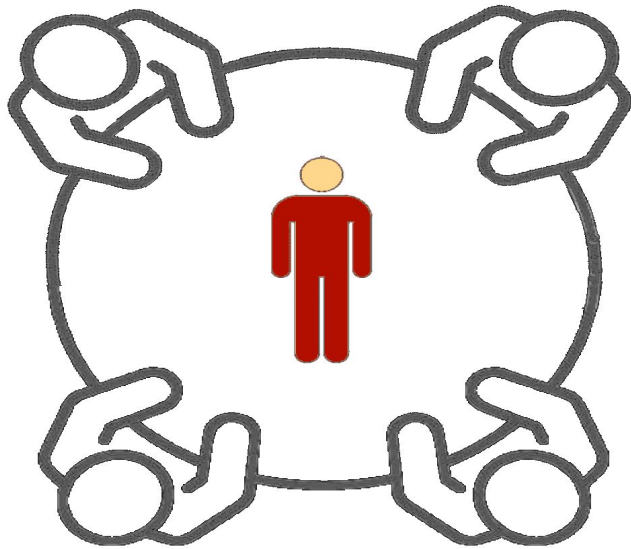
Geissler, Ryll, Leto, Uhlenhopp
doi: 10.1177/2168479017706405

Extent of patient involvement

Patient Public Involvement (PPI) in Medicines R&D, Clinical Research and across the care continuum

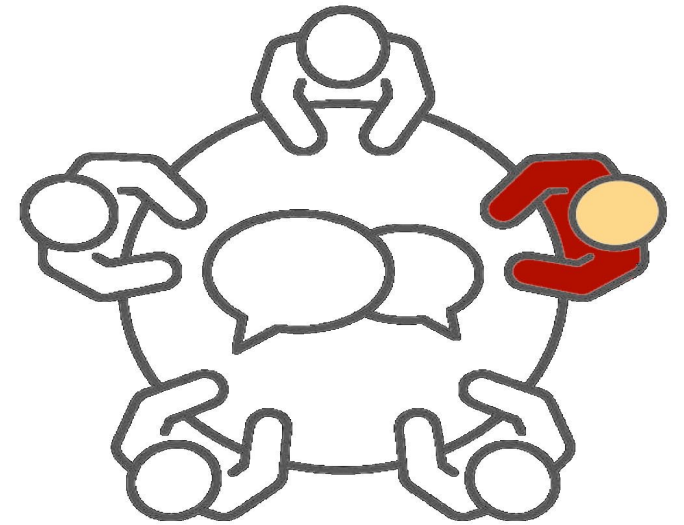


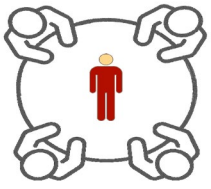
The care continuum and the value of PPI



Moving from Patient centrality to patient inclusion alongside stakeholders

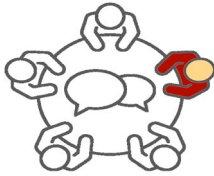
Patient partner – a value stakeholder





RECIPROCITY

Patient – Stakeholder exchange



Value of patient involvement for the stakeholder

Timely insights from the patient community:

- Enable patient relevant research
- Diversity and inclusion
- Unmet need identification
- Challenge assumptions
- Organized – cohorts
- Identify sites where specific condition is present
- DATA - ownership and readiness to share
- Clinical Trial design: retention, consent forms
- Patient reported outcomes (PROMs)

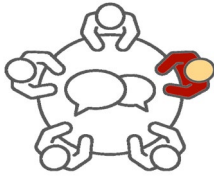
Value of Stakeholder involvement for the patient

Dialogue and exchange:

- Speed up research and innovation
- Venues and platforms for education, patient knowledge (health literacy) and citizen contribution
- Tailored communication with patients
- Unite information on a global level
- Trust - Acceptance



PATIENT EDUCATION FOR BETTER PATIENT INCLUSION



- **An education program**

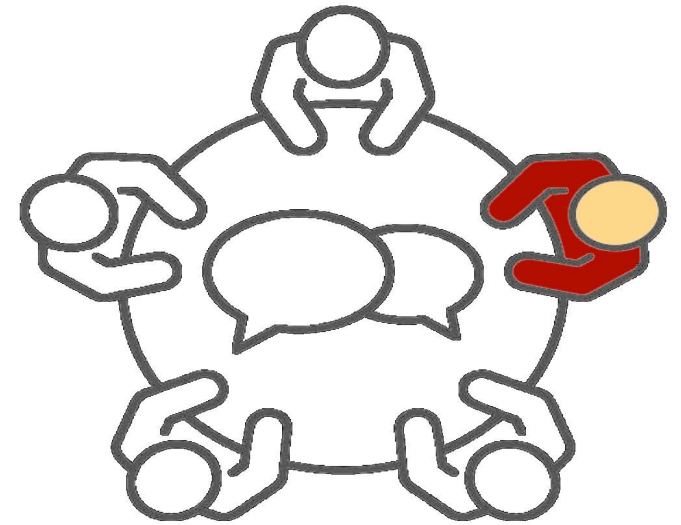
Dedicated & comprehensive

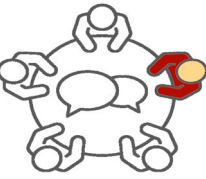
- **Expert training courses**

for a better understanding on patient engagement, partnerships, and collaborations with other stakeholders

- **Prepare patient experts**

to be effective advocates and advisors in industry, clinical research, regulatory bodies and the health authorities

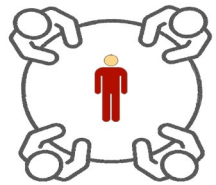




EUPATI – European Patients' Academy for Therapeutic Innovation

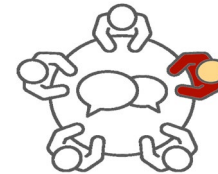
- Patient expert training course: for expert patients
- Online toolbox: For patient advocates and the public
- EUPATI “fellows”: Accredited

National platforms beyond Europe: Japan/Turkey;
in development: Czech Rep., Romania, Serbia



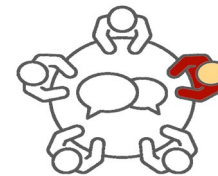
What's next?

The return on patient engagement/Inclusion initiatives



- Meaningfully assess the extent and impact of patient engagement
 - The need to develop quantitative tools and metrics (KPIs):
 - *The Patient engagement metrics selector and other measurement tools*
- International guidelines to enhance the quality of PPI reporting to strengthen the future of evidence base
- Collaboration needs to be systematically established
 - Remuneration; systematic inclusion in research

To develop accredited patient education programs that are relevant to different country contexts and language base.



thank
you