

# meaningful patient engagement in research

Bettina Ryll MD/PhD

Melanoma Patient Network Europe, founder

Vision Zero Cancer, strategist & PCM4EU WP co-lead



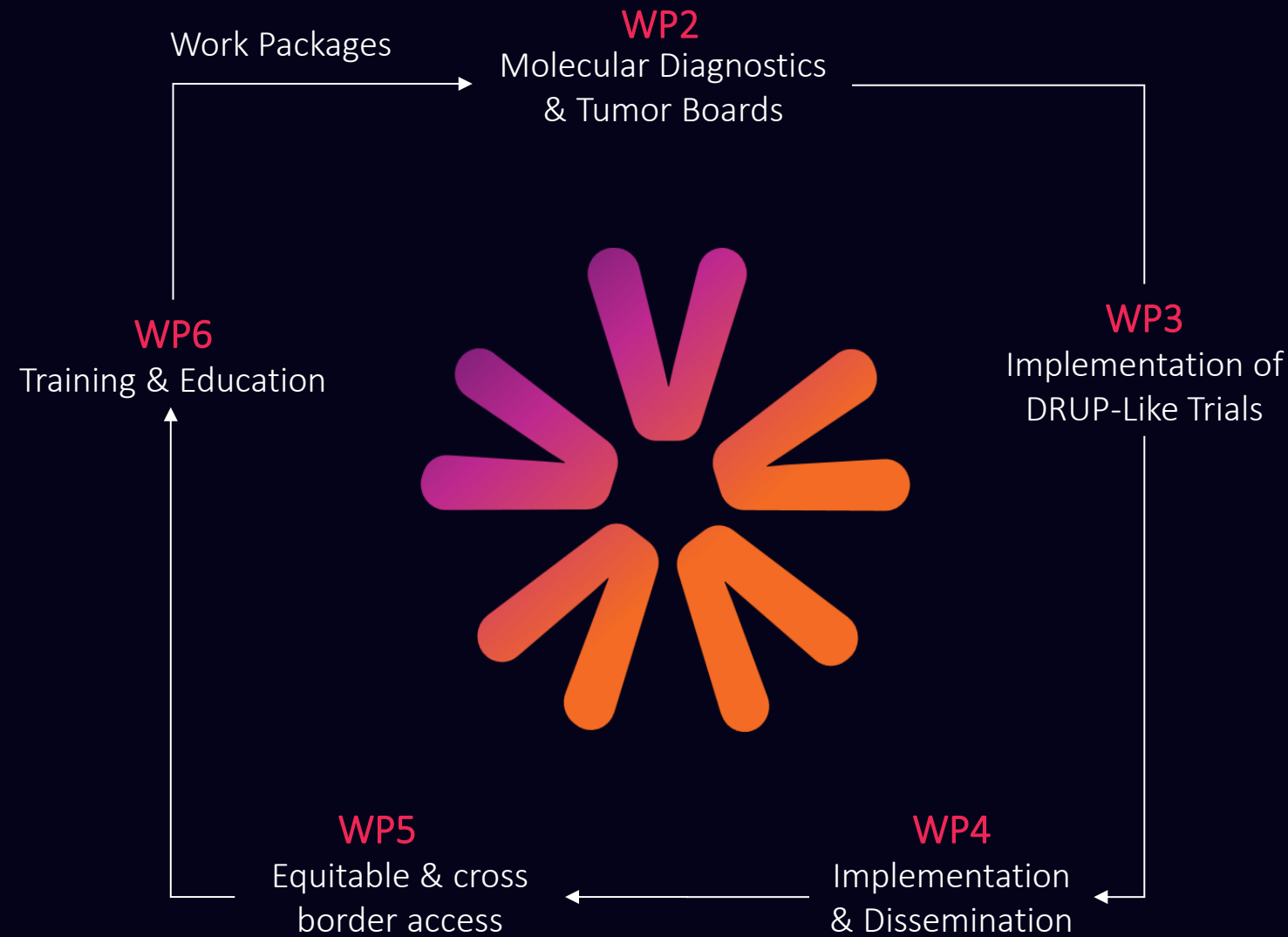
# civil society engagement

- a new norm
- increasingly expected in EU-funded projects, already a competitive advantage
- focus on **societal trust in research and innovation** and **better- more relevant, innovative and timely- outcomes**

## **‘Citizen, civil society and end-user engagement**

Citizen and civil society engagement is a programme principle and operational objective that refers to the opening up of R&I processes to society to develop **better, more innovative and more relevant outcomes**, and to **increase societal trust** in the processes and outcomes of R&I. Opening up the R&I system towards society and supporting citizens, civil society and end-users to participate in R&I – as sources of ideas, knowledge and/or data, as data collectors and/or analysers, and/or as testers and/or end users – enlarges the collective intelligence, capabilities and scope of the R&I and is likely to lead to greater creativity and robustness of the outcomes and **reduced time-to-market of the innovative products and services**. It also increases the relevance and responsiveness of R&I, ensuring that its **outcomes align with the needs, expectations and values of society**. Moreover, it is a key element for improving the transparency, **co-ownership and trust of society in the process and outcomes of R&I**. Conducting R&I openly, responsibly, transparently, and in adherence to the highest standards of research integrity and ethics is also important for **responding to increased science denial.** ....

source: [Horizon Europe program guidance, including citizen engagement](#)  
p54-56



**PCM4EU**

Personalised Cancer Medicine  
for all EU Citizens

- launched in January 2023
- 24 months- end 12/2024
- 17 partners, 15 EU countries
- coordination Leiden University Medical Centre (LUMC) - **Hans Gelderblom**



Funded by  
the European Union

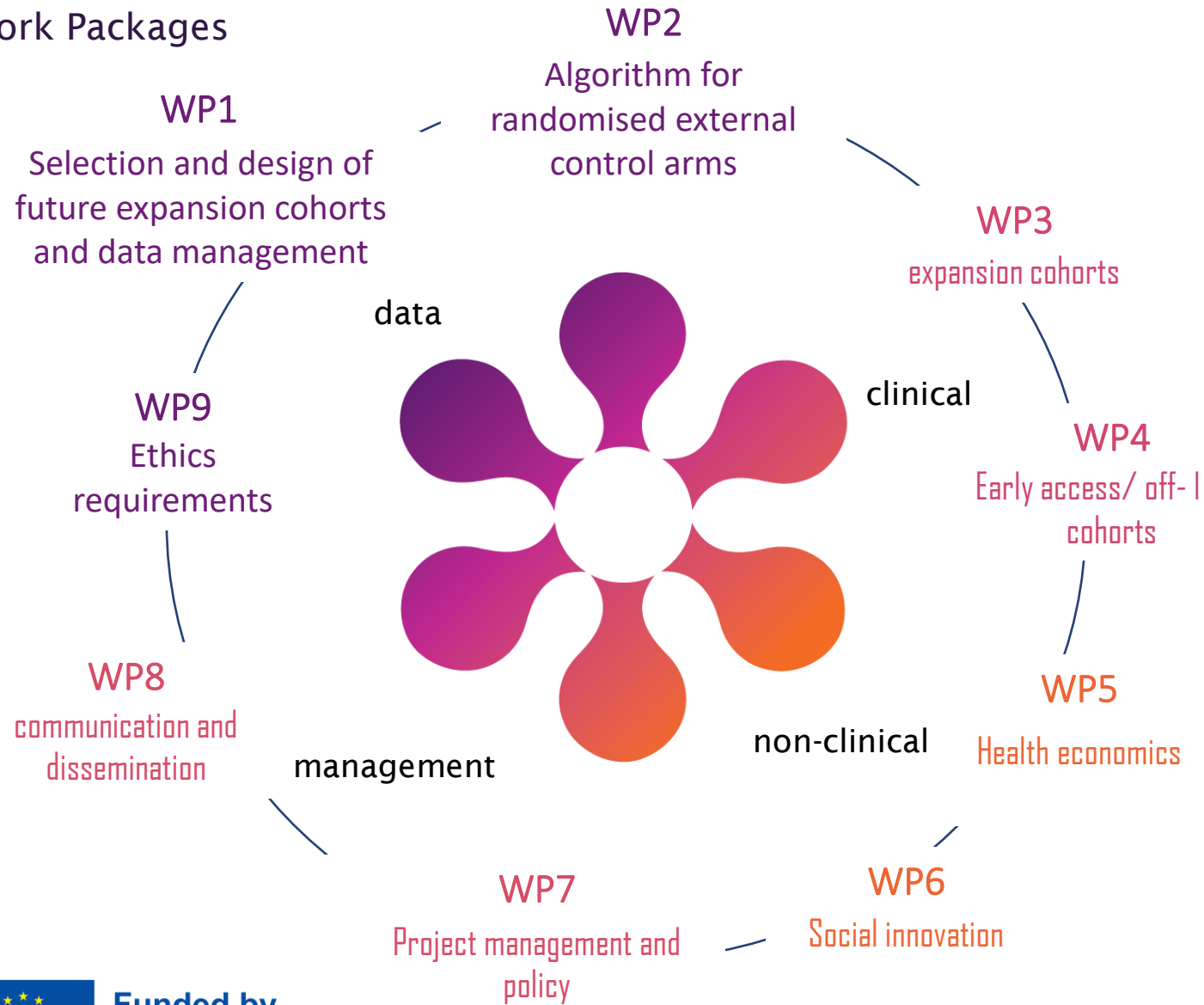


# Participating Partner Sites

PCM4EU

1. Oslo University Hospital, Oslo, Norway
2. Leiden University Medical Centre (LUMC), Leiden, The Netherlands
3. Stockholm School of Economics Institute for Research (SIR), Stockholm, Sweden
4. Capital Region, Copenhagen, Denmark
5. Helsinki University Hospital, Helsinki, Finland
6. Centre Leon Berard, Lyon, France
7. IPO PORTO, Porto, Portugal
8. Karolinska Institutet, Stockholm, Sweden
9. Region Skåne, Skåne, Sweden
10. Heidelberg University Hospital, Heidelberg, Germany
11. Maria Sklodowska-Curie Institute of Oncology, Warsaw, Poland
12. University Hospital of Split (KBC Split), Split, Croatia
13. European Institute of Oncology, Milan, Italy
14. Tartu University Hospital, Tartu, Estonia
15. National Institute of Oncology, Budapest, Hungary
16. Vall D'Hebron Institute of Oncology, Barcelona, Spain
17. National Cancer Institute, Vilnius, Lithuania

## Work Packages



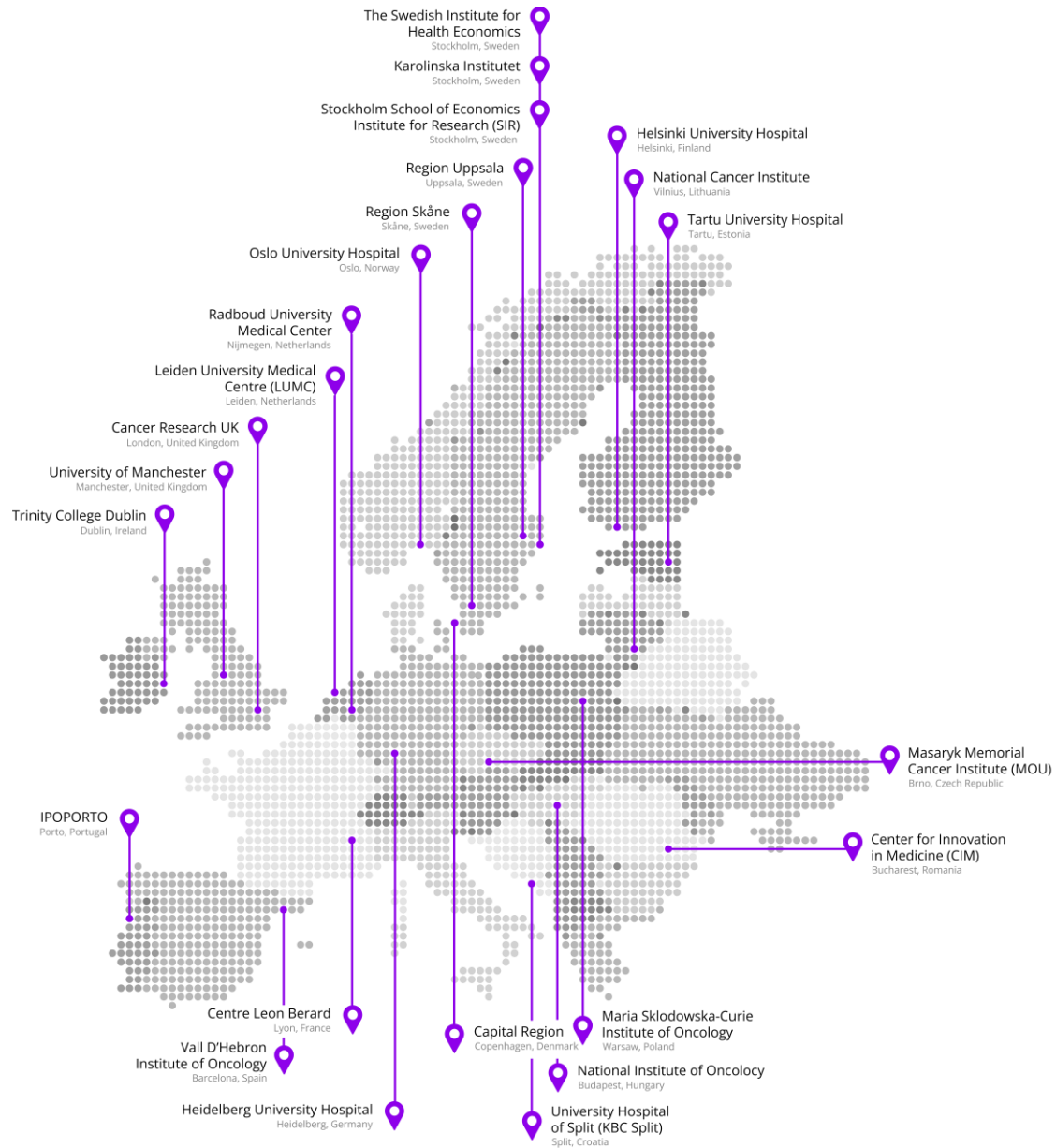
## PRIME-ROSE

Precision Cancer Medicine Repurposing System Using Pragmatic Clinical Trials

- to be launched July 2023
- 60 months- end 06/2028
- 24 partners, 18 EU countries
- coordination Oslo University Hospital (OUS) – **Kjetil Taskén**



Funded by  
the European Union



# Partner Sites

## PRIME-ROSE

1. Oslo University Hospital, Oslo, Norway
2. Leiden University Medical Centre (LUMC), Leiden, The Netherlands
3. Stockholm School of Economics Institute for Research (SIR), Stockholm, Sweden
4. Capital Region, Copenhagen, Denmark
5. Helsinki University Hospital, Helsinki, Finland
6. Centre Leon Berard, Lyon, France
7. IPO PORTO, Porto, Portugal
8. Region Uppsala, Uppsala, Sweden
9. The Swedish Institute for Health Economics, Stockholm, Sweden
10. Karolinska Institutet, Stockholm, Sweden
11. Region Skåne, Skåne, Sweden
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16. National Institute of Oncology, Budapest, Hungary
17. Vall D'Hebron Institute of Oncology, Barcelona, Spain
18. Radboud University Medical Center, Nijmegen, The Netherlands
19. National Cancer Institute, Vilnius, Lithuania
20. Cancer Research UK, London, United Kingdom
21. University of Manchester, Manchester, United Kingdom
22. Trinity College Dublin, Dublin, Ireland
23. Masaryk Memorial Cancer Institute (MOU), Brno, Czech Republic
24. Center for Innovation in Medicine (CIM), Bucharest, Romania

# disclaimer

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While BR drafted all figures, these represent the collective intelligence and learnings of communities that are actively involved in patient engagement in research: patient advocates, researchers, research institutions as well as research funders.

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# Patients versus patient advocates and domains of expertise

## Definition

### Patient\*

concerned with own condition

### Patient expert

Patient with specific high-level expertise

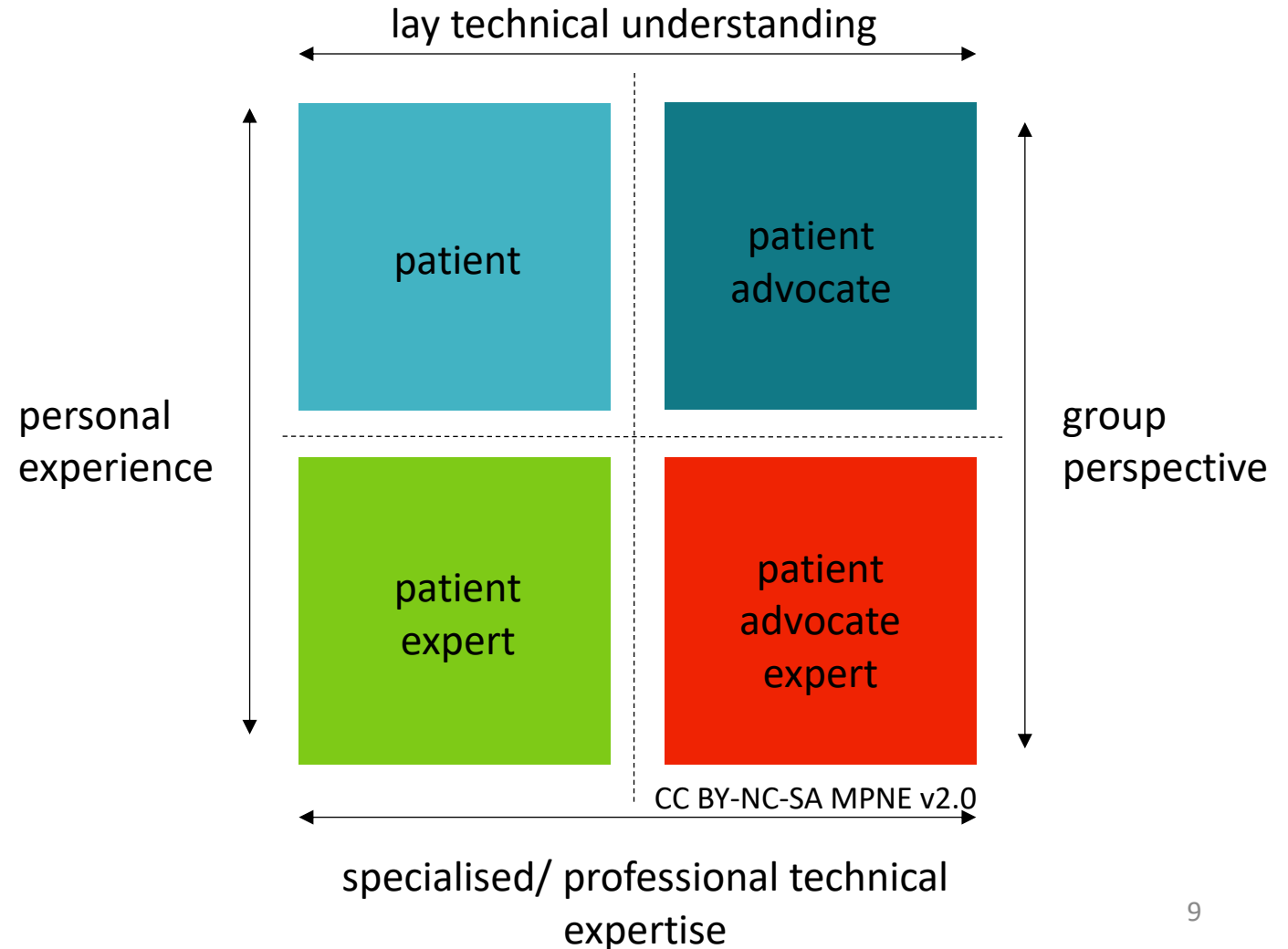
### Patient advocate\*

concerned about the group of people with condition

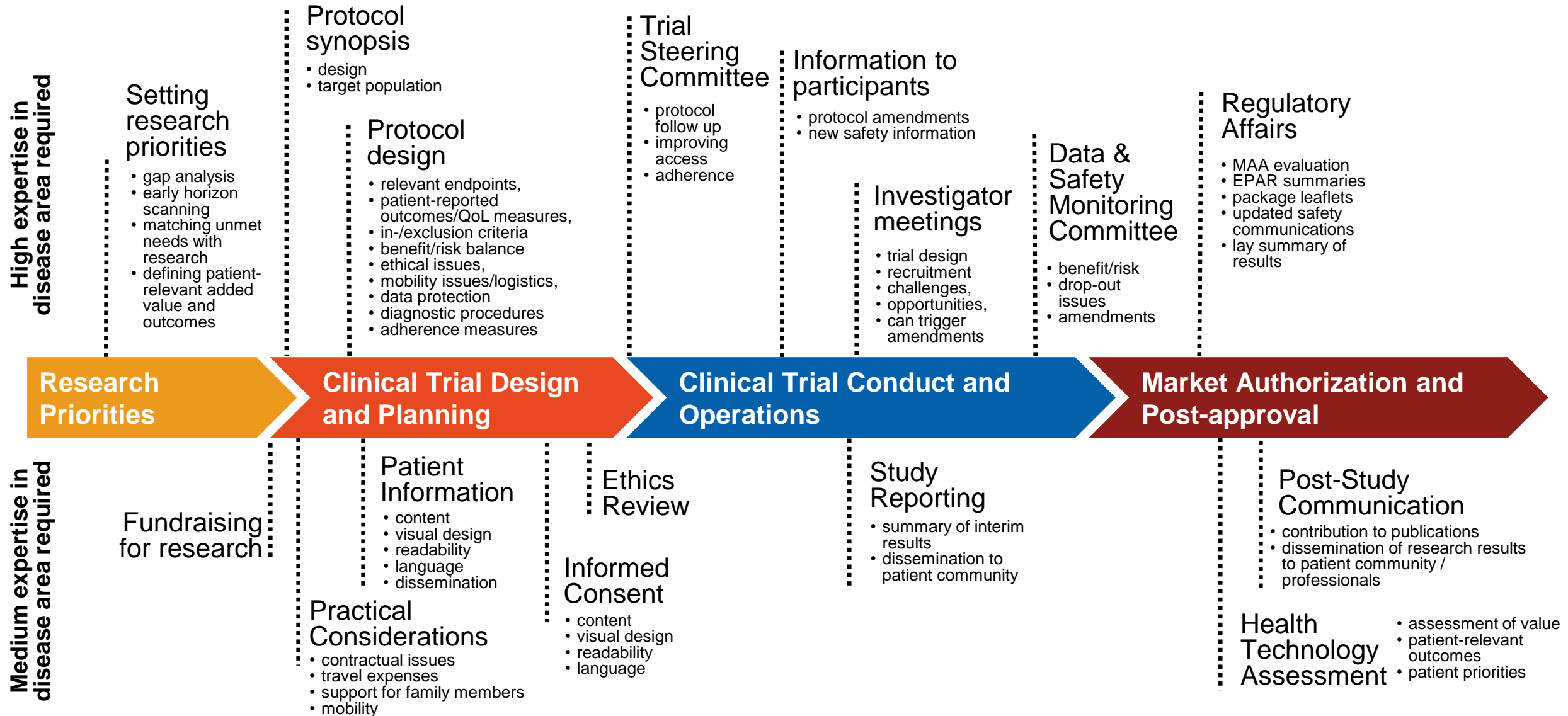
### Patient advocacy expert\*

Patient advocate with specific high-level expertise

\*part of the first definition by the ESMO PAWG in 2015



# Patient involvement in clinical development in practice



# structure for patient engagement

## who

citizens:  
lay patients and  
general public

civil society organisations:  
organised patients  
with/ without  
technical background

(organised) patients with technical  
background

B.Ryll

## why

**social responsibility** transparency  
and responsibility towards society,  
making Science accessible

**strategic alliances**  
group perspective on needs, expectations  
and values in a condition- commonalities  
and diversity/ variance; **important  
national stakeholder group**

**expertise**  
access to complementary/ novel  
expertise and networks

## what

outreach, awareness, trust;  
also: citizen councils

regular interaction, information  
exchange, important target group for  
education as POs are a trusted resource  
for patients

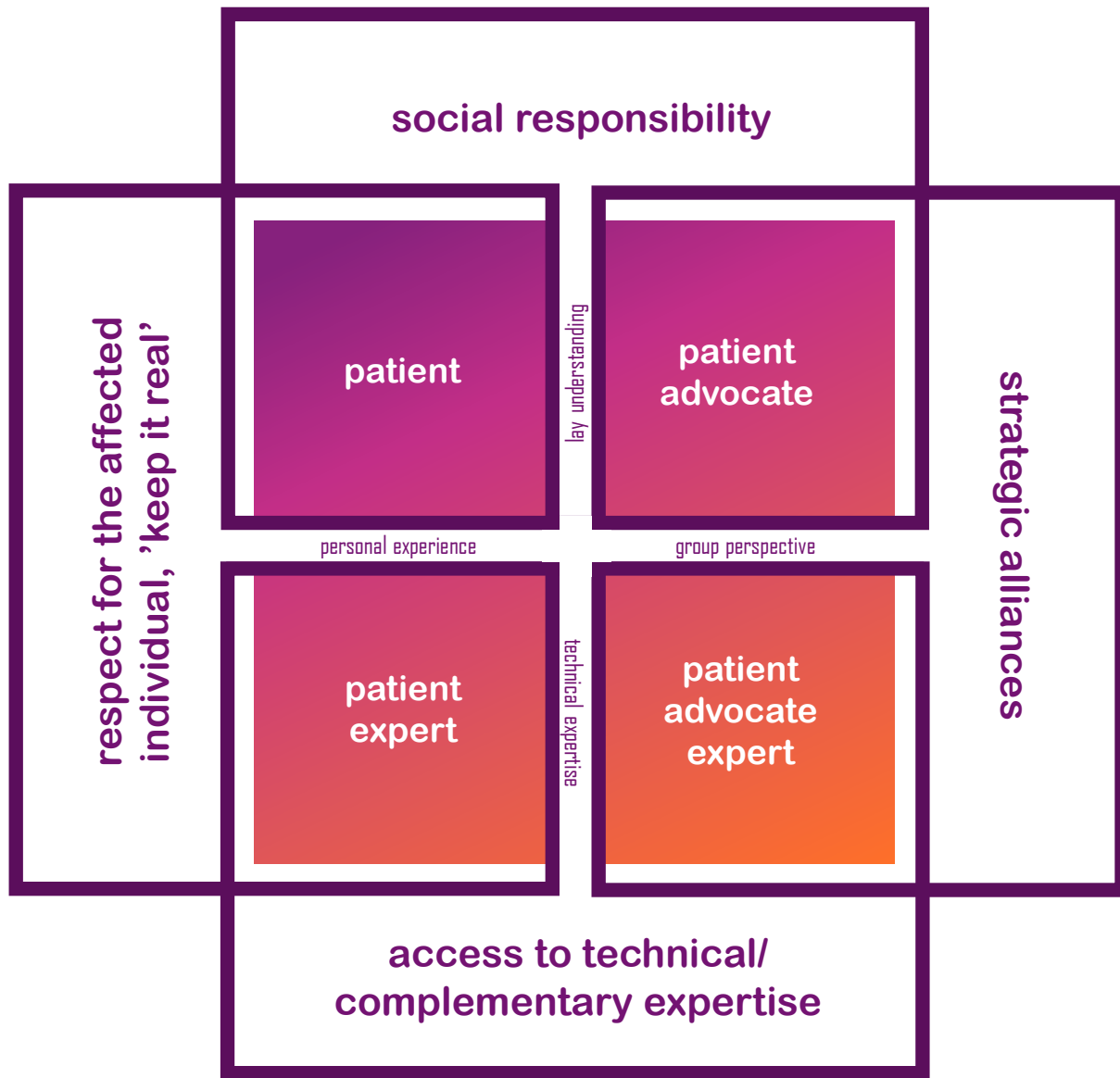
collaboration based on concrete  
projects for mutual benefit



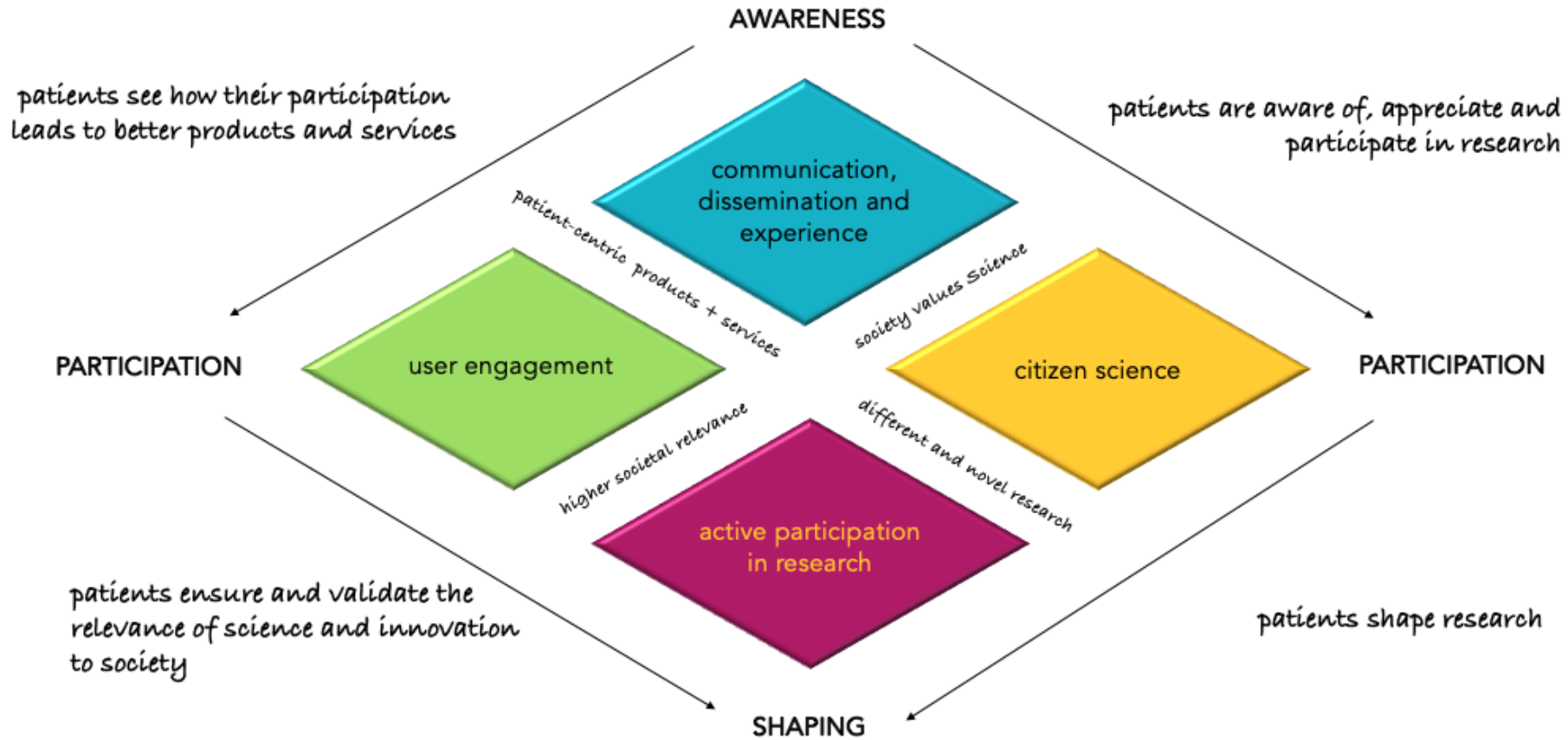
*directionality of communication and action*



# Concepts of patient engagement



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patient ability to define and shape



patient time invested



patient's expertise outside disease experience required



# Concepts of patient engagement

## who/ challenge

**citizens: lay patients and general public**  
*takes time, not everyone understands why this is important*

**civil society organisations:  
organised patients with/ without technical background**  
*highly heterogeneous community with variable levels of knowledge, specialists often hard to reach, one can get caught in politics*

**(organised) patients with technical background**  
*knowing where to find them, you are competing for their attention, relies heavily on trust*

## example activities

- lay communication, general press
- public lectures, Night of Science, Open Days
- novel approaches, e.g. Arts and Social Science, e.g. new EIT program

- patient group involved in trial design and running, research projects
- attend patient conferences, volunteer as speaker or educator
- this group should be a major target for education, especially those looking after patient forums- most effective against fake news
- national policy work

- trial strategy, design and analysis
- write research grants
- European policy work
- concrete projects- e.g. PCM4EU cross-border access to clinical trials

## benefit to researcher

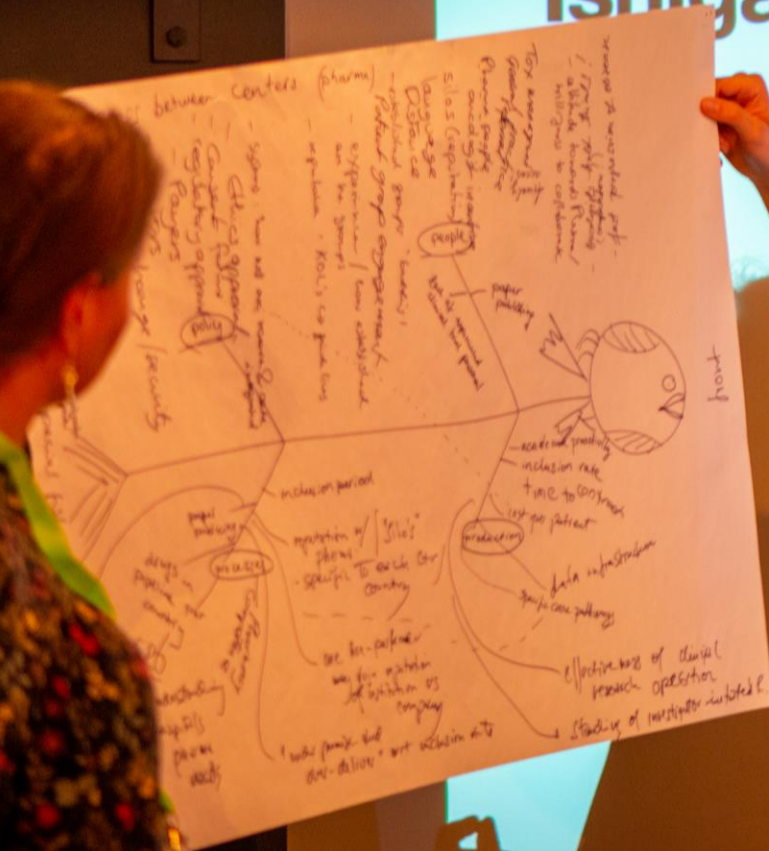
- improved communication, writing & presentation skills
- broader appreciation of your work outside the usual community
- motivation for staff
  
- depending on specific patient community
- understanding of the patient community in its diversity- problems often arise in odd places
- access to patient communities DO NOT ABUSE THIS
- support system for your patients
- strategic alliances
  
- unusual and complementary knowledge
- treat as collaboration between different disciplines
- opportunity to try new things

# Ishigawa ("Fishbone") Diagram

Bureaucracy  
Law  
Habit  
Tradition  
Policy

Patients  
Researchers  
Stakeholders  
Gatekeepers  
People

Production  
Drugs  
Diagnostics



# rules of engagement

- focus on a topic of shared relevance
- engagement for mutual benefit based on respect and trust
- fairness towards everyone: attention to diversity of perspectives and expertise as well as power imbalances in the room
- non-binding opportunity for experimentation, exploration and learning
- intellectual stretch & ambition & fun



# patient engagement in research should be

- meaningful and serve a purpose
- appropriate and proportionate
- respectful and constructive
- mutually beneficial

# References

- [Horizon Europe program guidance, including citizen engagement p54-56](#)

## MPNE material

- [Patient engagement in research 1-0-1](#)
- [Understanding the difference between patients- patient advocates and patient advocacy experts](#)
- [Different types of patient engagement in research](#)
- [V2A2- How to write accessible patient information](#)

Thank you

[bettina.ryll@mpneurope.org](mailto:bettina.ryll@mpneurope.org)