ACADEMY
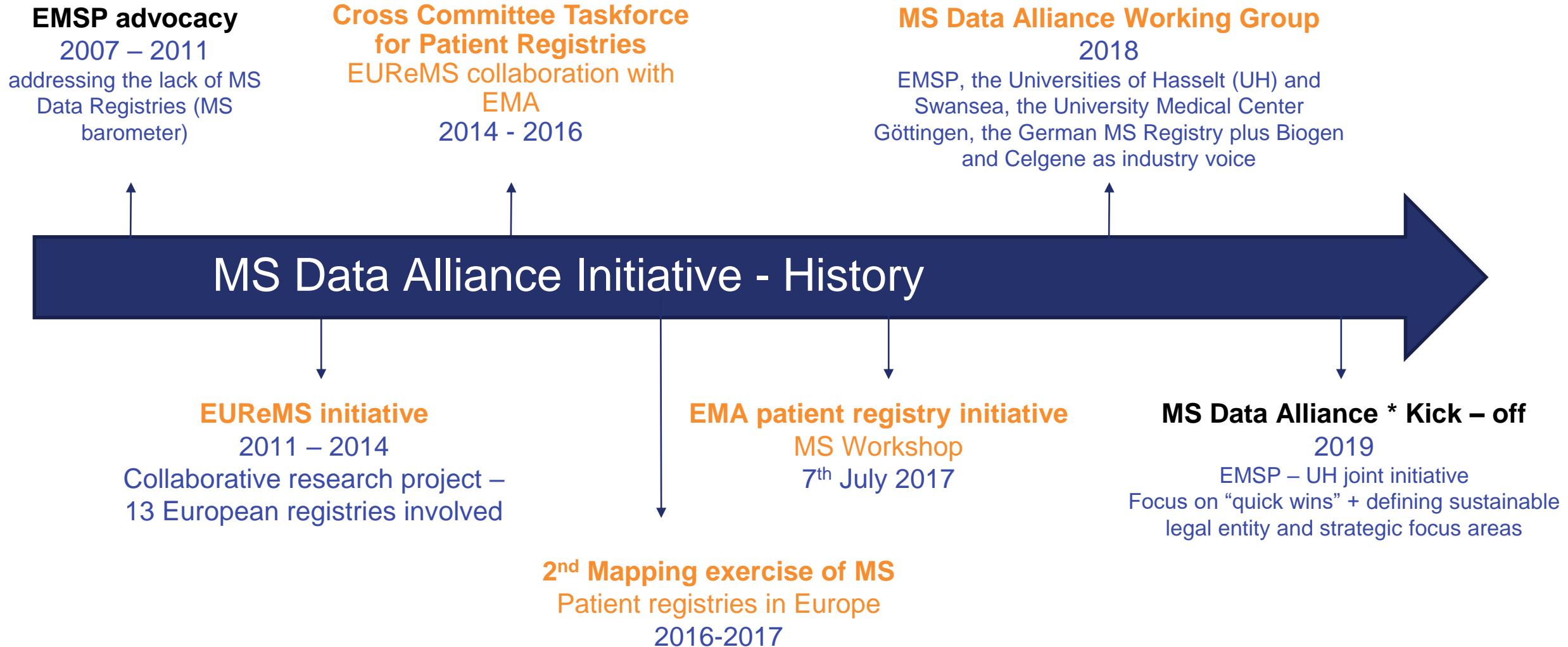## STRATEGIC FOCUS AREA 1

Raise awareness about the importance of research using real world MS data
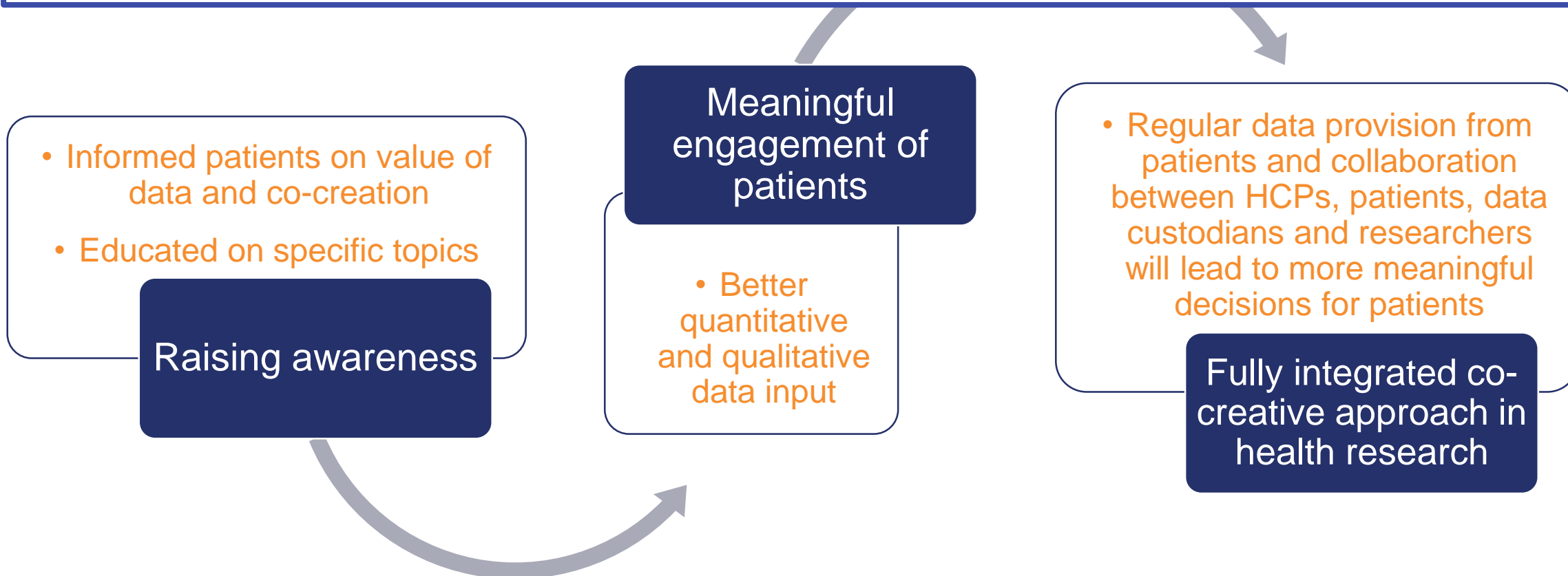
Pieter van Galen
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European Multiple Sclerosis Platform
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MS DATA ALLIANCE

We believe the perspectives of people with MS are central to establishing a trustworthy ecosystem for reusing health data for research and for learning health systems
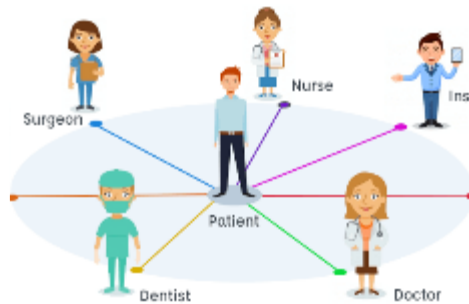
- Informed patients on value of data and co-creation
- Educated on specific topics

Raising awareness

Meaningful engagement of patients

- Better quantitative and qualitative data input

- Regular data provision from patients and collaboration between HCPs, patients, data custodians and researchers will lead to more meaningful decisions for patients

Fully integrated co-creative approach in health research

The current challenges

Understanding

Patient centricity

Reliable and regular data input

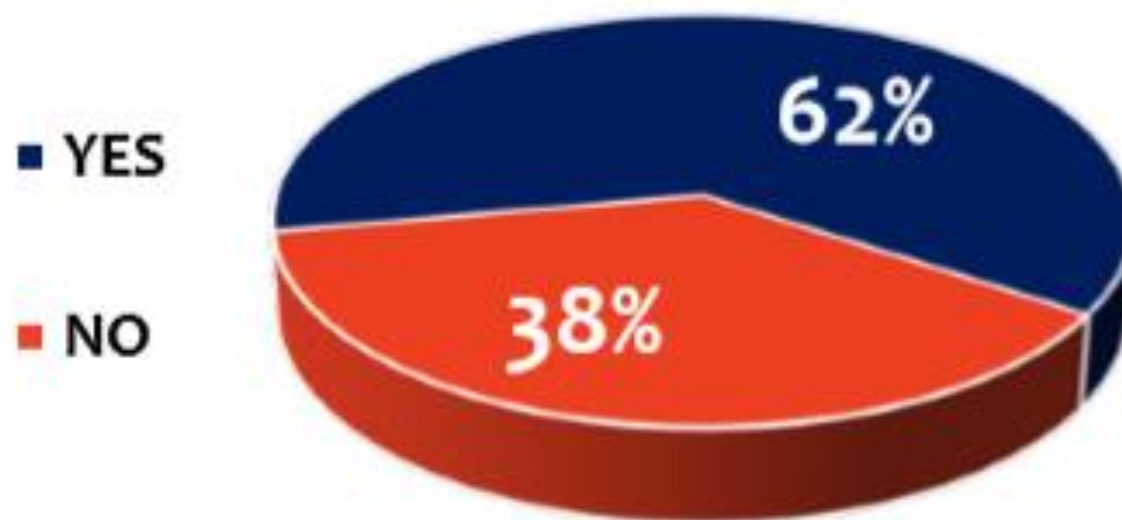Bridging the gap between patients and the other stakeholders

Findings from the MS Barometer
Improvement is needed on:

38% of European Countries do **not** have a MS data collection on MS at National level

1. Access to treatment and care
2. **Research and data collection**
3. Employment for young people
4. Patient empowerment

- YES
- NO

62%

38%

A move is needed from Disease Registries to Patient Registries

Disease Registries

1. Epidemiological research
2. Clinical research
3. Natural history of the disease
4. Disease surveillance
5. Treatment evolution (efficacy/safety)
6. Genetic mutations database
7. **Healthcare/Societal Services planning**

Patient expectations

1. **Healthcare/Societal Services planning**
2. Treatment evolution (efficacy/safety)
3. Natural history of the disease
4. Epidemiological research
5. Clinical research
6. Disease surveillance
7. Genetic mutations database

Source: Event Report: EP debate: Can real world data advance equity of health care?

Real world data can become the co-driver of regulatory and reimbursement decisions and can reduce the costs incurred by health care systems and improve access to medicines

Pharmacovigilance

Therapy effectiveness

Health Technology
Assessment and
reimbursement decisions

We aim to launch a multi-faceted motivation campaign to engage people with MS in decisions about the use of their data
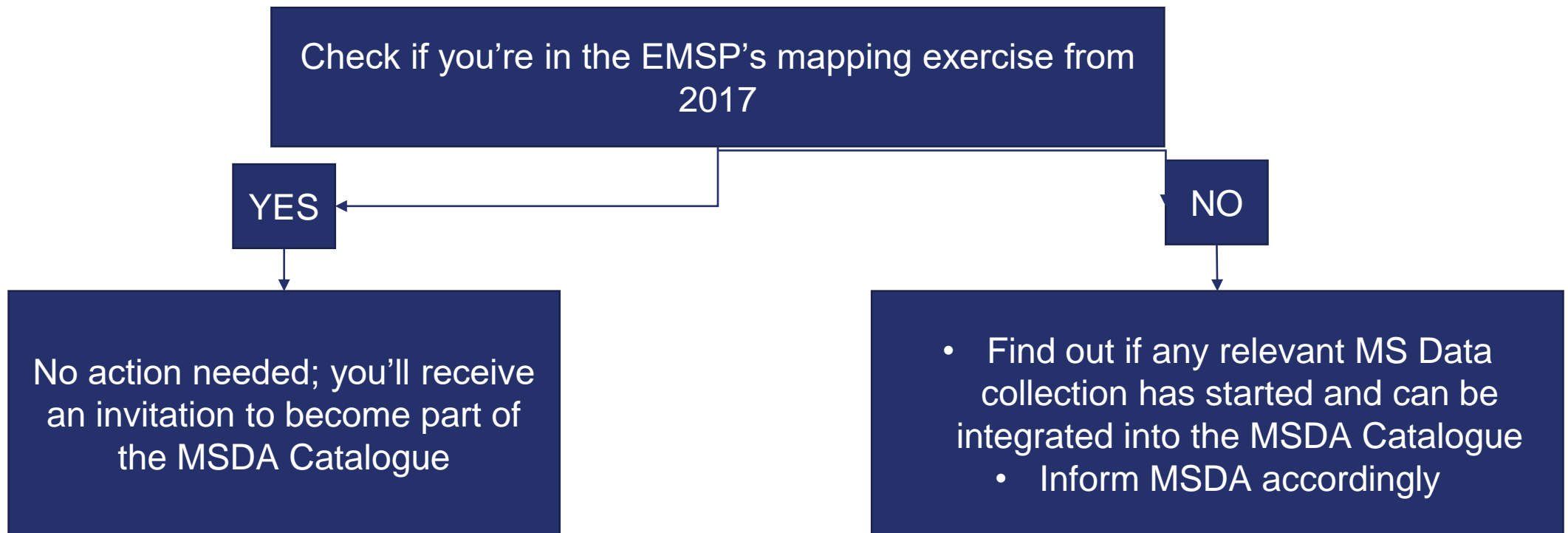
In collaboration with

How can MS patient organizations contribute? (1/2)

Check if you're in the EMSP's mapping exercise from 2017

YES

NO

No action needed; you'll receive an invitation to become part of the MSDA Catalogue

- Find out if any relevant MS Data collection has started and can be integrated into the MSDA Catalogue
- Inform MSDA accordingly

How can MS patient organizations contribute? (2/2)

Pieter van Galen

European Multiple Sclerosis platform

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Or add me on linkedin!