

# Patient and Healthcare Professional Involvement in EUnetHTA Activities

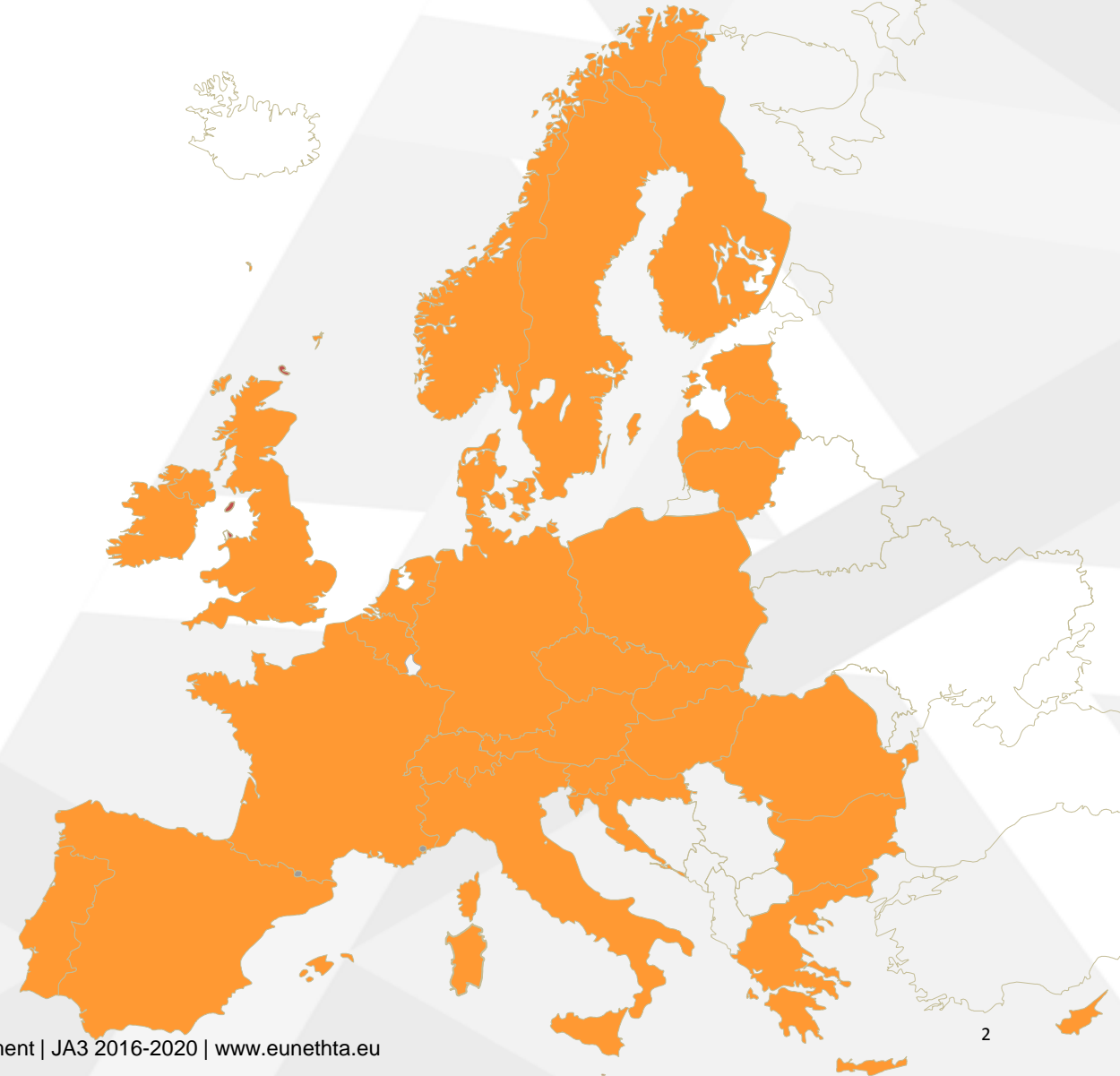
Michelle Mujoomdar, PhD - Senior Scientific Officer  
EUnetHTA JA3 directorate, Zorginstituut Nederland

PCWP/HCPWP Joint Meeting  
EMA – 27 June 2017














# EUnetHTA JA3 Participants

**81** partners consisting of national, regional and non-for-profit agencies that produce or contribute to HTA

**Project Coordinator:**  
The Dutch National Health  
Care Institute (ZIN)



# Organisational and Governance Structure

DG SANTE and CHAFEA 						
Executive Board	WP1 Network Coordination - Dutch Health Care Institute 					
	WP2 Dissemination	WP3 Evaluation	WP4 Joint Production	WP5 Evidence Generation	WP6 Quality Management	WP7 Implementation
	Lead: AETS-ISCIH 	Lead: TLV 	Lead: NIPHNO  Co-lead: LBI  ZIN 	Lead: HAS  Co-lead: GBA 	Lead: IQWiG  Co-lead: KCE 	Lead: NICE  Co-lead: Agenas 

# Summary of select activities in JA3

## **WP4 Joint Production**

- To produce rapid REA on other technologies and on pharmaceuticals
- To provide a system for topic selection and prioritization

## **WP5 Evidence Generation**

- To conduct Early Dialogues (joint HTA or parallel/joint with regulators)
- To link additional data collection to on-going activities

## **WP6 Quality Management**

- To provide quality management for EUnetHTA joint products
- To further develop methodologies and tools for joint work if necessary

# Summary of select activities in JA3

## **WP4 Joint Production**

- To produce rapid REA on other technologies and on pharmaceuticals
- To provide a system for topic selection and prioritization

## **WP5 Evidence Generation**

- To conduct Early Dialogues (joint HTA or parallel/joint with regulators)
- To link additional data collection to on-going activities

## **WP6 Quality Management**

- To provide quality management for EUnetHTA joint products
- To further develop methodologies and tools for joint work if necessary

# WP4 – Joint Production

# Planning for Patient Involvement in WP4 – Joint Production

- Patient involvement was a focused discussion at the F2F meeting for WP4 in Sept 2016
- Objectives were:
  - to discuss how we can better involve patients in the production process of EUnetHTA assessments.
  - to enhance the impact of patients' perspectives in EUnetHTA's assessments.
  - to share experiences so we can define a concrete proposal for future work.

# Patient Involvement in WP4 – Joint Production

- Variable experience with involving patients with WP4 partners
- Patients were involved in several phases of the HTA process – scoping, review of the assessment report, and decision-making
- The methods used varied between agencies



# Patient Involvement in WP4 – Joint Production

- **Patients** preferred over representatives
- In some cases (e.g. screening or health priority setting) **healthy citizens** should be involved
- Local, regional, and **national patients** are preferred over supranational
- Patients should be **reimbursed** – if possible – for their time giving input.
- **Disclosure** of material and immaterial benefits – along with and COI is required
- **Methods** to involve patients should be appropriate and validated; results transparent and open to public access.

# Patient & HCP Involvement in WP4 – Joint Production

- General agreement that involving patients and HCP during the scoping phase is particularly helpful
  - To ensure inclusion of patient relevant outcomes
  - To consider QoL, ethical, and social issues
  - To better understand the clinical condition, care pathway, and current treatments available
  - To understand what constitutes a clinically meaningful difference
- General agreement that choice of method will depend on the topic and activity. Method needs to be fit-for-purpose.

# WP5 – Evidence generation

# Patient Involvement in Early Dialogues - Preliminary Thoughts

- Build on experiences and lessons from Shaping European Early Dialogues (SEED) project
- Consider new and different ways of involving patients – e.g, approaches used by other HTA agencies
- For Parallel Consultation with EMA, explore opportunities to coordinate approaches for patient involvement
- Respective role of European networks of associations and national associations should be clarified
- Some (limited) budget available for patient and expert involvement

# Challenges

- Limited experience with pharmaceutical joint REAS in JA3
- Aligning HTA process – respecting national policies
  - Same applies to collaboration with EMA
- European-level versus national organisations
- Limited resources

# Opportunities

- To learn how PCWP and HCPWP engages with EMA
  - Strategic and operational
- Areas of focus for work plans
  - Areas of overlap / synergy with EUnetHTA or EUnetHTA/EMA joint work plan

# Thank you

Email: MMujoomdar@zinl.nl

Twitter: @M\_Mujoomdar