



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

# EMA's engagement with patients

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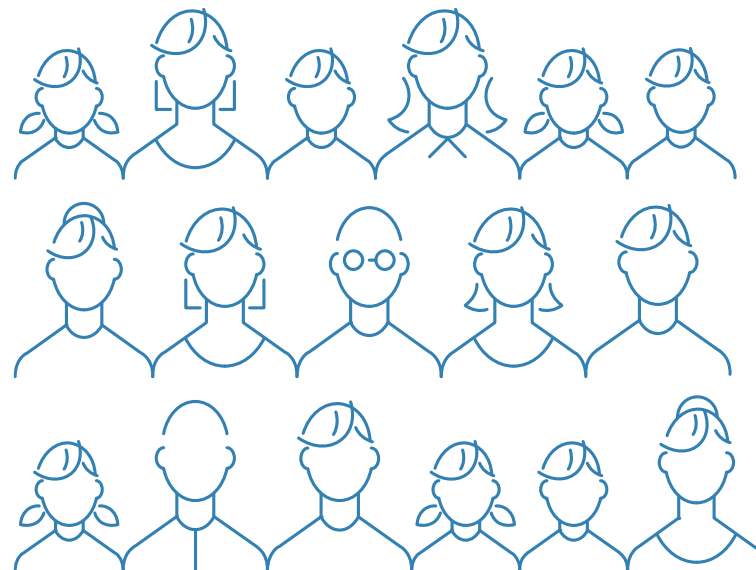
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# Patient engagement: **Integral element of EMA activities**



# Increasing and varied involvement in different activities

## Representing their *community*

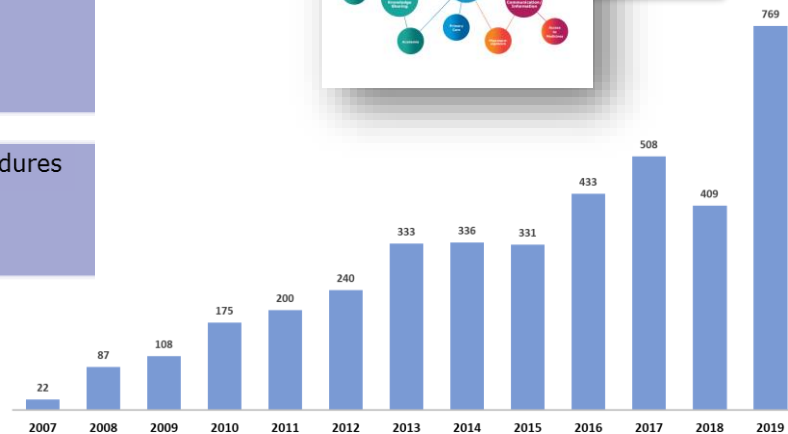
- Management Board
- EMA Scientific Committee Members

## Representing their *organisations*

- Working Party (PCWP or HCPWP)
- EMA consultations
- Workshops

## *Individual* experts

- Scientific Advice / Protocol Assistance Procedures
- Scientific Advisory/ad hoc expert Groups
- Scientific Committee consultations
- Review of documents



Patient involvement in medicine-related activities



## Patients to contribute directly to scientific discussions

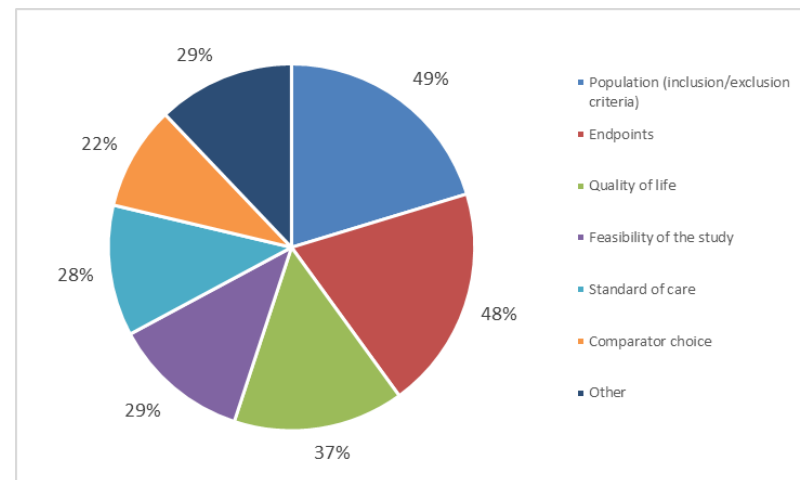
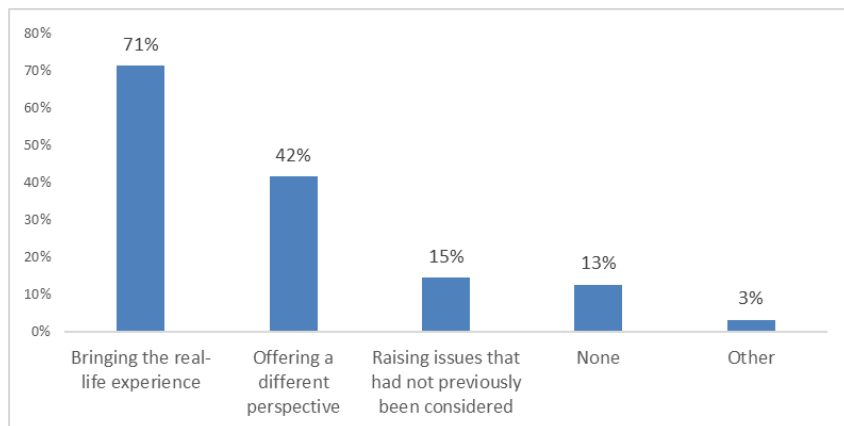
- Committee (full voting) membership
- Scientific advice procedures
- Scientific Advisory Groups (SAGs) / Ad-hoc expert group meetings
- Committees/Working Parties consultations (f2f /questionnaires/surveys)
- Stakeholder meetings
- Public hearings / meetings
- EMA workshops & public consultations on development /update of regulatory guidance
- Review of package leaflets, medicine overviews and and safety communications (appropriate language / increase awareness)

# Continuous monitoring and measuring value / impact

## EXAMPLE:

### 3 year survey $\approx$ 300 Scientific Advice procedures:

- 52% of the patient`s comments resulted in further discussion
- 20% of the patient`s input resulted in a modification of the final advice



**REVIEW OF DOCUMENTS:  
50% of comments led to  
changes**



## Summary messages

Engaging with patients;

- brings everyday aspects of living with a condition into scientific discussions
- helps bridge the gap between clinical trial data and real world data
- increases transparency, awareness and understanding
- Value demonstrated; ultimately, listening to patients leads to more meaningful outcomes for all