



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

How are patients involved in SAGs?

Experience and impact of patient involvement

Training session for patients and consumers involved in EMA activities
10/12/13

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An agency of the European Union





SAG Meeting Organisation

EMA scientific secretariat

- Co-ordination and running of the meetings
- Preparation of documents

Committee adopts agenda and additional list of participants

Receive/Check Declaration of Interests

Issue invitation

Send two weeks before the meeting



Typical Questions for SAG (Oncology)

- Benefit-risk negative or marginally positive
- Clinical meaningfulness of benefits
- Clinical impact of risks
- Guidelines



Should patient representatives be involved in SAGs?

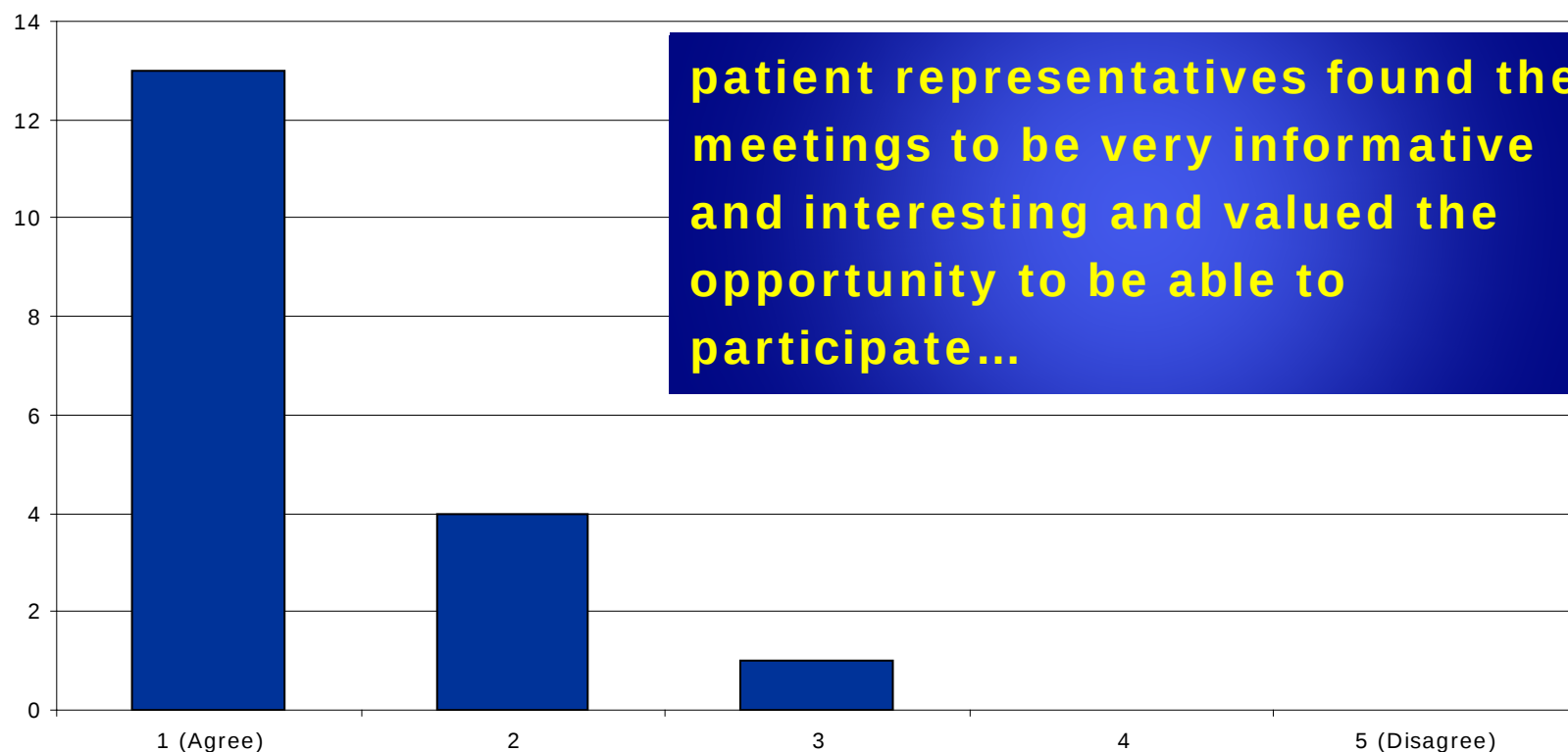
- Statistics for 2013
 - 22/26(85%) SAG meetings had one or two patient representatives
- Some myths
 - Discussion too technical for patients to contribute
 - Patients contribution will have little impact
- 2011 Survey





Are patients able to follow the discussion?

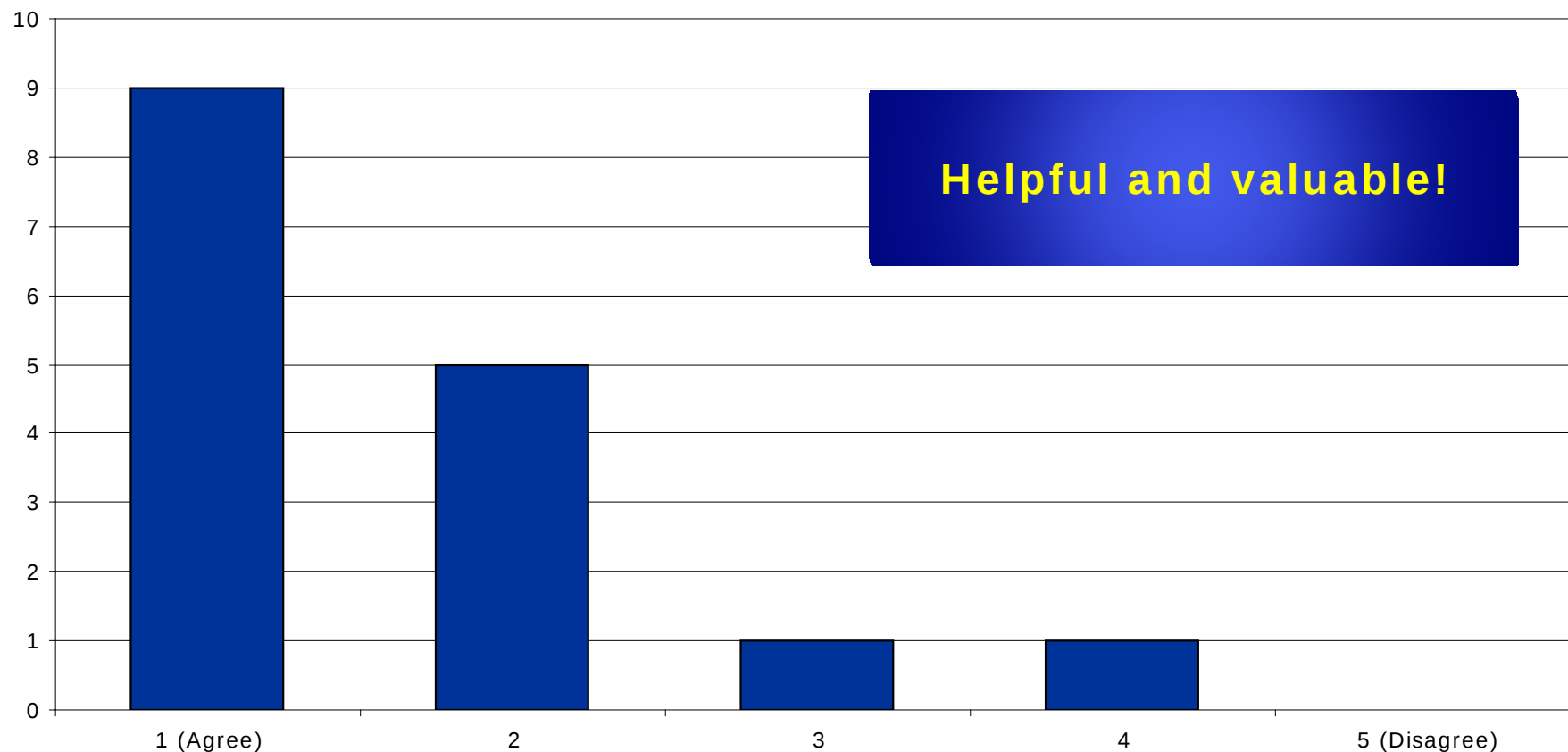
I was able to follow the discussion





Are patients' views taken into account?

I feel my comments were taken into account during the discussion





Chairpersons and rapporteurs

- The overall impression is that the **patient contribution is variable**, and can depend on the type of questions addressed during the SAG and on the individual patient who attended;
- On the whole, the assessment of contribution ranged from being beneficial (able to obtain patient views with **an actual impact on the outcome**) to having no actual impact;
- In all cases **patients were well integrated in the dynamic of the SAGs** and the meetings ran smoothly.



Conclusions

- SAGs: important tool for bringing patients' values and preferences into the system
- Overall interactions with patients groups have proved useful;
- They bring a crucial patient perspective to the discussions on medicinal products
- Can help to provide valuable insights such as acceptable levels of associated risks