

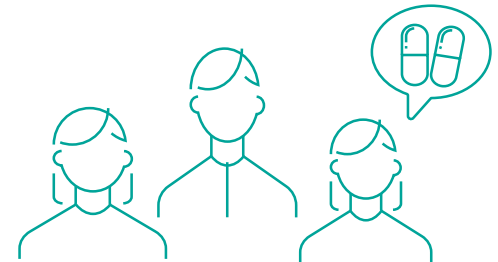


EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

# Survey Results of Patient Representatives attending Scientific Advisory Groups or Ad Hoc Expert Meetings

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Data from 2010-2017



Presented by Sophie Groeneveld on 02 June 2021  
Public and Stakeholder Engagement

An agency of the European Union



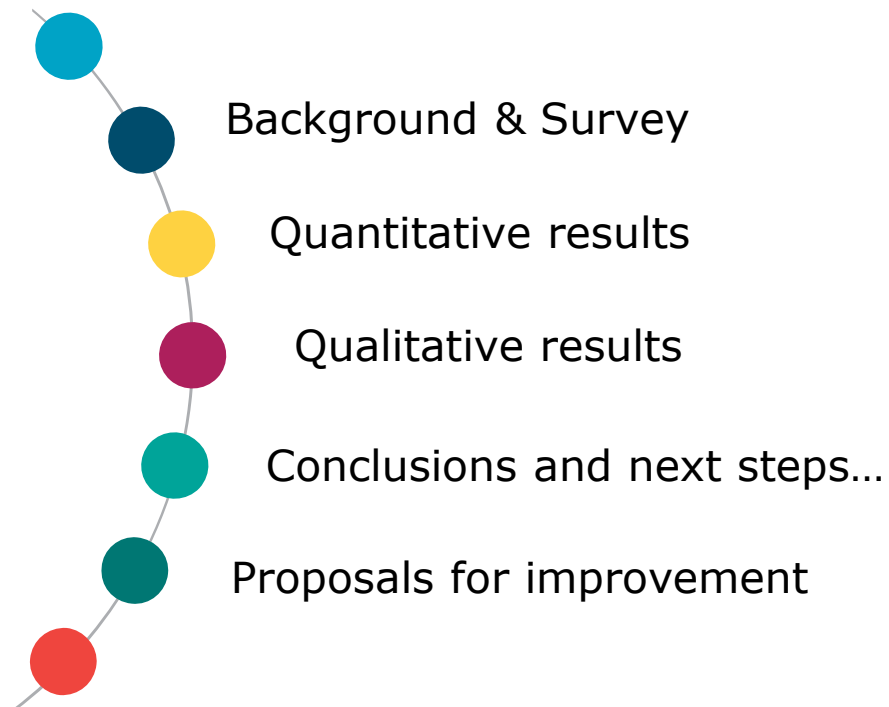


## What are SAG / Ad Hoc meetings?

- Convened during the **assessment of medicines** when the Committee encounters specific questions best answered by specialists in the field, including **patient representatives**
- Generally convened by the **CHMP** or the **PRAC**
- SAG meetings contain core members and invited experts (i.e. patient representatives)
- During a SAG or Ad Hoc meeting, patient representatives can **answer questions** and contribute at any time they feel it appropriate
- **After the meeting**, patient representatives are sent draft minutes for agreement as well as a **survey** to provide feedback on their overall experience with the meeting



# Overview of today's presentation





# Background & Survey

- After each SAG or Ad Hoc meeting, patients were sent a link to a survey
- Data was anonymously gathered through *SurveyMonkey*.
- Survey consisted of 10 questions
- Questions 2 – 9 asked for patients' experience using a scale: *Agree – 2 – 3 – 4 – Disagree*

The **aim** of the analysis was to **uncover positive aspects** of the meeting as well as aspects that could be **improved**.

**143 eligible responses between 2010-2017**

Questionnaire for patients in expert meetings

SurveyMonkey

#100



COMPLETE

Collector:  
Started:  
Last Modified:  
Time Spent:  
IP Address

PAGE 1

Q1: Product and meeting date:

PAGE 2: Pre-meeting

Q2: The meeting arrangements were well taken care of (e.g. travel, meeting room)

Rating

Q3: I received sufficient and understandable background information on what a SAG is and how it fits in the Agency's work

Rating

Q4: I received sufficient and understandable information on the issue(s) for discussion at the meeting

Rating

Q5: I knew what was expected of my participation at the meeting

Rating

PAGE 3: During the meeting

Q6: I was able to follow the discussion

Rating

Q7: Was the patients' view specifically requested?

Q8: I was given adequate opportunities to provide input to the discussion

Rating

Q9: I feel my comments were taken into account during the discussion

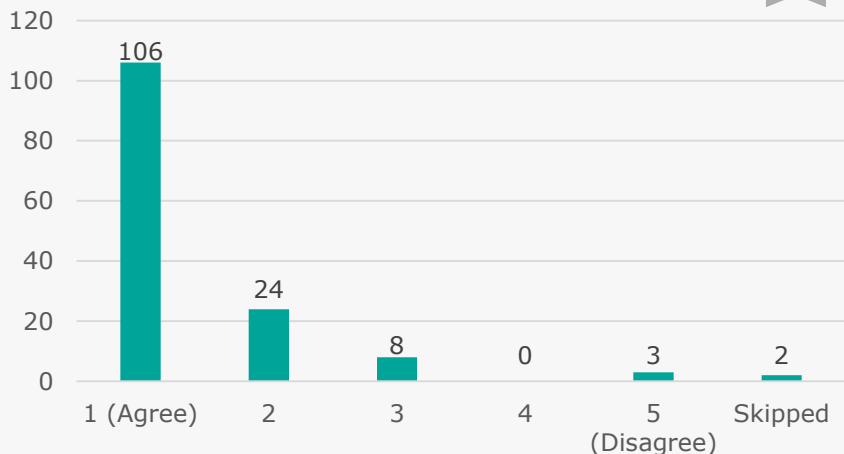
Rating

Q10: Additional comments:

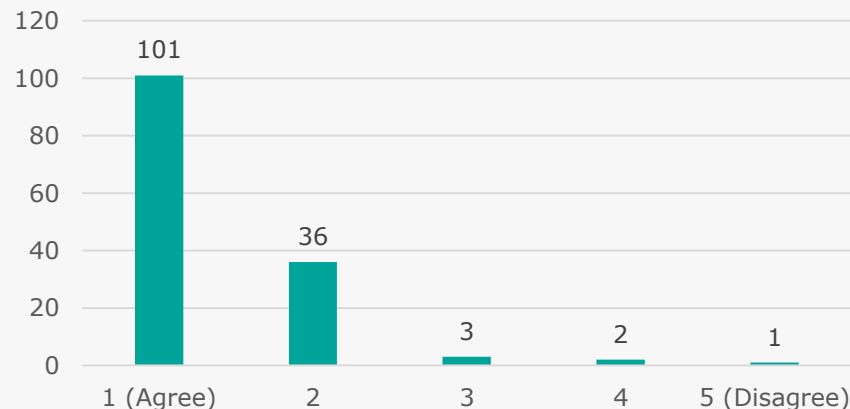


## Quantitative results: Pre-meeting

The meeting arrangements were well taken care of (e.g. travel, meeting room)

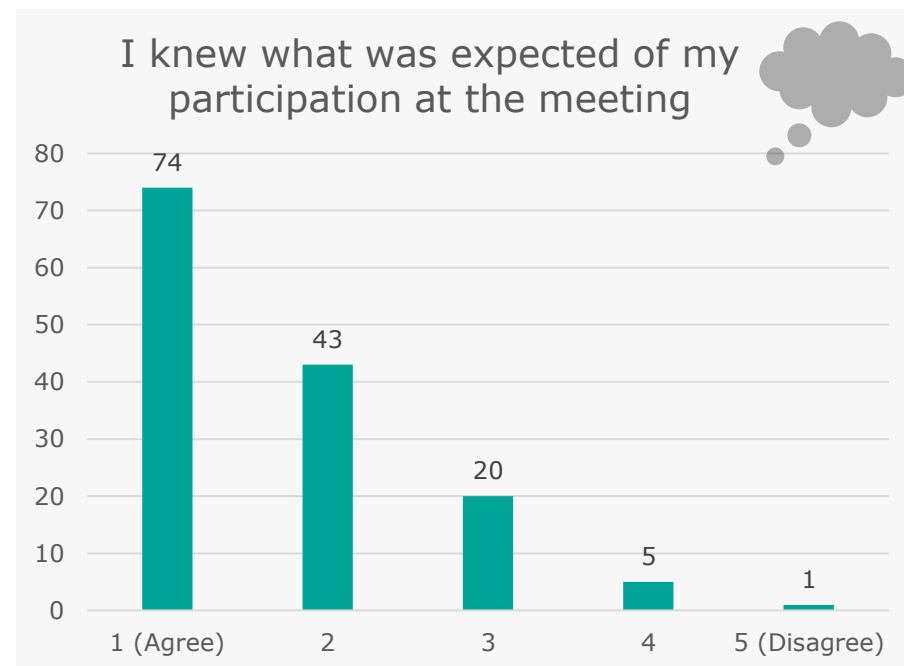
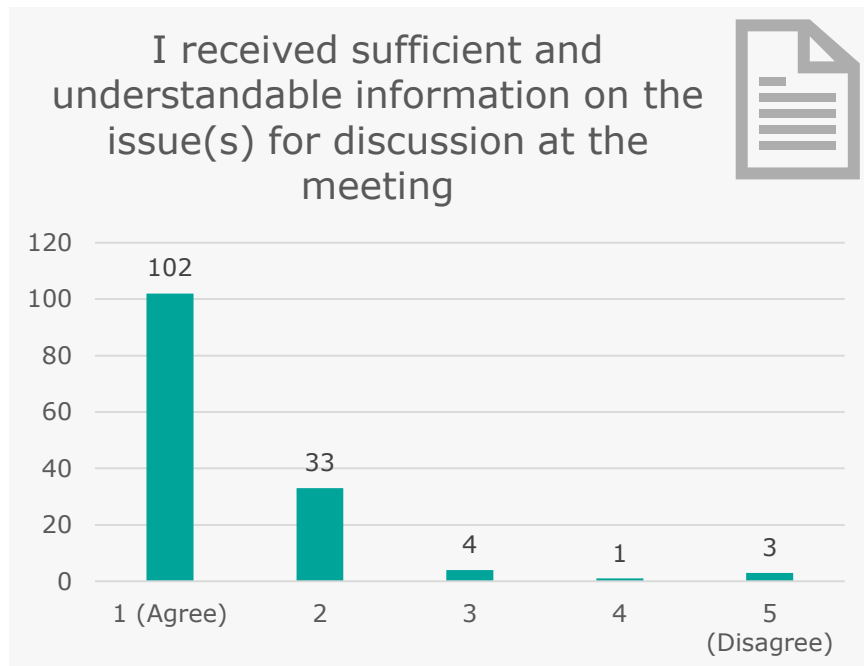


I received sufficient and understandable background information on what a SAG is and how it fits with the Agency's work

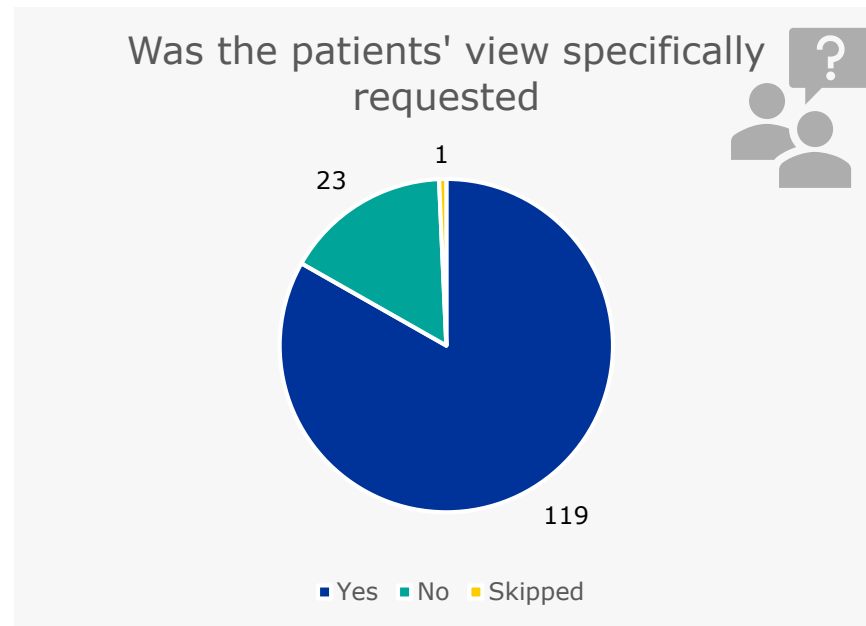
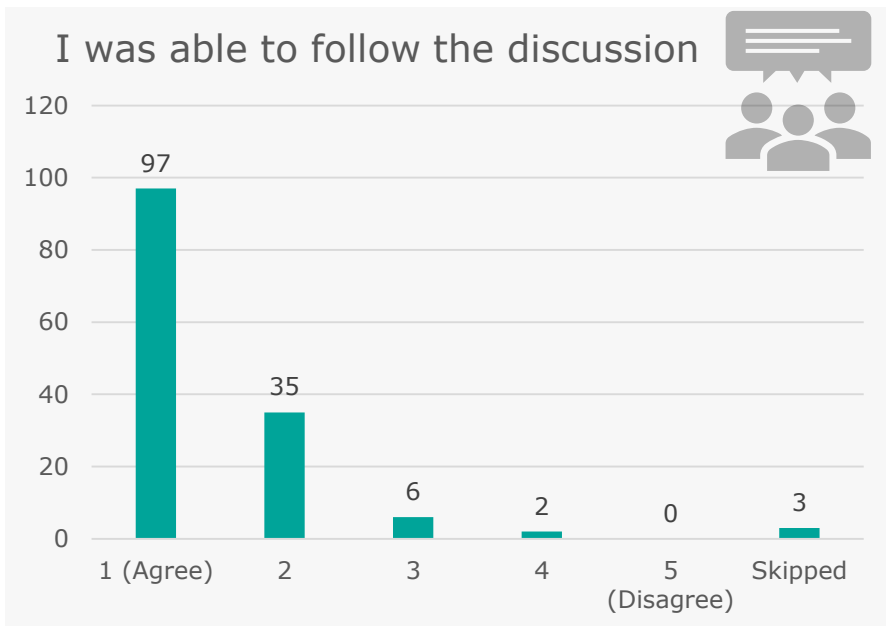




## Quantitative results cont.: Pre-meeting

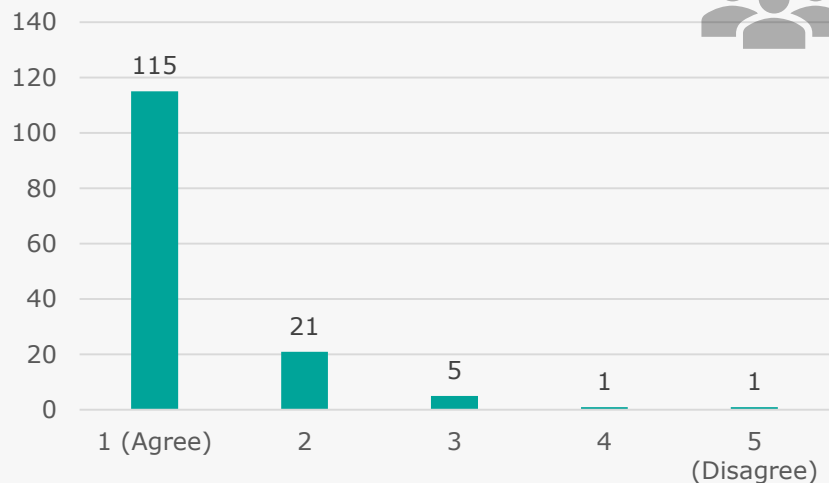


# Quantitative results: During the meeting

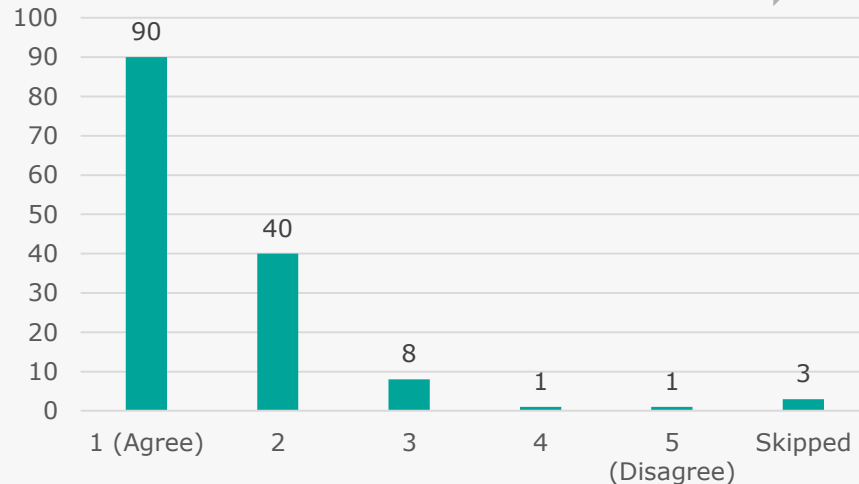


## Quantitative results cont.: During the meeting

I was given adequate opportunities to provide input to the discussion



I feel my comments were taken into account during the discussion





# Qualitative Data: Positive comments

The patient's perspective was strongly fostered and highlighted in the minutes

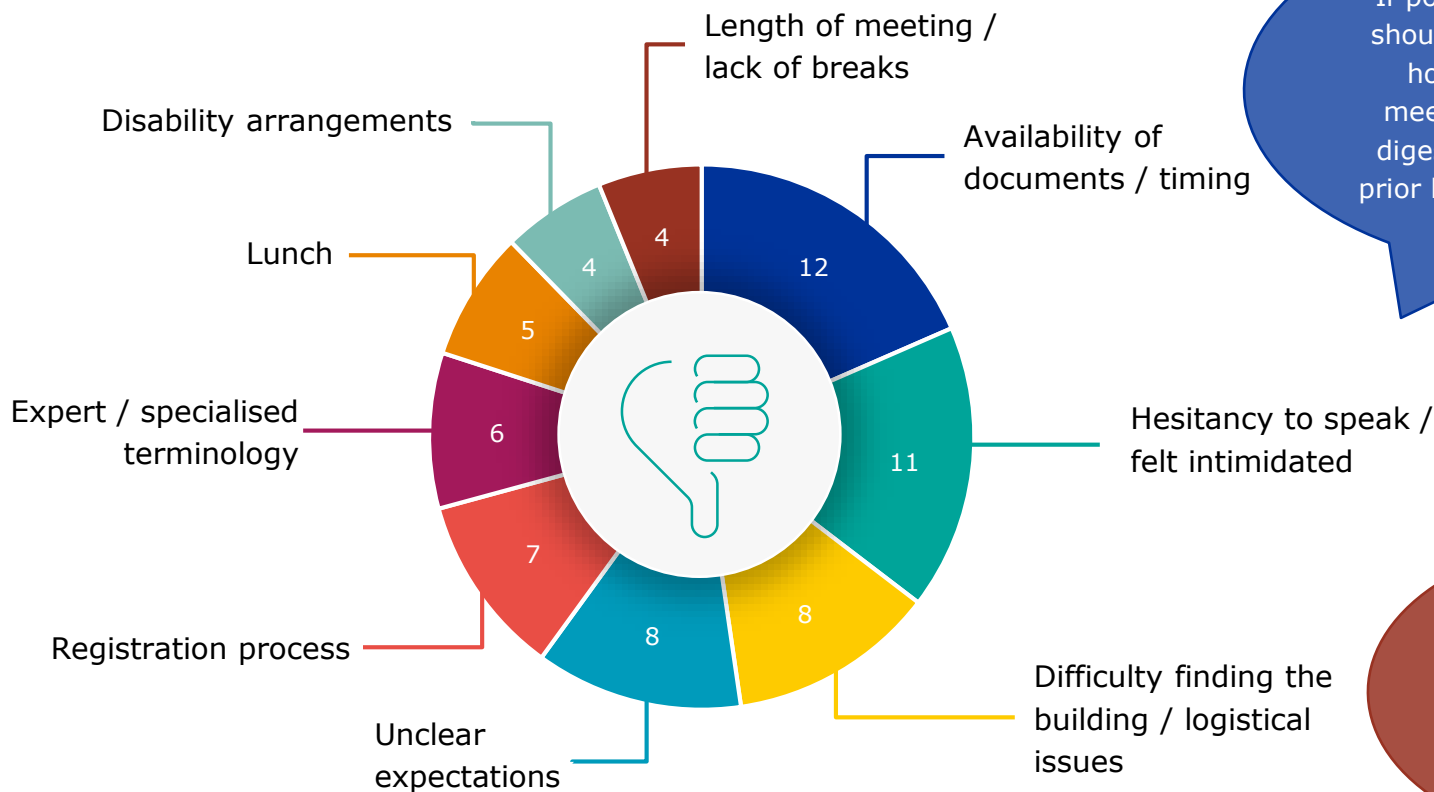
EMA staff (as always) was very friendly and helpful

Would be pleased to take part in similar such meetings in the future





# Qualitative Data: Negative comments



If possible, the briefing data should be sent more than 48 hours in advance of the meeting as there is a lot to digest when one has had no prior knowledge of the product

I struggled with some terminology like relative and absolute risk.

It was a very long meeting with only one 15-minute break. For me as a patient this is very challenging

## Conclusions & Next steps...



### Areas of **success**:

- Overall good and enjoyable experience
- Sufficient understandable background information
- Adequate opportunities to speak

### Areas of **concern**:

- Unclear expectations of participation
- Timing of documents
- Hesitancy to speak
- Terminology

- **Continue recording and analysing** the results coming in from the survey.
- Analyse data from **2020**, to show how patients experienced **virtual** SAG and Ad Hoc meetings.
- Further proposals to improve survey and patient experience...



# Proposals for improvement

## Improving the survey

- EUSurvey Tool
- Introduce a defined 5-point Likert scale
- Inform patients what the survey is for and why their answers are valuable to the Agency
- Maximise response rate by informing how long the survey is, how long it takes to complete and what web browser to use

## Improving patient experience

- Inform patients that documents will be forwarded as ready but often only a few days before the meeting.
- Proposal to include a survey question asking what patients struggled to understand (i.e. scientific terminology)
- Proposal to implement survey for Chairs and Rapporteurs
- Further explore ways to create less intimidating space/experience for patients
- Updating infosheet – call for volunteers



# Any questions?

## Further information

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