



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

# Satisfaction survey on involvement of patients, consumers and healthcare professionals during 2016

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15<sup>th</sup> March 2017, PCWP/HCPWP Joint meeting

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An agency of the European Union





# I. Methodology of the survey

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- Aim
- Target audience
- Questionnaire structure



### Aim:

- To gather feedback from patients, consumers and healthcare professionals who have been involved in EMA activities and identify areas for improvement.

### Target audience:

- All patients, consumers and healthcare professionals who participated in any EMA activity during 2016.

### Questionnaire structure:

- 5 main blocks on questions – General information, General Interaction, Logistics, Future participation and Suggestions for improvement.
- Questionnaire included both closed and open answers to questions.
- All questions were obligatory to answer.



## Patients and consumers

17 questions

Questionnaire sent to:  
248 patients and consumers

Number of responses:  
95/248

Response rate:  
38%



## Healthcare professionals

15 questions

Questionnaire sent to:  
144 HCP

Number of responses:  
44

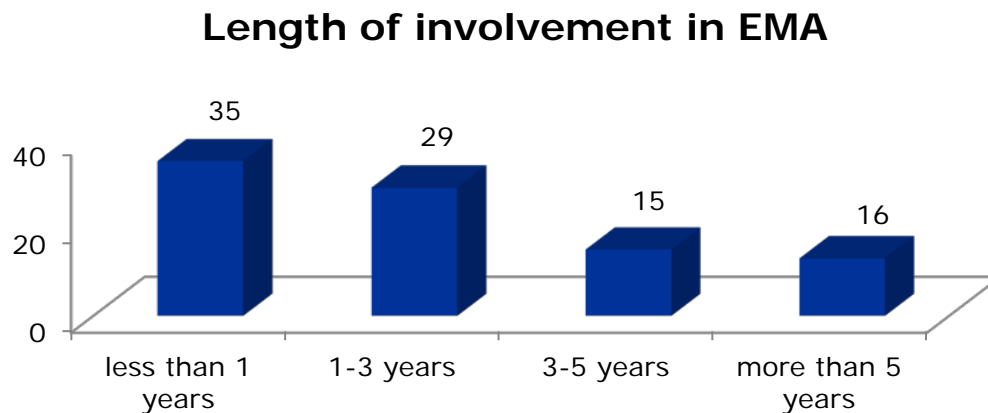
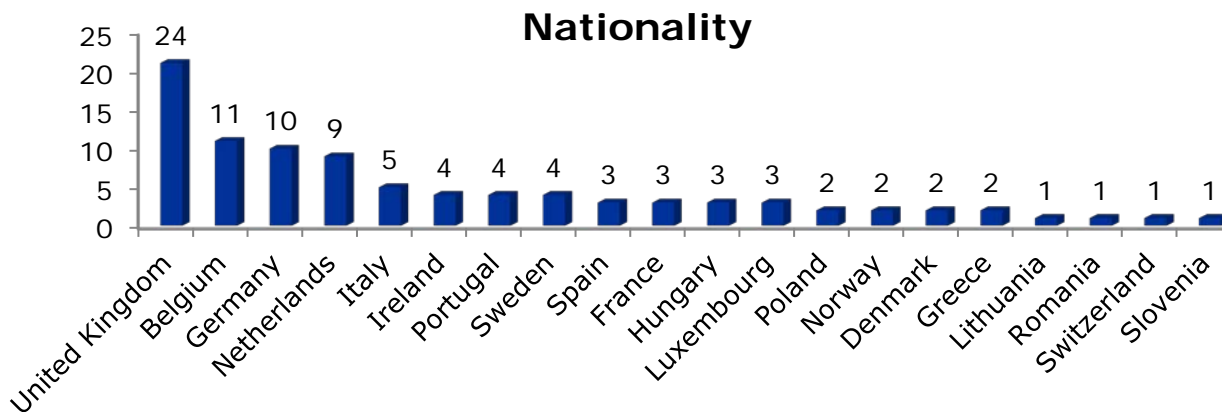
Response rate:  
34%



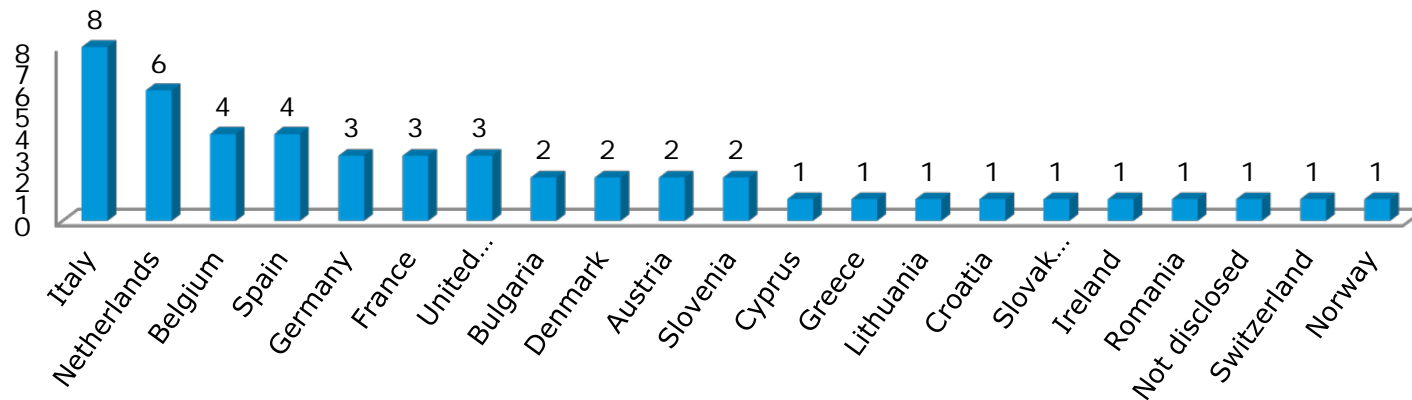
## II. General information

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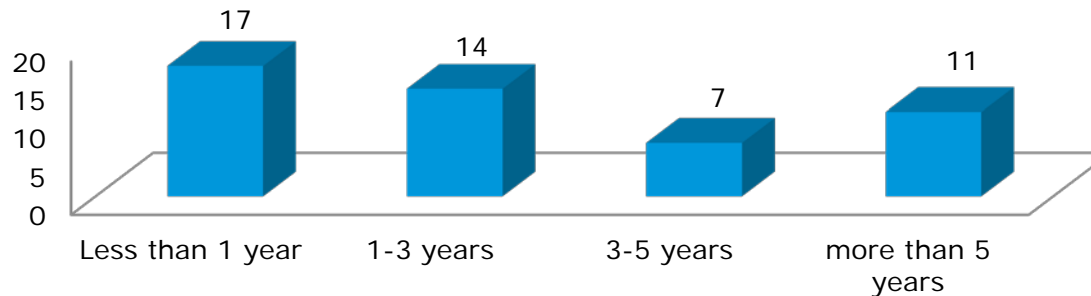
- Nationality
- Length of involvement in EMA



## Nationality



## Length of involvement in EMA





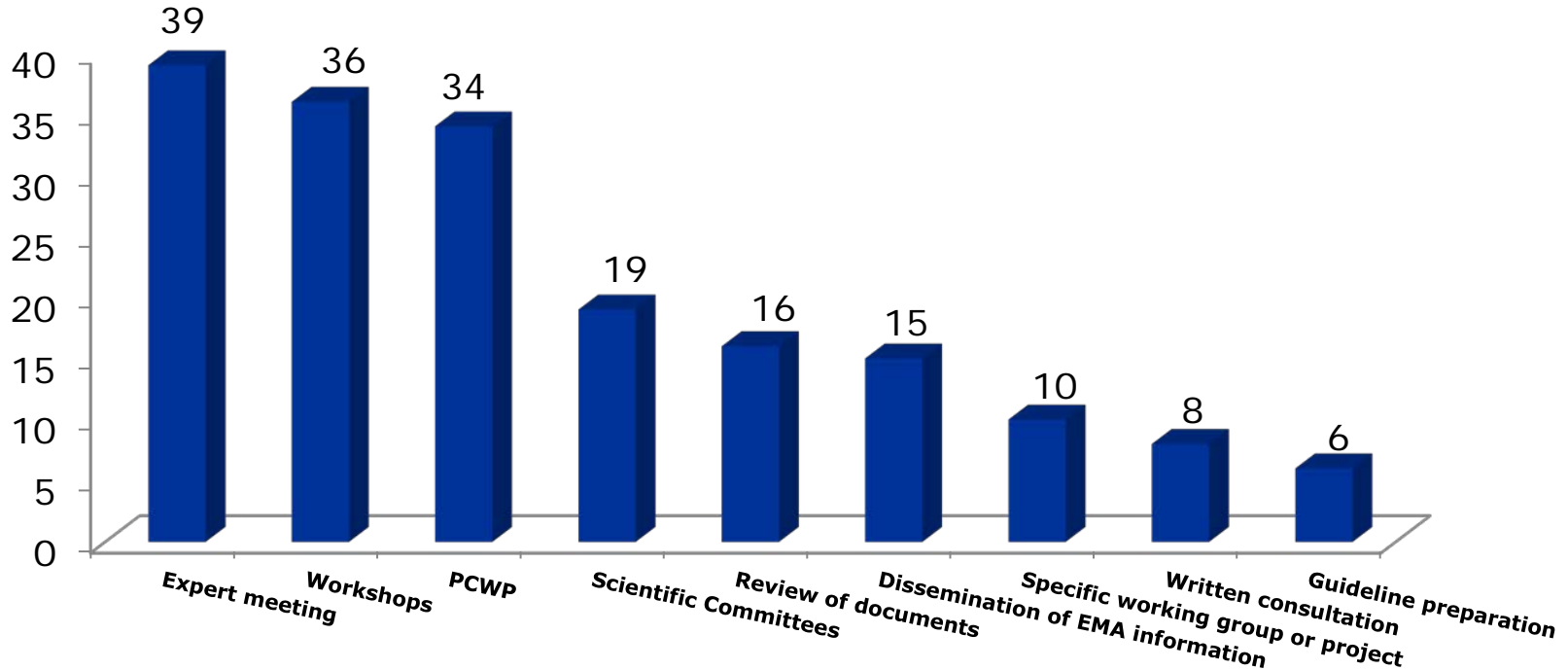
### III. General interaction

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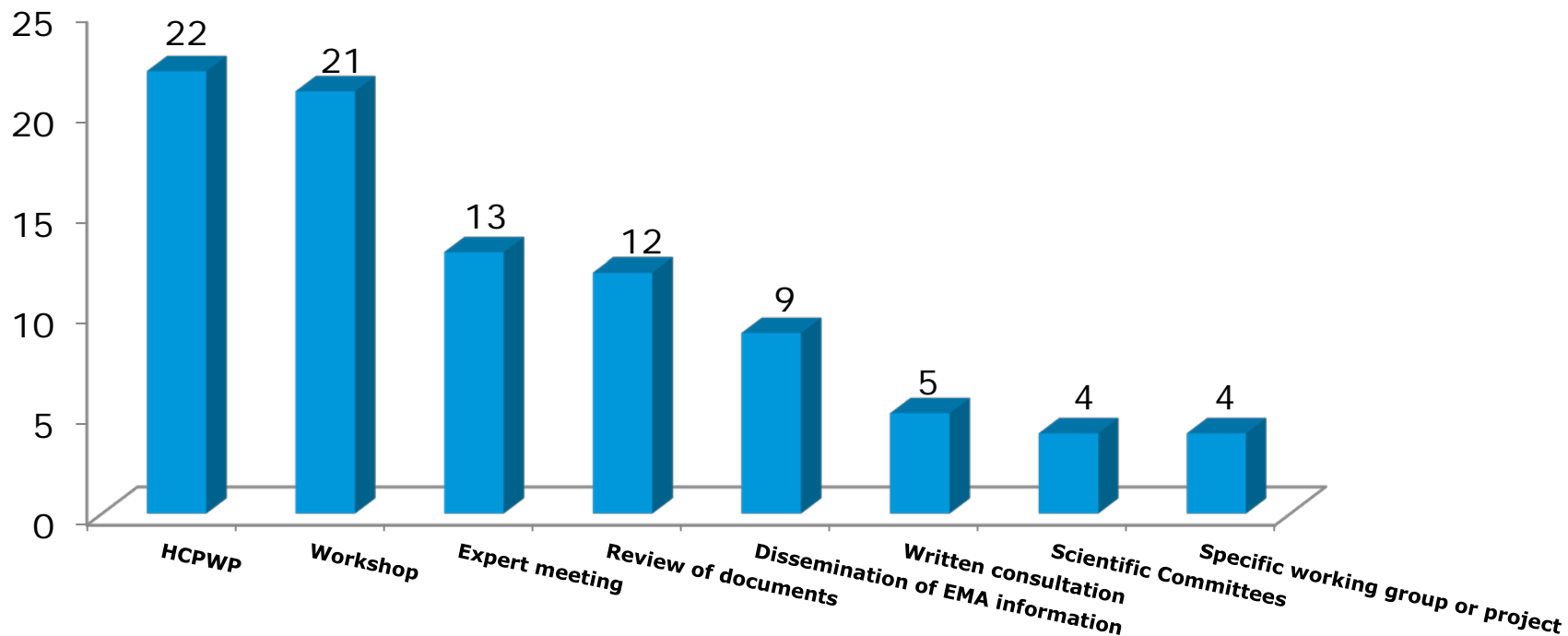
- What EMA activities have you been involved in during 2016?
- How do you find the overall interaction between you and EMA?
- How would you rate the level of support you received prior to the specific activity?
- How would you rate the level of follow-up you received after participating in EMA activities?
- How would you rate EMA`s initiative of involving patients, consumers and healthcare professionals in its activities?



What EMA activities that you have been involved in during 2016?

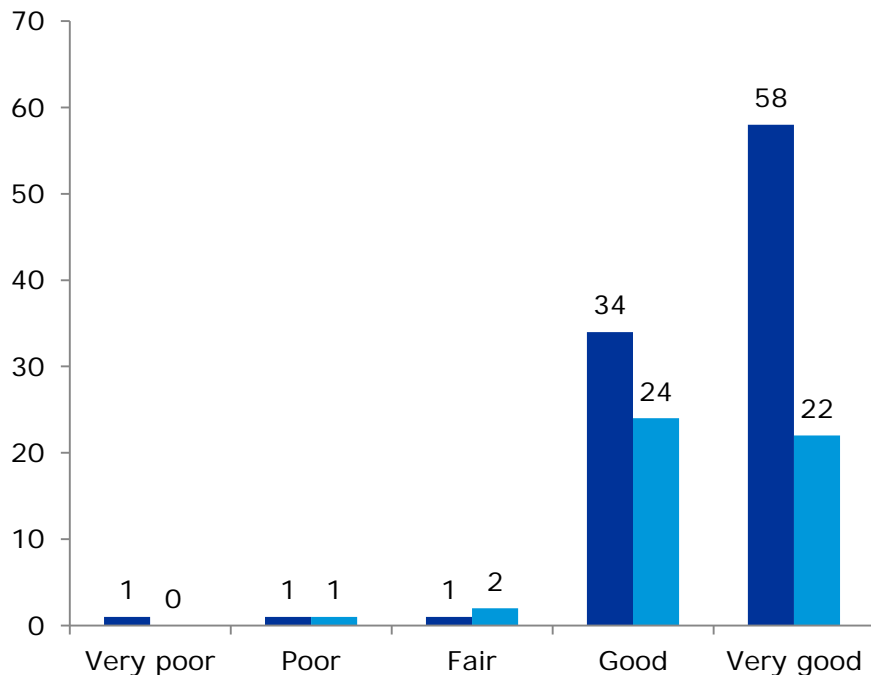


What EMA activities that you have been involved in during 2016?

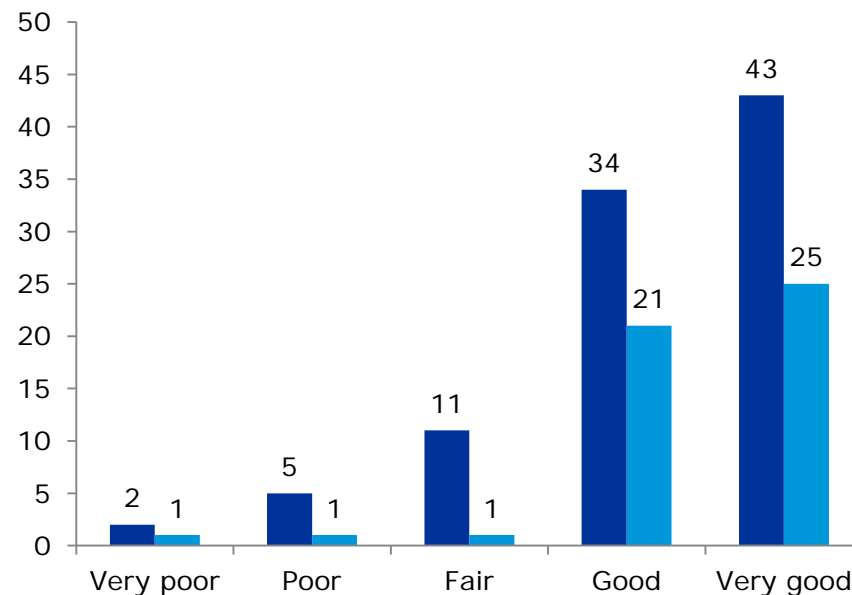




### How do you find the overall interaction between you and EMA?



### How would you rate the level of support you received prior to the specific activity?



■ Patients and consumers ■ Healthcare professionals

+ *"People at EMA were **very quick to react** and help me, very good feeling."*

*"Members and managers of the scientific team have been very helpful to phone me and to **explain the procedures.**"*

*"Helpful, friendly, people in EMA are great! It's my **pleasure working with them.**"*

- *"... **registration online** is too heavy takes too long."*

*"The **credit card system for food**, the unbelievably complex system to reclaim expenses or secure a hotel room all seem designed to stop people from claiming money back."*

*"I did not receive any **support prior to the meeting** other than logistics/admin"*



*“The experience is that **the office is very swift and constructive** in responding and to my satisfaction.”*

*“This is very effective but I also reward **the personal approach** very much, it is an example of showing interest from both sides.”*

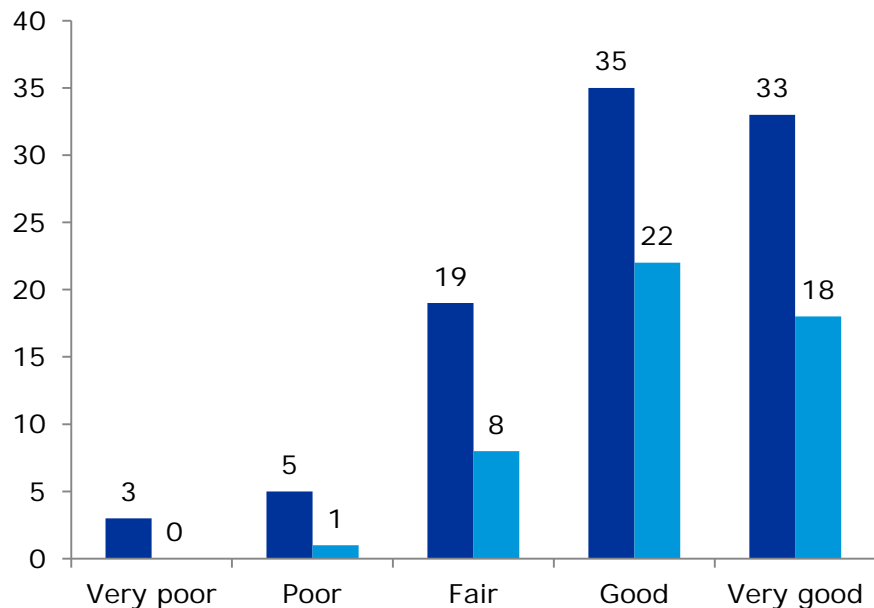
*“Very fast and **very polite** and efficient.”*

*“One issue may be **timing** a little. Generally there is considerable paperwork and not so much time to appropriate address everything.”*

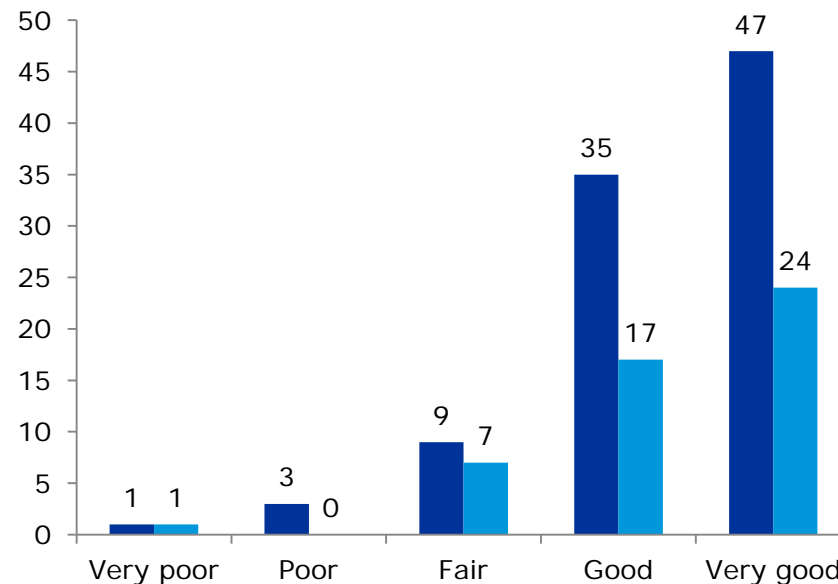
*“I **don't get involved in preparations preceding the Scientific committee meetings** and therefore can't provide input. Trying to give input during the meeting is very difficult when you don't have had access to documents.”*



How would you rate the level of follow-up you received after participating in EMA activities?



How would you rate EMA initiative of involving patients, consumers and healthcare professionals in its activities?



■ Patients and consumers ■ Healthcare professionals

*"I always get the final drafts, so that's okay."*

*"I felt that **patients opinions and information are taken seriously for further decisions**. This is for us very important and I feel grateful that I could take part in this process for the new drug."*

*"Great that it is happening at all, and beyond that, the fact that it seems **a well-integrated process within EMA**, and very supportive of people becoming involved."*

*"I had a couple of emails thanking me for participation, and a promise that I would **receive the final outcome of the meeting** as well - so far that **hasn't happened**."*

*"I got a thank you. That is all."*

*"It's very hard to **gain information about drug assessment progress** either by telephone or on your very confusing website."*



*“Very good because of the double service, **receiving information by mail and online.**”*

*“Glad to see that further involvement **of general practitioners/family doctors** is being facilitated.”*

*“Extremely well and **experience an open mind and willingness** to view issue from our scope of practice.”*

*“**Final documents** incorporating suggestions **not made available.**”*

*“I think **involving HCPs is difficult** in an environment that has to be very 'regulatory', i.e. has a main focus on updating SPCs and writing HCP communications. And that can't quite understand that HCPs rarely read SmPCs.”*





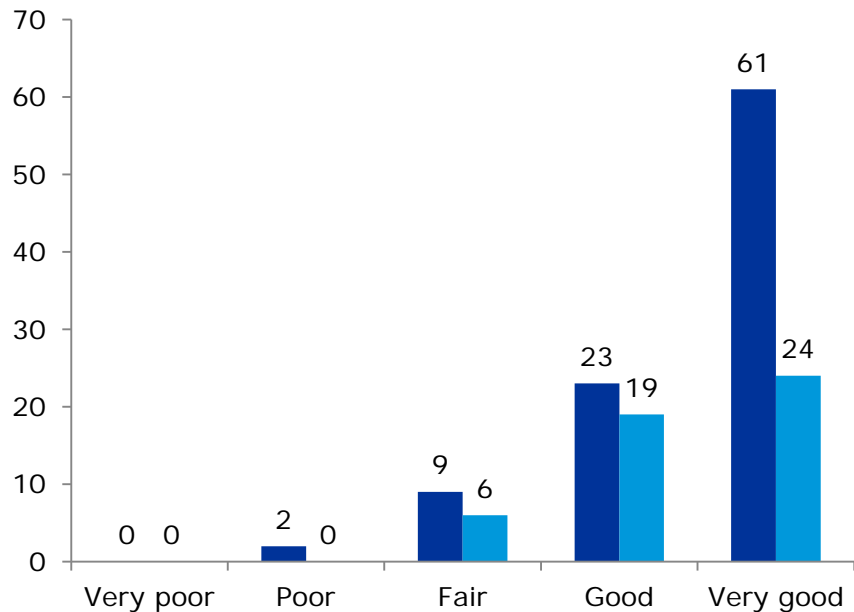
## IV. Logistics

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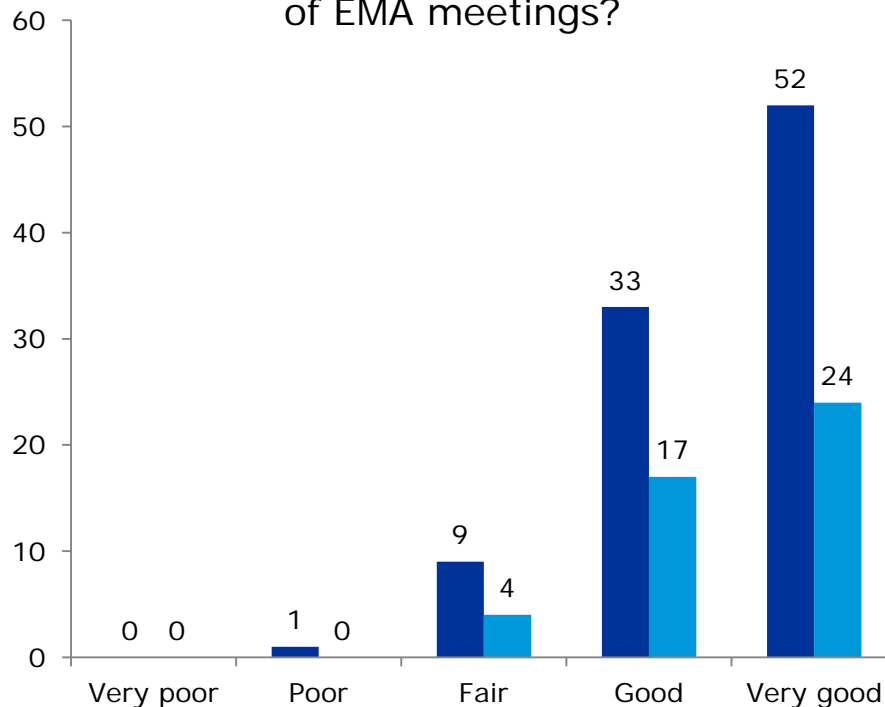
- How would you rate the practical arrangements/facilities provided by EMA? (e.g. invitations, travel arrangements, room, meeting services)
- How would you rate the organization of EMA meetings? (e.g. topics, agendas, documents circulated, minutes)
- How would you rate the overall level of financial support provided?



### How would you rate the practical arrangements/facilities provided by EMA?



### How would you rate the organisation of EMA meetings?



■ Patients and consumers ■ Healthcare professionals



*"It's always perfect. I admire all the efforts of people involved in such arrangements and I thank them very, very much."*

*"I was **unable to travel** that day, so **a teleconference was arranged** and that all went very well."*

*"I was **given all of the information I needed**, as well as conversations with several EMA staff before the teleconference to check that I knew the minimum I had to read and respond to in the meeting. I was also told I could read more if I had an interest, and **at all times I was referred back to during the meeting and people were very good at stating which document they were talking about**, which page, etc. all very good."*



*"Some speakers give their **presentations without having sent them before** so participant can't take notes into the printed out documents."*

*"There were **sometimes issues with EUDRA download links**, leading to delay access to documents and extra time for project assistants to ensure documents were sent."*

*"**Flight tickets came very late** (day before). The room number of the meeting was different then on the invitation, because I was almost too late."*

*"Invitations, meeting services generally ok, **expenses terrible**. It is trying to get the money back out of you is the problem."*



**+** *"Efficient, very quick and helpful. An example for many other organisations."*

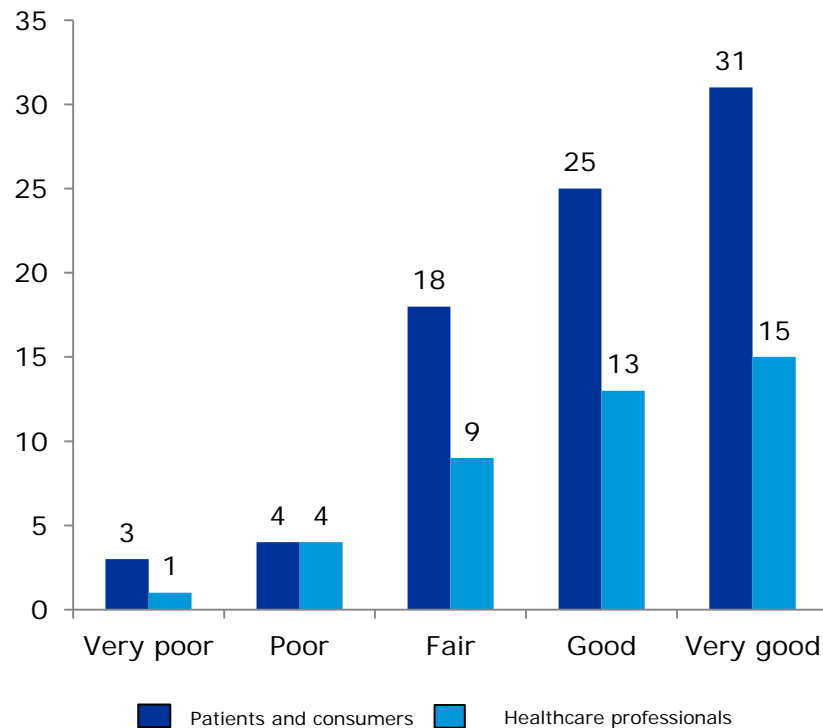
*"More than perfect, **all is very well thought over.**"*

**-** *"But, again, **lots of paperwork.** Sometimes - when looking at the agenda - I wonder about the relevance of some points on the agenda."*

*"We have **received invitations very late** and we don't have the time for reactions."*



### How would you rate the overall level of financial support provided?




*"For me the **financial support** was enough."*


*"It is often expensive to come to London and the allowance covers these extra costs that might deter me otherwise."*

*"Not so much the rate but **the difficulties that go with it.**"*

*"I accept that travel would have been arranged for me so that I would not have been at all 'out of pocket' to attend a meeting. However, taking the meeting as a teleconference did mean I lost a few hours of work, so the **policy of not paying for peoples' time for activities** I think is something that may need to be reviewed - after all EMA staff and pharmaceutical staff are paid to be at meetings, so the other experts (patients/public) should also be recompensed."*



*"Covers travels expenses, not my time, but my organisation support EMA activities, so this works very well. "*



*"I get an allowance that **barely covers my expenses** and it's only the possibility of getting a senior discount on the train that gives me a little extra. When I still worked, I had to take **unpaid leave to go the meetings** and thus lost income every time."*





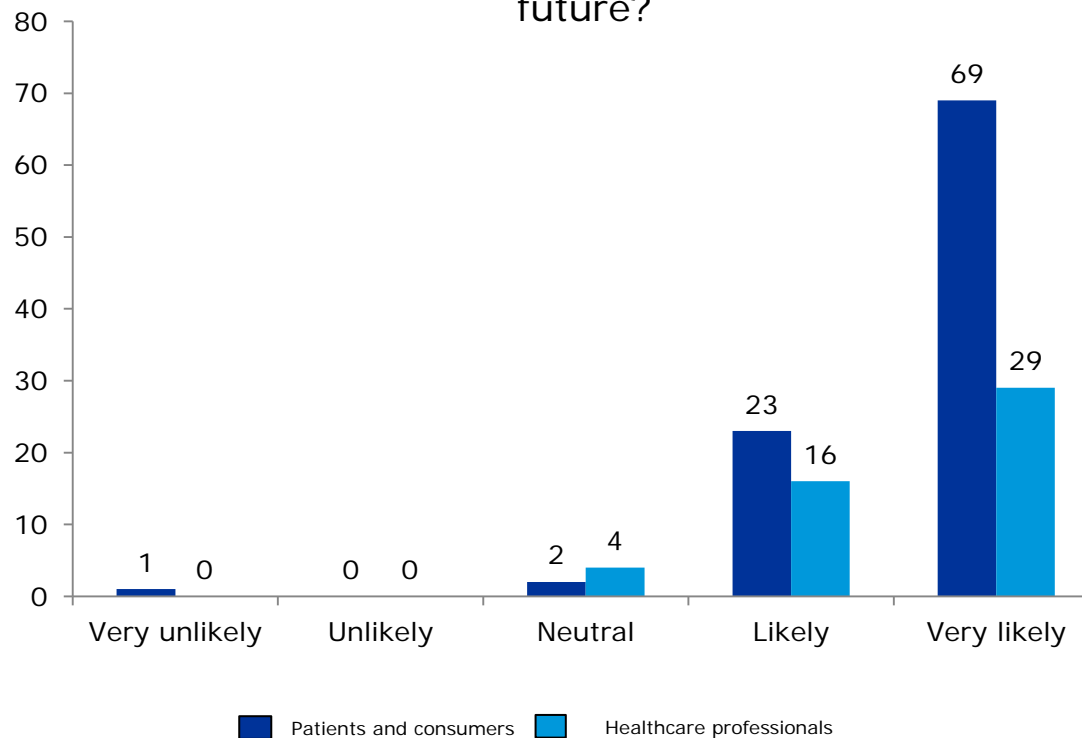
## V. Future participation

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- Based on your experience, how likely would you be to participate in any EMA activity in the future?



Based on your experience, how likely would you be to participate in any EMA activity in the future?





*“Excellent responses by people working there. The technology could be improved. EMA's role is important so I **would encourage more patients to join**. However it's very technical and hard to understand for patients.”*

*“I would appreciate to be allowed to **discuss the application papers with other patients** or expert.”*

*“It depends on the **time commitment as well as the subject matter**. With no backfill the day job awaits!”*



## VI. Other comments

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*“**Better define patient roles and responsibilities** (e.g. better understanding of confidentiality) and perhaps **provide some short training or mentoring at start.**”*

*“The timeliness were very tight and the process was quite rushed. It **would be beneficial** to have appropriate time available to complete the process.”*

*“**I would encourage patients to be involved in every session.** It is invaluable to have someone there who can present the view from the patient perspective.”*

*“**I would suggest that the raw data should be sent out 4 days in advance.** Given some of the arguments were still being formulated, those could come 48 hours prior to the meeting.”*



*“Overall, I am convinced that both sides EMA and HCPs take advantage. **A further improvement could be pre-meeting dissemination of specific questions related to the topics on the agenda** in order to stimulate discussions and to get a closer figure of opinions of the various stakeholders.”*

*“It seems to me that the EMA is now more seeking input and advice from the HCP than before, with the aim to better fulfil patient needs.”*

*“When looking for input it may be helpful to **set out the time commitment and the minimum level of expertise required**. Some may be more willing to engage on particular topics if the commitment was explicit and the confidence to engage supported.”*



## VII. Way forward – proposals for improvement

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1. Maintain high standards of involvement and integration of patients, consumers and healthcare professionals across wide range of EMA activities and continuously aim for improving those standards.
2. Explore ways to streamline Declaration of Interest (DoI)/registration process.
3. Look at providing additional *one-to-one* support prior to the activity, especially regarding the involvement in scientific committees.
4. Expand current educational and training materials – EMA Basics, webinars etc.
5. Endeavour to send out the documents earlier to allow adequate preparation.
6. Explore how to improve feedback for each activity.
7. Explore further options on financial support.





# Any questions?

Nathalie Bere

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