



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

# Survey on Involvement of Healthcare Professionals, Patients and Consumers in 2014 - Results

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04 March 2015 – PCWP/HCPWP meeting



Presented by Merel Stroucken on 4 March 2015  
Patients and Healthcare Professionals – Stakeholders and Communication Division

An agency of the European Union



# Background

**Aim:** To gather feedback from patients, consumers, healthcare professionals and their organisations on their involvement in 2014



Timeline

**15 – 30 Jan 2015**



No of questions

**18**

**16**



No of responses

**51/140**

**34/108**



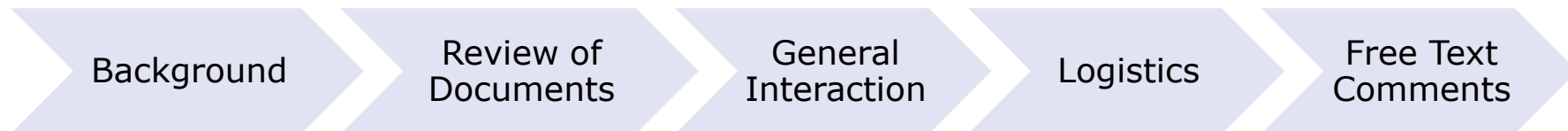
Response rate

**36.4 %**

**31.5 %**



# Set-up



- 1.** Collect and analyse results (Q1)
- 2.** Identify areas for improvement + corresponding actions (Q2)
- 3.** Report on survey as annex to annual report on interaction (Q3)

**Background**Review of  
DocumentsGeneral  
Interaction

Logistics

Free Text  
Comments

### 3. Top 3 reported EMA activities

#### Patients and Consumers (51)

- |   |                    |
|---|--------------------|
| 1. PCWP                                       | <b>32 (66.7 %)</b> |
| 2. Workshop or conference<br>organised by EMA | <b>25 (52.1 %)</b> |
| 3. Review of information                      | <b>20 (41.6%)</b>  |

#### Healthcare Professionals (34)

- |  |                    |
|--|--------------------|
| 1. HCPWP                               | <b>13 (38.2 %)</b> |
| 2. Product related<br>expert meetings  | <b>9 (26.4%)</b>   |
| 3. Workshop /<br>Review of information | <b>7 (20.6%)</b>   |



Background

**Review of Documents**

General Interaction

Logistics

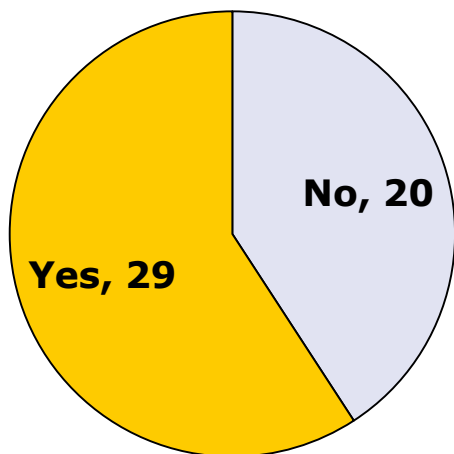
Free Text Comments

## 4. Did you take part in the review of documents?

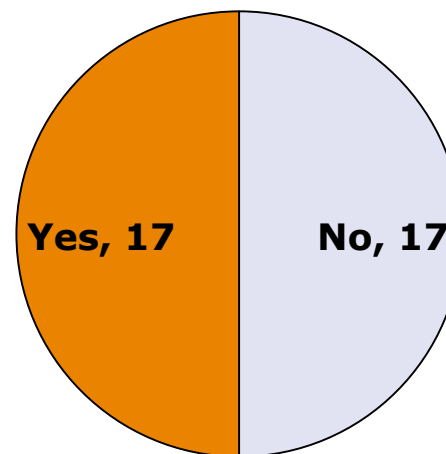
*PCO: Package leaflet, EPAR summary or safety communication;*

*HCP: SmPC, DHPC or safety communication*

### Patients and Consumers



### Healthcare Professionals





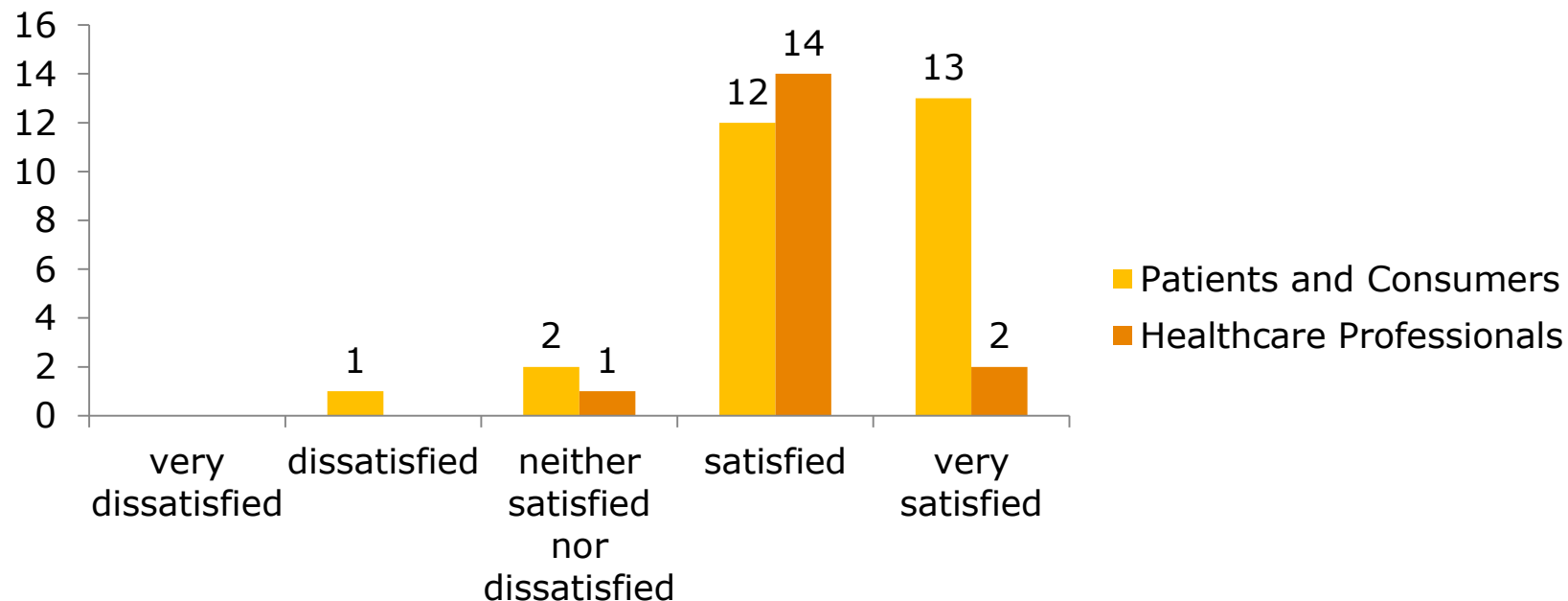
Background

**Review of  
Documents**General  
Interaction

Logistics

Free Text  
Comments

## 5. How satisfied are you with the overall review procedure?





Background

**Review of  
Documents**General  
Interaction

Logistics

Free Text  
Comments

## 5. How satisfied are you with the overall review procedure?

*"The process worked well but as I recall the deadline was quite short which may be difficult in view of heavy workload." (PCO)*

*"I was somewhat disappointed that so little of our feedback was adopted, but I appreciate the reasons for this." (PCO)*



Background

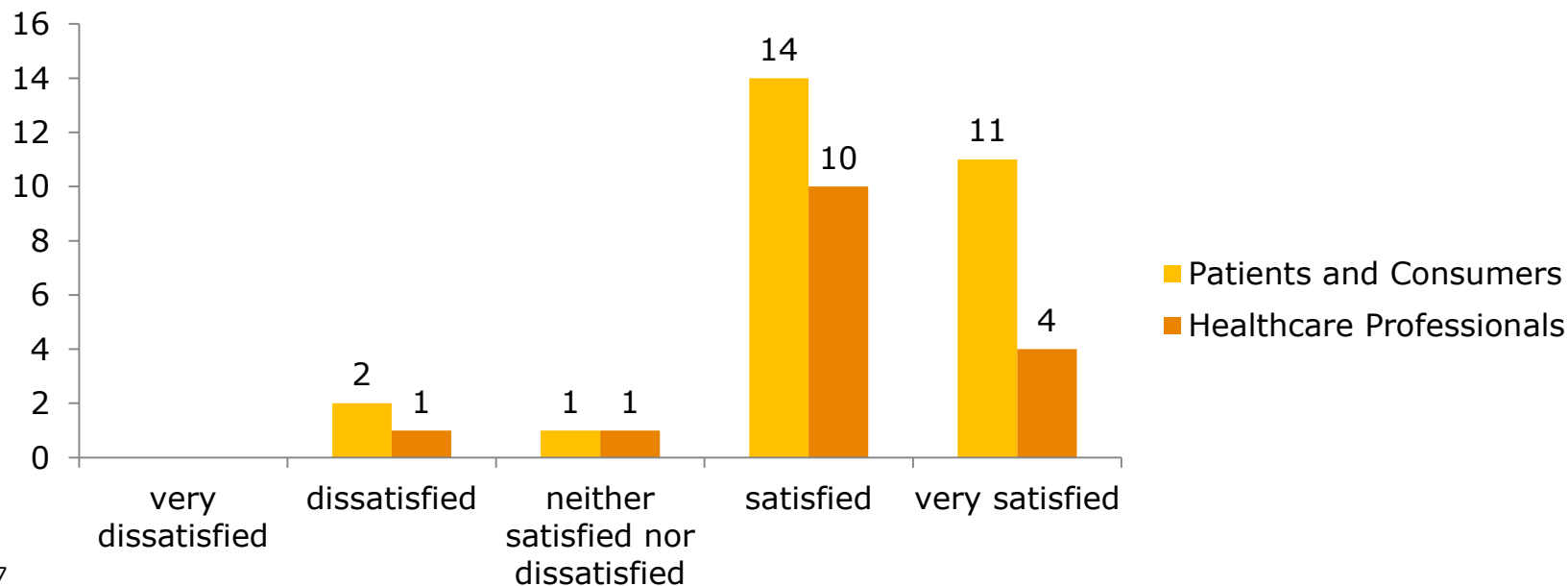
**Review of Documents**

General Interaction

Logistics

Free Text Comments

## 6. How satisfied are you with the feedback you received on the documents you reviewed?







Background

**Review of  
Documents**General  
Interaction

Logistics

Free Text  
Comments

## 6. How satisfied are you with the feedback you received on the documents you reviewed?

*"Pleased that Nathalie provided me with feedback on why so few of my comments were disregarded." (PCO)*

*"Procedurally the admin was good." (PCO)*

*"No feedback received." (PCO + HCP)*



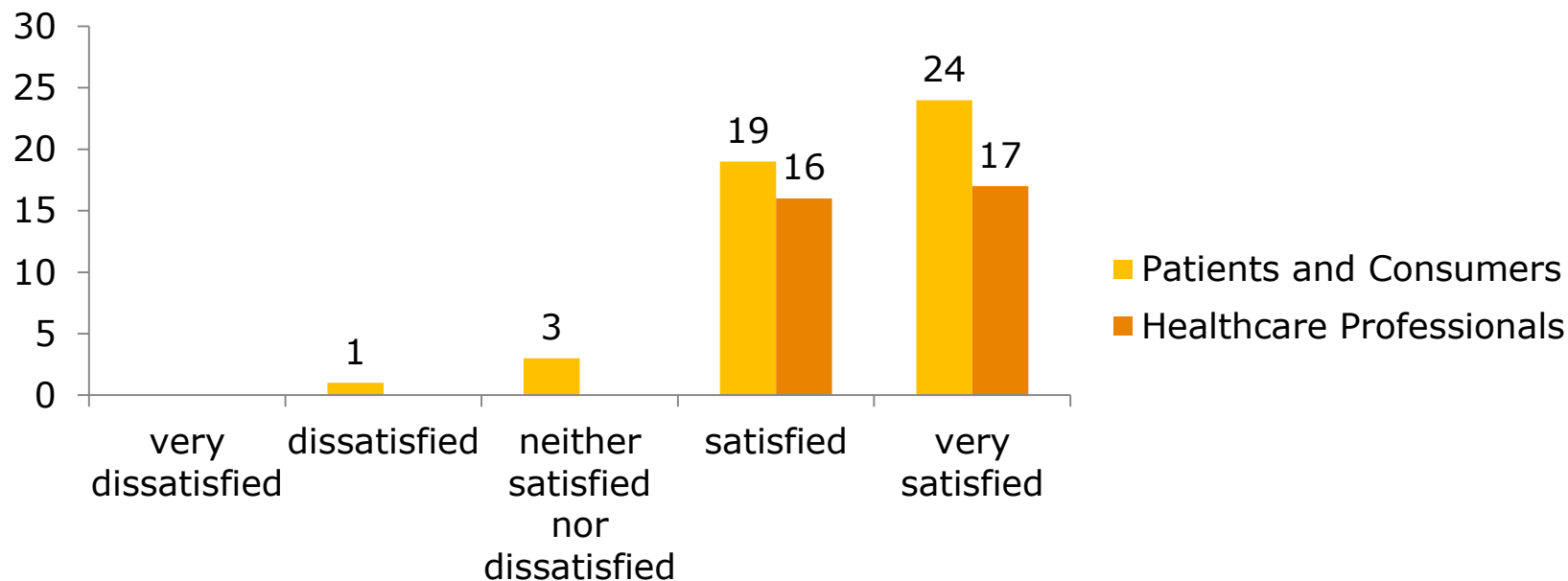
Background

Review of  
Documents**General  
Interaction**

Logistics

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Comments

## 7. How satisfied are you with the overall interaction between you and the EMA?





Background

Review of  
Documents**General  
Interaction**

Logistics

Free Text  
Comments

## 7. How satisfied are you with the overall interaction between you and the EMA?

*"One single contact point would help." (PCO)*

*"The EMA seems very open and willing to listen to patient organisations." (PCO)*

*"The content of the workshop I attended was excellent, but the bureaucracy involved in registering/submitting declaration of interest etc. was extremely cumbersome and frustrating and took far longer than should be expected. I imagine that in some cases, it would be enough to discourage participation of some individuals altogether." (PCO)*

*"Prompt and informative response to emails, efficient support to patients who wish to become patient experts." (PCO)*

*"Consultations could be sent with a longer deadline to allow (more of) our members to provide a response." (HCP)*



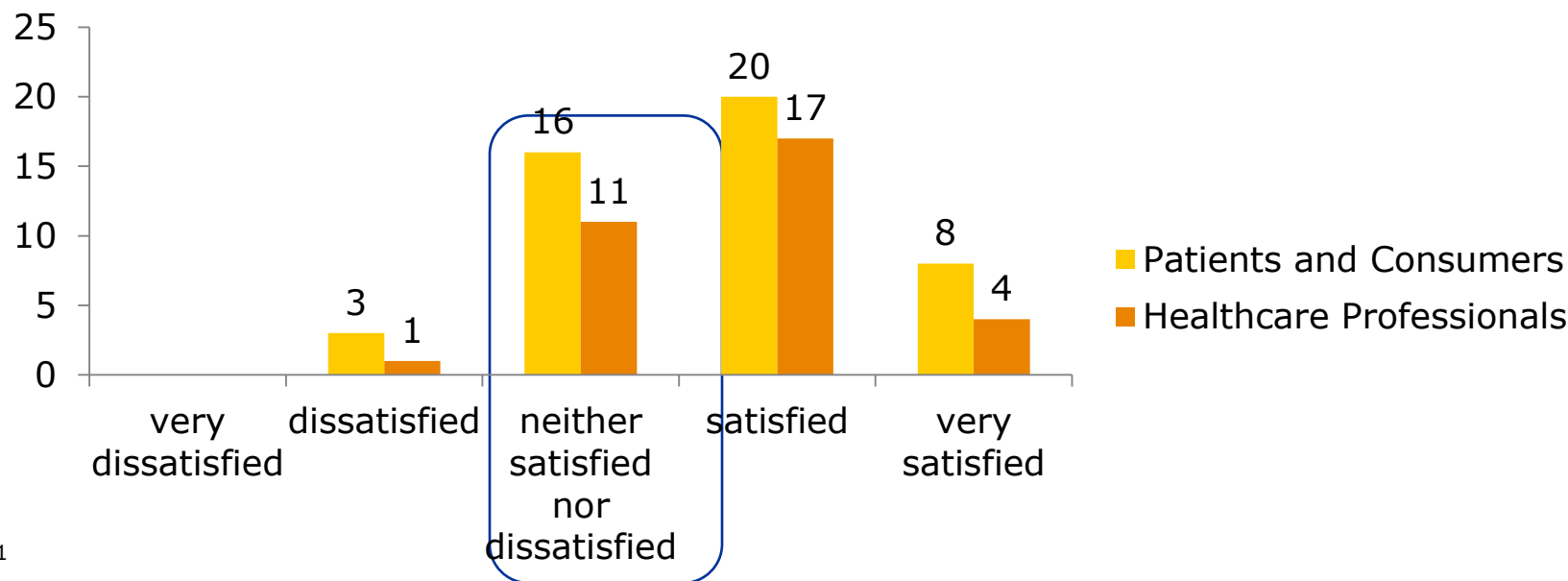
Background

Review of  
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Interaction**

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Comments

## 8. Do you feel that your involvement has made a difference?





Background

Review of  
Documents**General  
Interaction**

Logistics

Free Text  
Comments

## 8. Do you feel that your involvement has made a difference?

*"Hard to judge as I've never had feedback on my involvement directly." (PCO)*

*"If the difference is not measurable or tangible it is difficult to assess, but the general opinion is positive impression is positive." (PCO)*

*"Was not informed about the final result (but maybe my organisation was?)" (HCP)*



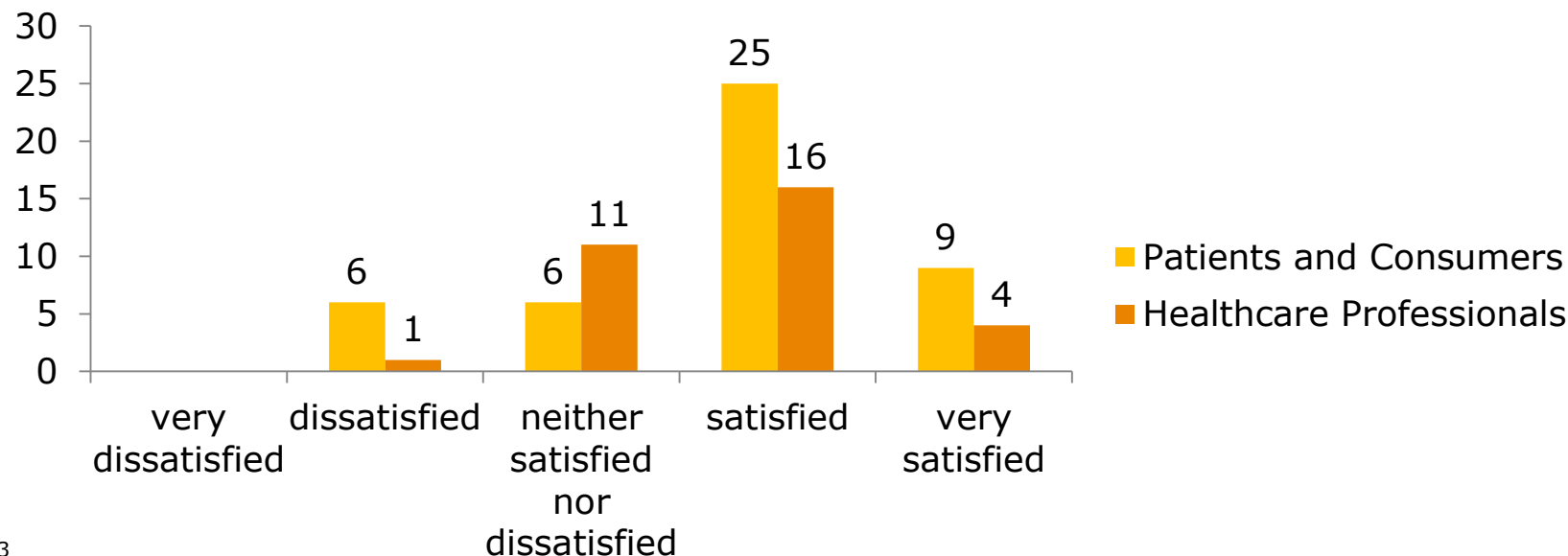
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Interaction**

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Comments

## 9. Do you feel that PCOs / HCPs are adequately represented within the Agency's work?





Background

Review of  
Documents**General  
Interaction**

Logistics

Free Text  
Comments

## 9. Do you feel that PCOs / HCPs are adequately represented within the Agency's work?

*"Not enough because PCWP should be open to all the civic organization." (PCO)*

*"From my preliminary observation, there is good representation of patients within the agency's work." (PCO)*

*"Would prefer to see more patients than staff members of patient organisations." (PCO)*

*"Can be always improved as the industry is always present everywhere; the problem with professionals is that it is not that core task as this is caring/treating for patients so their advisory role is always an additional task." (HCP)*

*"I do not have any idea." (HCP)*



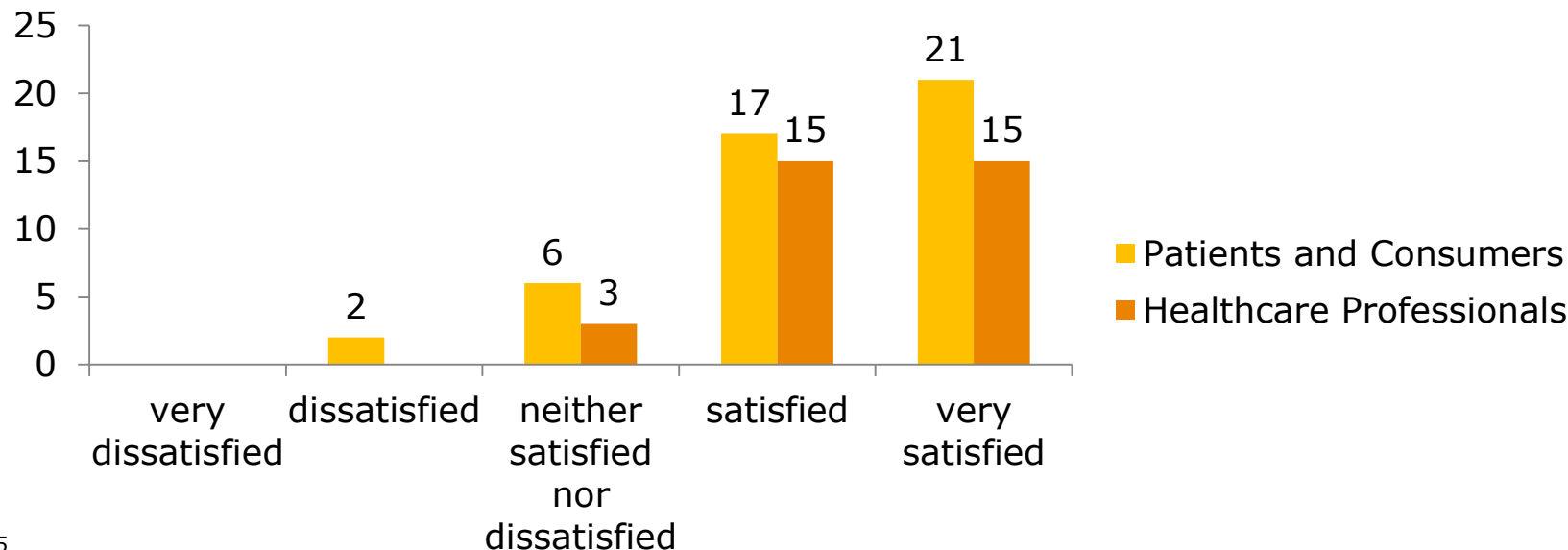
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Review of  
Documents**General  
Interaction**

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Comments

## 10. How satisfied are you with the level of support you received to participate in a specific activity?







Background

Review of  
Documents**General  
Interaction**

Logistics

Free Text  
Comments

## 10. How satisfied are you with the level of support you received to participate in a specific activity?

*"We have appreciated a lot support and training during the 2 meetings in November. If possible, next time can be useful to share and explain with enough time ALL the possible interaction between EMA and patient/consumers' organization." (PCO)*

*"A mentor is necessary for a new participant." (PCO)*

*"Always excellent facilities and training help." (PCO)*

*"Comprehensive training, but more interaction or examples would have been good." (PCO)*



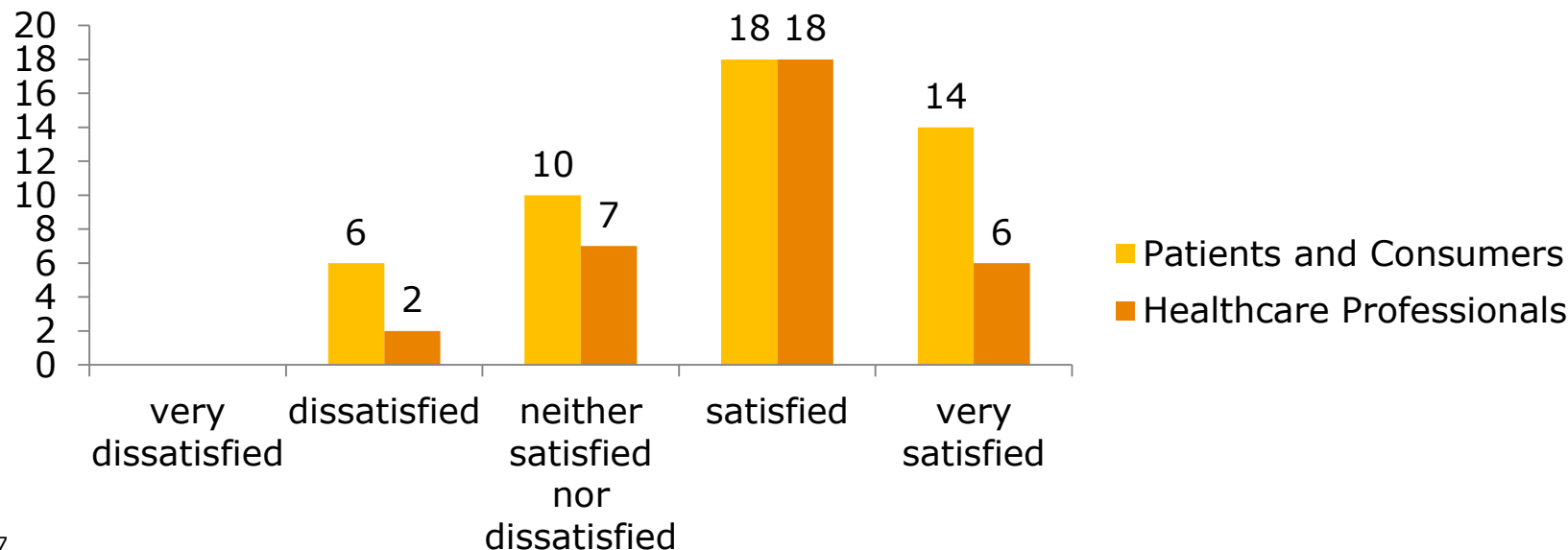
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Documents**General  
Interaction**

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Comments

## 11. Do you feel the Agency takes enough initiative to involve PCOs / HCPs?





Background

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Documents**General  
Interaction**

Logistics

Free Text  
Comments

## 11. Do you feel the Agency takes enough initiative to involve PCOs / HCPs?

*"I'm satisfied by the will of EMA to involve patient representers but I think it could be improved with a better balance between numbers of patients and professionals." (PCO)*

*"EMA make efforts to involve patients but longer timescales would make this input easier i.e. longer review periods for patient input, and longer to find patients to input and register with the EMA systems." (PCO)*

*"It would be helpful to have a little more in depth training in specific things. I attended a very broad training session which was great - but there was a huge amount to cover and only sufficient time for a very broad, whistle-stop overview of most things (the day was well organised and very informative)." (PCO)*

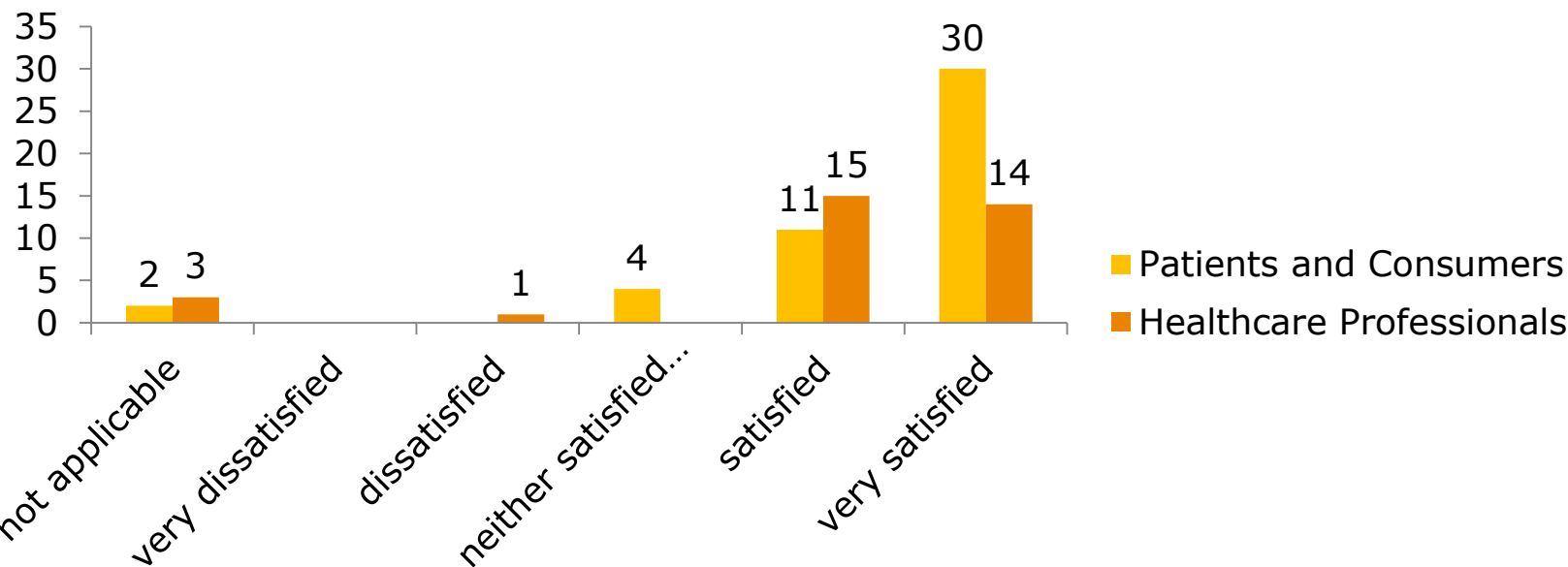
*"The initiative is not so much a problem at all. For me personally, some discussions are held over topics which basically have already been decided." (HCP)*



Background

Review of  
DocumentsGeneral  
Interaction**Logistics**Free Text  
Comments

## 12. How satisfied are you with the practical arrangements/facilities provided by the EMA?





Background

Review of  
DocumentsGeneral  
Interaction**Logistics**Free Text  
Comments

## 12. How satisfied are you with the practical arrangements/facilities provided by the EMA?

*"Excellent organization, just a comment: why we cannot use own credit card or cash inside the EMA building?" (PCO)*

*"Exceptional help and travel arrangements from the EMA." (PCO)*

*"There was considerable bureaucracy involved. it was necessary to queue for over 15 minutes at the front desk, then queue all over again for registration at the event, which was somewhat frustrating." (PCO)*

*"For breakout sessions, the plenary rooms are not the best option (I couldn't hear much of the discussion at the other end of the group). Suggest used of dedicated / smaller individual rooms for such workshop / small group activities." (HCP)*

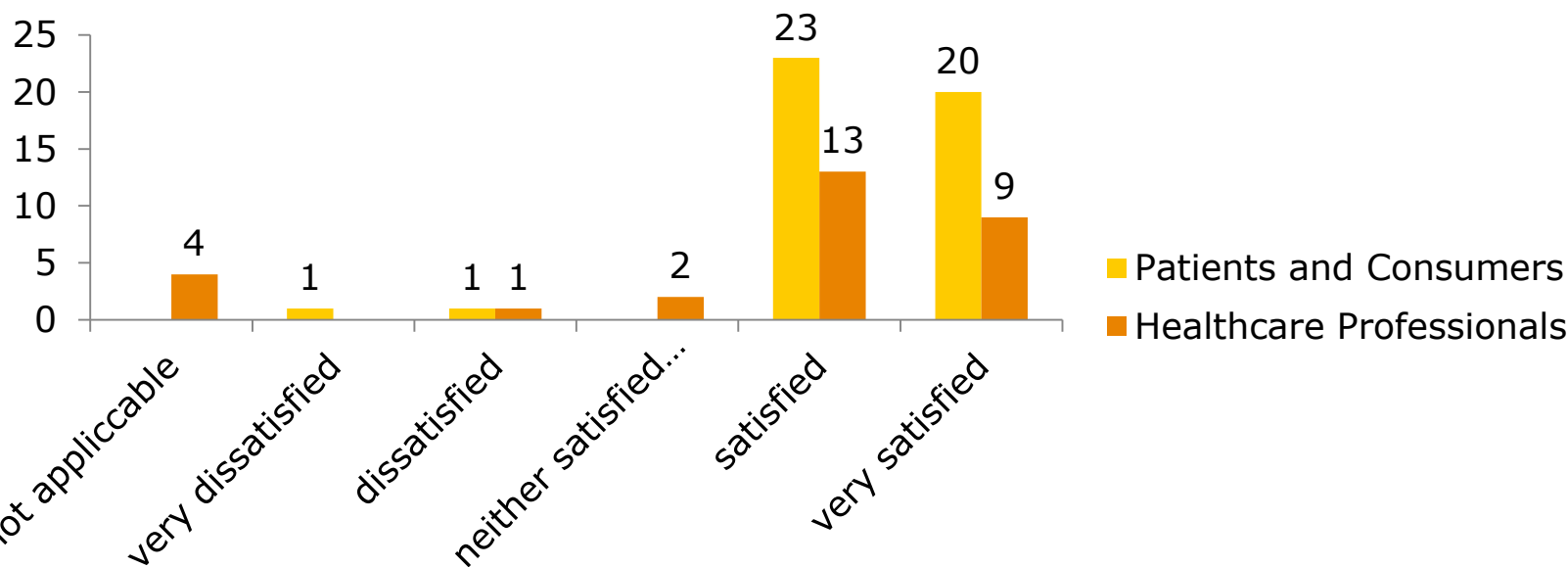
*"The webpage is difficult." (HCP)*



Background

Review of  
DocumentsGeneral  
Interaction**Logistics**Free Text  
Comments

## 13. How satisfied are you with the organisation of EMA meetings? (e.g. invitations, travel arrangements, rooms, meeting services)





Background

Review of  
DocumentsGeneral  
Interaction**Logistics**Free Text  
Comments

## 13. How satisfied are you with the organisation of EMA meetings? (e.g. invitations, travel arrangements, rooms, meeting services)

*"Too much pages to study, too much difficult." (PCO)*

*"The schedules are very tight, though!" (PCO)*

*"High level of topics, speakers and documents. Just a comment: we have received all documents few days before the meeting, probably in the future it will be better to send it previously." (PCO)*

*"Faultless admin" (PCO)*

*"Never enough time to read the vast literature I have received." (PCO)*

*"Would appreciate that participants are asked to contribute to the topics." (PCO)*

*"Agendas and supporting documents could be sent earlier (e.g. more than two days, especially if these two days are non-working days))." (HCP)*

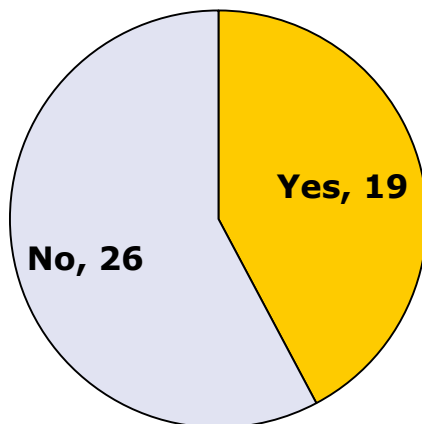


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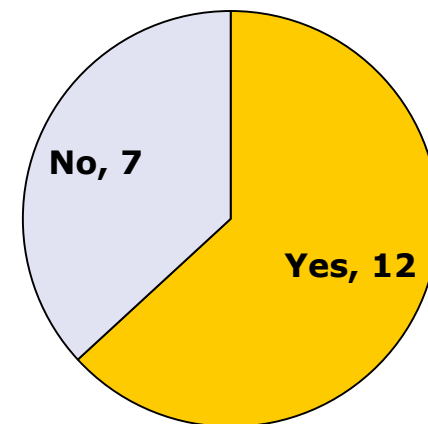
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## Patients and Consumers only

**14. Did you receive extra financial support to participate in an EMA meeting? (i.e. daily expense allowance)**



**15. Did the extra allowance have an impact on whether you were able to participate?**







Background

Review of  
DocumentsGeneral  
Interaction**Logistics**Free Text  
Comments

## Patients and Consumers only

**14. Did you receive extra financial support to participate in an EMA meeting? (i.e. daily expense allowance)**

**15. Did the extra allowance have an impact on whether you were able to participate?**

*"As non profit organization, we cannot cover expenses for a journey to London without the support of EMA."*

*"This makes such a difference - to be able to attend and give of your time."*

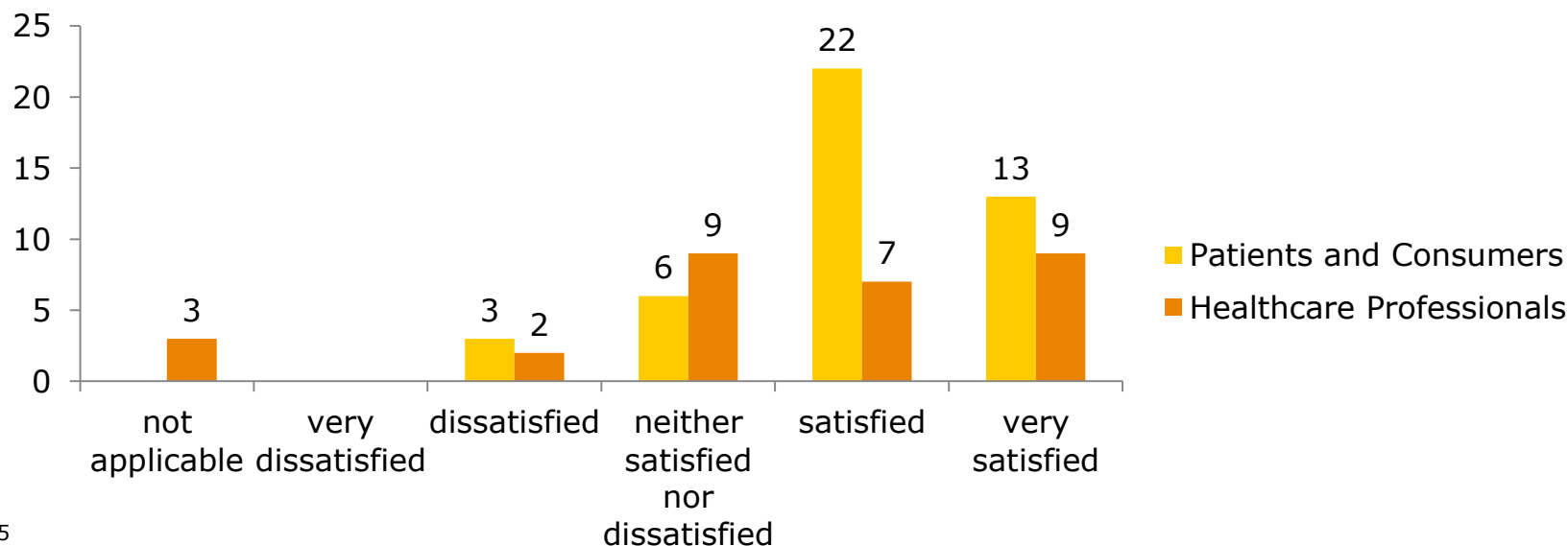
*"This is critical for being able to participate for people with low income / pension allowance is important for small patient entity."*



Background

Review of  
DocumentsGeneral  
Interaction**Logistics**Free Text  
Comments

## 16. How satisfied are you with the overall level of financial support provided?





Background

Review of  
DocumentsGeneral  
Interaction**Logistics**Free Text  
Comments

## 16. How satisfied are you with the overall level of financial support provided?

*"We have appreciated the so quick reimbursement, it is important because we anticipate with own resources." (PCO)*

*"It is a pity that my organisation is not receiving any financial support for the reviewing we are doing." (PCO)*

*"I received one small sum for attending a meeting. I have not been compensated for my time in reading documents and attending TCs." (PCO)*

*"At least the current travel costs are covered." (PCO)*

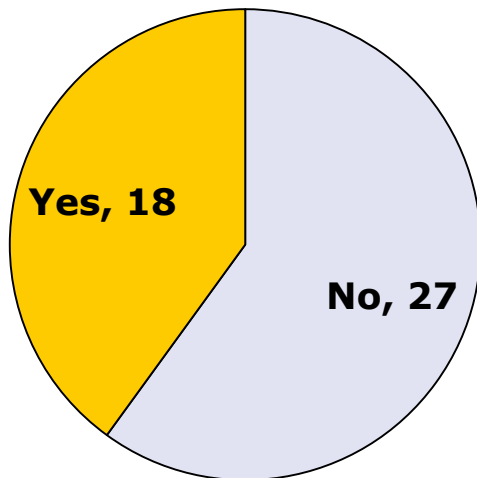


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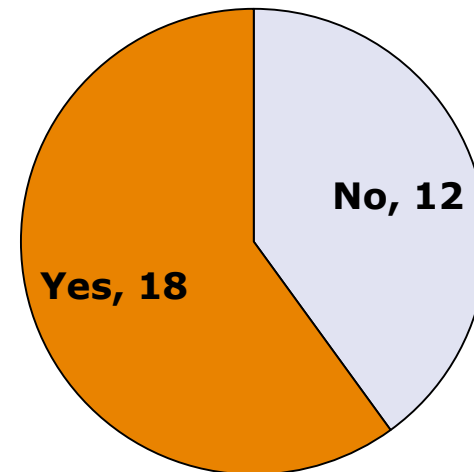
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Interaction**Logistics**Free Text  
Comments

## 17. Would you like to see your participation acknowledged?

### Patients and Consumers



### Healthcare Professionals





Background

Review of  
DocumentsGeneral  
Interaction**Logistics**Free Text  
Comments

## 17. Would you like to see your participation acknowledged?

*"Possibly for a specific, specialised activity tied to a particular topic, but not for general activities." (PCO)*

*"It would be useful a.) for internal reporting purposes and b.) if the EMA would like to see its work more widely publicised, e.g. information about our participation could go on the [name of organisation] website. So a certificate accompanied by a short paragraph about the event would be very helpful." (PCO)*

*"I think this would be a waste of paper and resources, unless an electronic version could be made?" (HCP)*

*"Certificate of nomination (fulfilment of requirements) and certificate of attendance." (HCP)*



Background

Review of  
DocumentsGeneral  
Interaction

Logistics

**Free Text  
Comments**

## 18. Free text comments (PCO)

*"We have really appreciated the EMA relationship with the PCWP. In order to improve this relationship, we believe useful to co-define the agenda of next meetings according the needs of the organizations."*

*"The EMA is an excellent organisation that is genuinely patient friendly and shows by its words and actions that it wants to be involved in and listen to the views of patients and consumers. Thank You."*

*"The EMA is very supportive to patients' organizations and offers valuable resources and training to enable them to effectively engage on a number of potentially technical issues."*

*"The PCWG can be a real discussion forum, members should be asked more often to contribute to its works with presentations, reports, surveys on topics of interest to all patients."*

*"For the massive task of changing the healthcare systems in Europe towards more efficiency and less waste of resources, but also towards more equality in access to quality healthcare for ALL EU citizens, an even closer cooperation between all stakeholders for a truly innovative, safe, but affordable and therefore sustainable healthcare is a must - and EMA has to play a leading role in this development".*



Background

Review of  
DocumentsGeneral  
Interaction

Logistics

**Free Text  
Comments**

## 18. Free text comments (HCP)

*"the members of the EMA team are allways very competent and helpful!"*

*"Maybe the work can be longer the first day, but shorter the second one because of flights."*

*"Being able to participate in EMA activities as an expert is a very valuable experience, one may feel that one takes part in the process of real decision-taking, and is also very inspiring intellectually. Moreover, being able to offer one's experience to the needs of the EMA and subsequently patients across Europe is an honour one can only dream of. I would be happy to work for the EMA as often as possible within my field of expertise and am truly looking forward to further assignments."*

*"There is a lot of work which remains unacknowledged, a lot of one`s free time spent on activities, with no proof of attendance, participation etc."*

*"More focused tasks for the group may help. Some of the discussions seem to be held because they should be on the agenda, but no clear goal is defined."*