



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

2023 Satisfaction survey – PCO engagement with EMA

Analysis of results

Patients and Consumers' Working Party meeting – June 2023

Presented by Giulia Gabrielli
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An agency of the European Union



Satisfaction survey to all eligible organisation

- Previous satisfaction surveys of individual experts
- Need to map perceptions and needs of eligible organisation
- HCP organisations also surveyed

42	Granted EMA eligibility status	<ul style="list-style-type: none"> • Scrutinised against eligibility criteria • Listed on EMA website • Annually assessed • Priority for interaction
22	Members of PCWP	<ul style="list-style-type: none"> • 3-year mandate • Up to 4 meetings/year • Priority for consultation on EMA strategies and policies

EMA 'eligibility' criteria Transparent on the funding of the organisation

- | | |
|----------------------|------------------|
| ▶ Legitimacy | ▶ Structure |
| ▶ Mission/activities | ▶ Accountability |
| ▶ Representation | ▶ Transparency |




SURVEY RUN FROM 23 FEBRUARY TO 24 MARCH - SENT TO ALL 42 ELIGIBLE ORGANISATIONS

Survey goals

A dark blue parallelogram pointing to the right, containing the text 'Assess organisations' satisfaction' in white.

Assess
organisations'
satisfaction

A light blue parallelogram pointing to the right, containing the text 'Gather feedback and information' in white.

Gather
feedback and
information

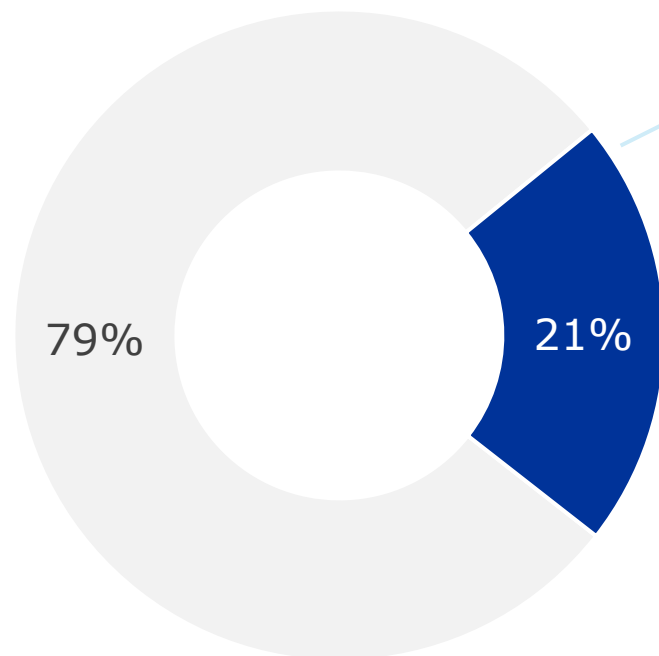
A yellow parallelogram pointing to the right, containing the text 'Improve engagement activities' in white.

Improve
engagement
activities



SURVEY RUN FROM 23 FEBRUARY TO 24 MARCH - SENT TO ALL 42 ELIGIBLE ORGANISATIONS

Breakdown of participants



Responders (N=9)

European Cancer Patient Coalition (ECPC)

European Heart Network (EHN)*

European Lung Foundation (ELF)

European MEN Alliance (EMENA)

Europa Uomo (EUomo)*

European Organisation for Rare Diseases (EURORDIS)*

International Alliance of Dermatology Patient Organisations
(IADPO/GlobalSkin)

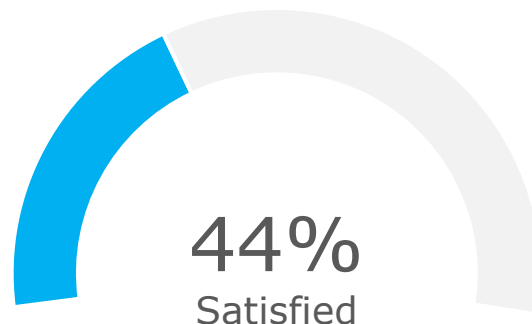
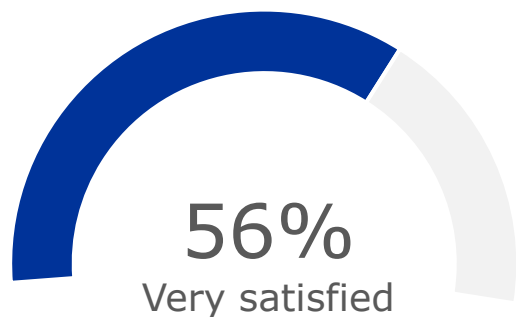
**International Patient Organisation for Primary
Immunodeficiencies (IPOPI)***

European Pulmonary Hypertension Association (PHA)

***PCWP member**



How satisfied are you with your current level of engagement with EMA?



Answers: rating 1-5
1=not at all satisfied
2=slightly satisfied
3=moderately satisfied
4=satisfied
5=very satisfied

Recurring remarks:



Community
representation



Variety of
activities



Good interactions
with EMA

How satisfied are you with your current level of engagement with EMA? Some comments received

+

We are able to represent our community's views, concerns, needs and expectations.

-

During evaluations patients are consulted indirectly via the CHMP Early Dialogue, but thereafter not systematically.

-

Sometimes timelines for engagement are quite tight.

+

Interaction is always professional and pleasant.

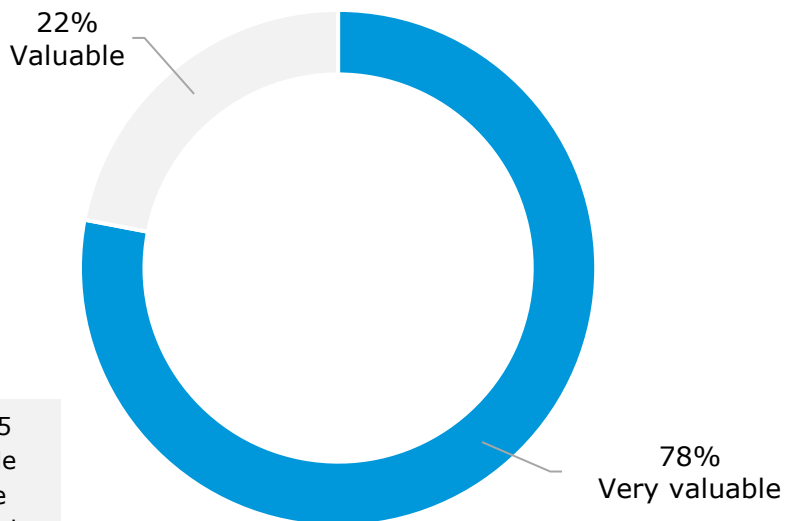
+

Had the opportunity to learn a lot over the 10 years of engagement with EMA.

-

One concern remains the difficulty to prepare patient advocates for some consultations.

How would you rate the value of being an eligible organisation?



Answers: rating 1-5
1=not at all valuable
2=slightly valuable
3=moderately valuable
4=valuable
5=very valuable

Recurring remarks:



Legitimacy to organisations



Regular communication/information updates



EU representation



Access to PCWP

What do you consider is the value, to EMA, of engaging with your organisation? Comments received

“

Bringing the patients' voice to regulatory procedures

“

Providing information and discussion

“

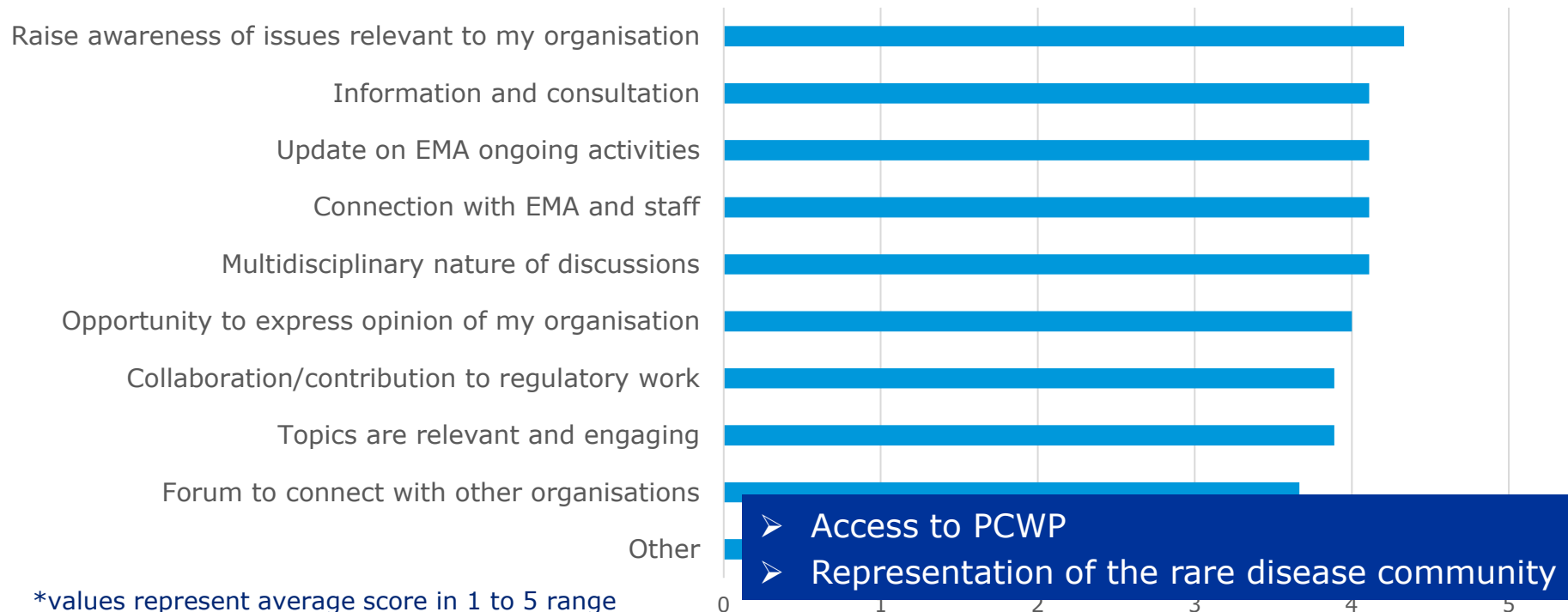
A chance to review EMA materials to ensure suitability for patient audience.

“

Acquiring knowledge and understanding of the bigger challenges in medicines

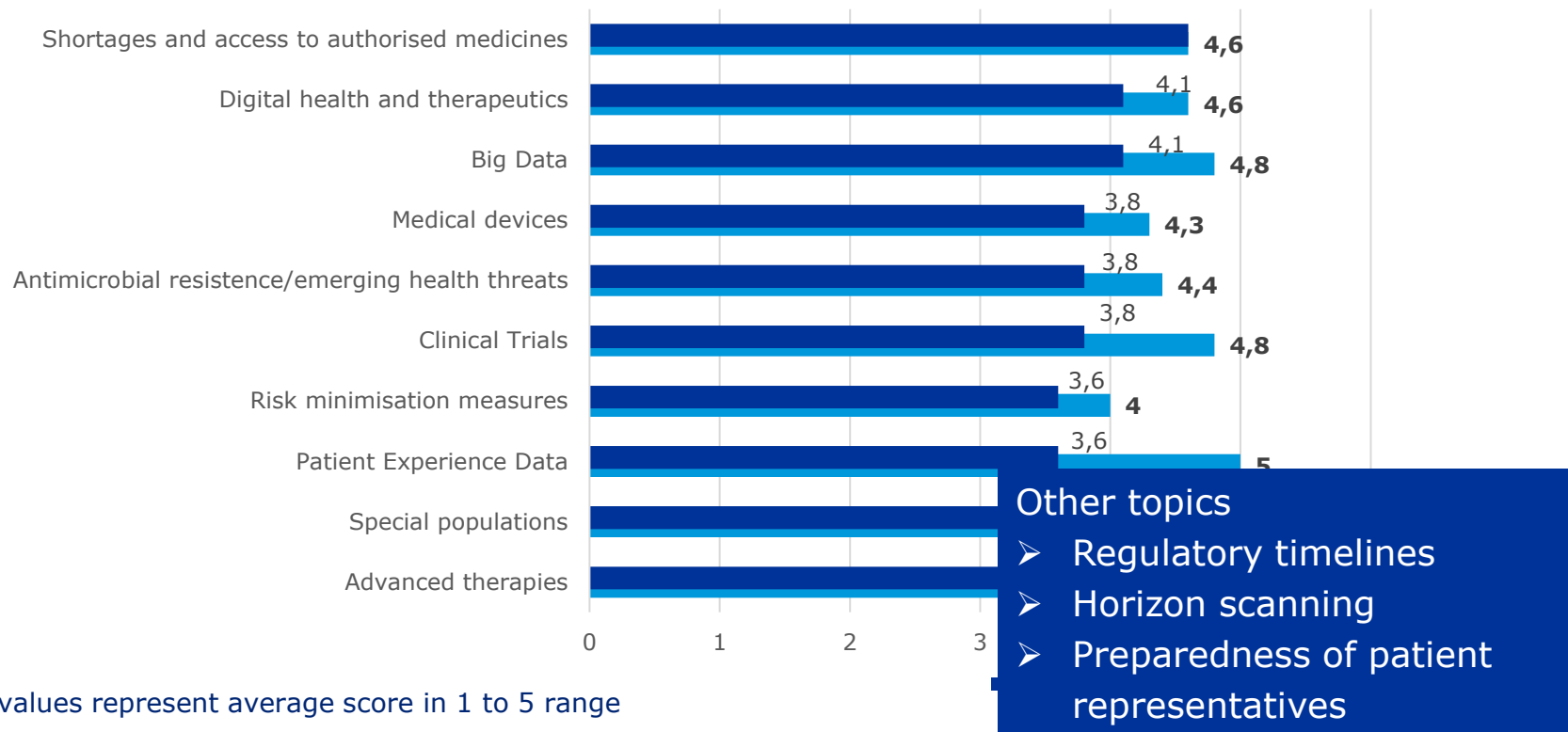


Value of engaging with EMA*



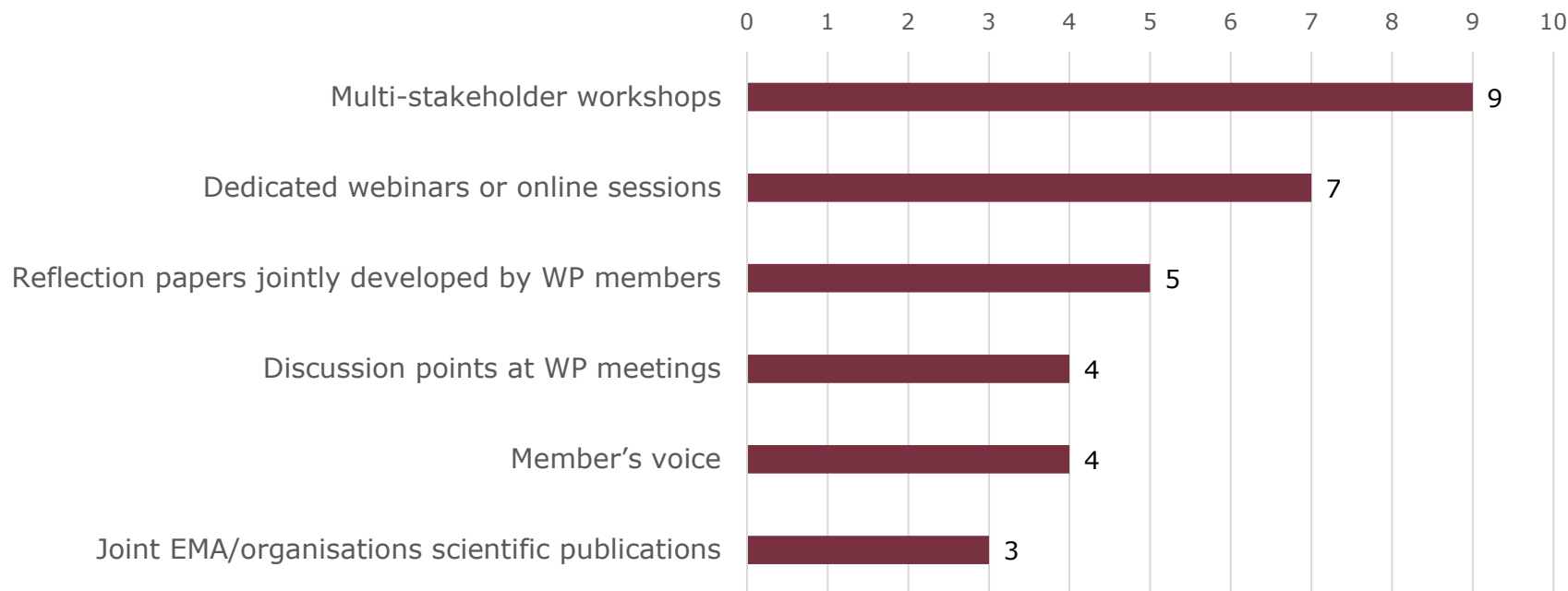


Topics of interest*



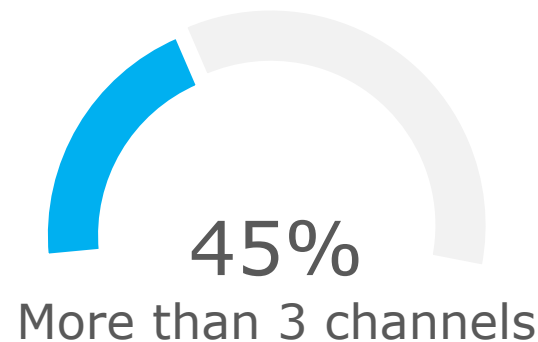


Methodologies for engagement*



*values represent number of preferences
indicated by organisations

How does your organisation promote visibility of its interactions with EMA?



Other:
Social media
Training activities
Conferences
Articles in scientific papers
Interviews



“

Workshop organised and attended by patients, HCPs and HMAs as I feel that some NCAs do not understand the value of collaboration.

“

Did not agree with the presentations on the new working parties when there is not the possibility of applying on being recommended as a patient representative.

“

EMA's structured involvement of the patient voice is setting an example for other EU institutions and agencies.



Conclusion

- Generally high satisfaction and positive comments
- Low participation rate leaves questions about the “silent majority”
- High recognised value of engaging with EMA for organisations
- Topic interests and engagement methodologies reflective of Agency’s priorities and ongoing work
- Concerns raised over aspect of product-specific involvement (timelines, complex content, difficulties identifying patient experts)
- Results to feed into discussion on PCWP work



Any questions?

Further information

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