



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Renewal of the Human Medicines Highlights Newsletter: Results of the satisfaction survey

PCWP/HCPWP joint meeting, 28 June 2023

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An agency of the European Union



The Human Medicines Highlights Newsletter

Frequency: monthly

Subscribers: 900-100 (database)

Primarily intended for patients, consumers and healthcare professionals

Provides links with no additional content to information published during previous month: MA granted, positive/negative opinions, safety updates...

Other content under very broad headings, undifferentiated: Events, publications, "other"

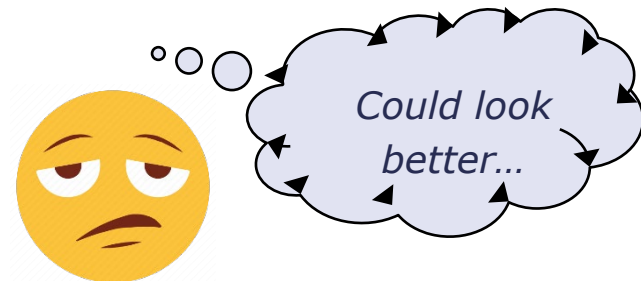


Newsletter renewal project 2023

Does the newsletter meet its audience's needs?

- Primarily intended for non-profit stakeholders (HCPs, patients) but most readers are from industry
- Transitioning to a new tool → opportunity to improve content to make it better aligned with its target stakeholders' needs
- Look can be improved
- Consider multilingual interface

First step: survey of the target audience to evaluate perception, identify improvement needs, likes and dislikes

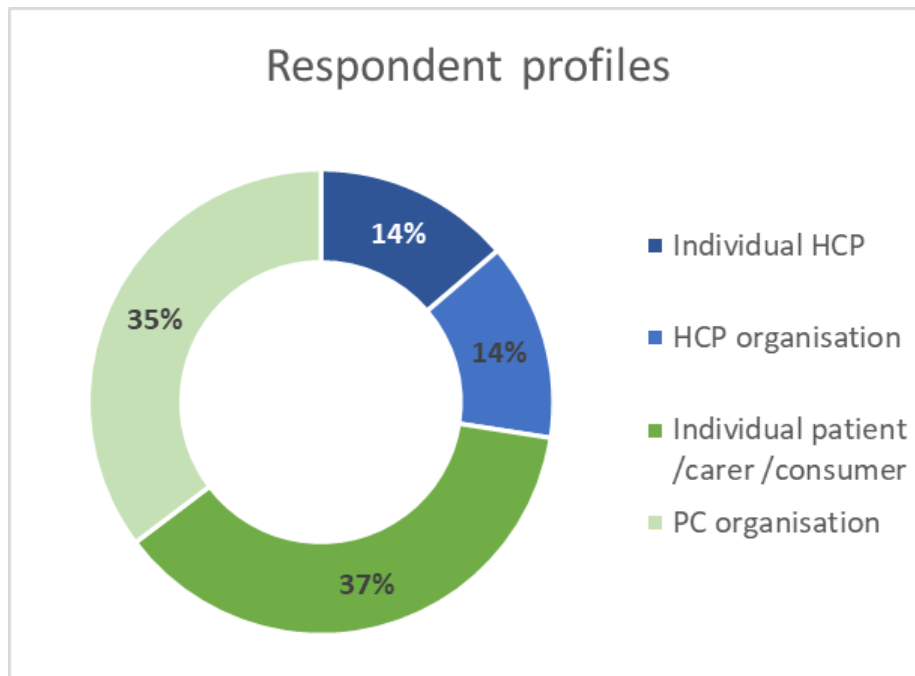


- [HMA/EMA Task Force on Availability of authorised medicines for human and veterinary use \(TFAAM\): Steering Committee composition](#)
- [DRAFT Qualification opinion for the iBox Scoring System as a secondary efficacy endpoint in clinical trials investigating novel immunosuppressive medicines in kidney transplant patients](#) - deadline for comments 17 November 2022
- [Notification on arrangements for requesting EMA certificates through urgent and standard procedure for December 2022](#)
- [EMA mid-year report 2022](#)
- [Key performance indicators \(KPIs\) to monitor the European clinical trials environment](#)
- [European Medicines Agency's Data Protection Notice](#)
- [Records of data processing activity for the raw data proof-of-concept pilot](#)

Events

- [Management Board meeting](#) - 15-16 June 2022 - [Minutes](#)
- [Management Board meeting](#) - 6 October 2022 - [Agenda](#), [Highlights](#)
- [Multi-stakeholder workshop: Patient experience data in medicines development and regulatory decision-making](#) - 21 September 2022
- [Meeting of the Nitrosamine Implementation Oversight Group](#) - 30 November 2022
- [Human Variations electronic application forms Q&A Clinics – Session 3](#) - 29 November 2022
- [Human Variations electronic application forms Q&A Clinics – Session 2](#) - 22 November 2022
- [Ninth Meeting of the Nitrosamine Implementation Oversight Group](#) - 21 November 2022

Survey responses



Survey sent to 80 eligible organisations + 457 individual subscribers

4 May–16 June 2023 using the EUSurvey online tool

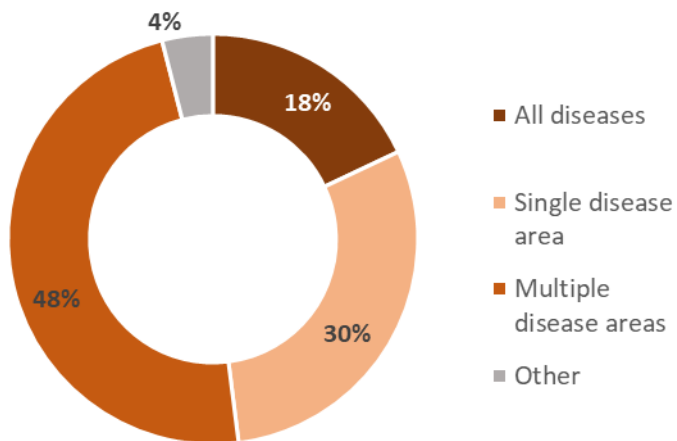
Total responses received: 51

- Individual HCPs: 7
- For HCP organisations: 7
- Individual patients/consumers: 19
- For PC organisations: 18

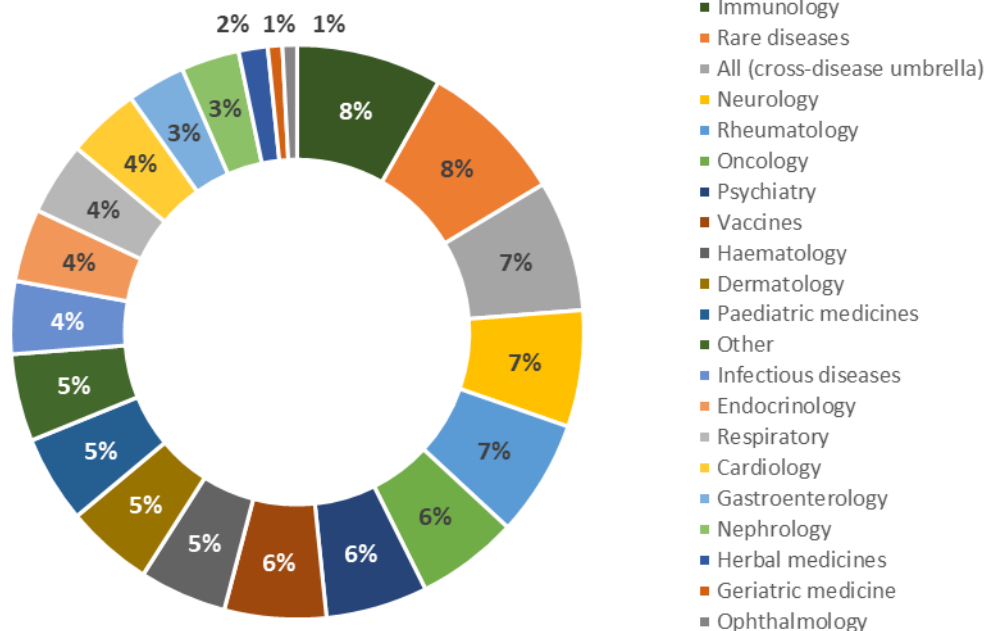


Areas of interest

Spread of interests

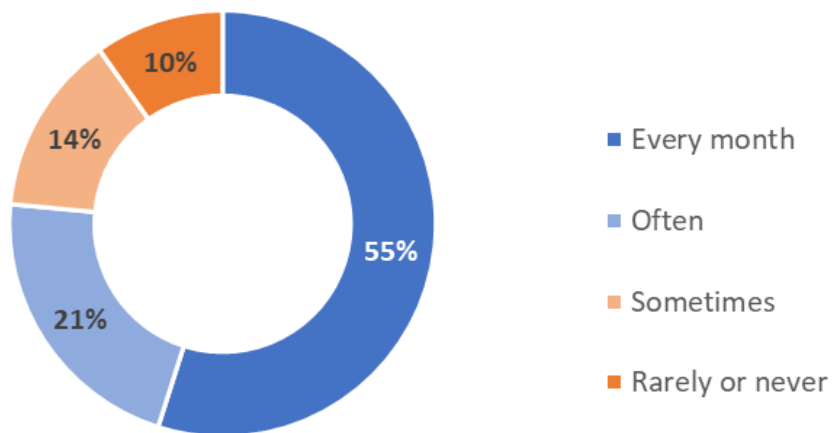


Areas of interest (multiple choices)



How often do recipients read the HMM newsletter?

How often do you read the HMM Newsletter or parts of it?



Comments:

"I only scan the disease areas I am interested in, but I rarely click on links to get further information."

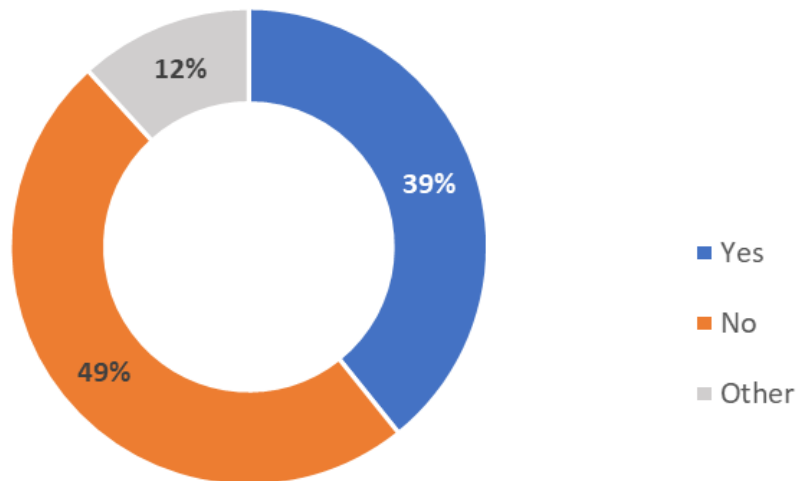
"It brings a well-summarised structure of the developments on medicines at EU level."

"Always ... I usually skim through and then focus on the news/topics which pertain my field of interest."

"I get so many emails daily..."

Do they disseminate the newsletter?

Do you disseminate the newsletter or parts of it?



Comments:

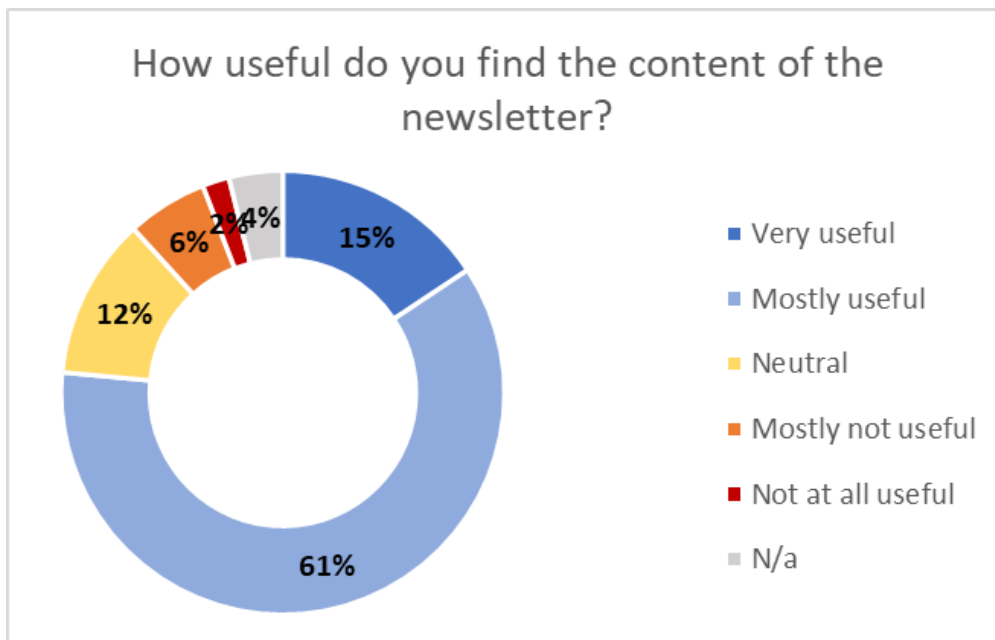
"Sometimes when information is relevant"

"Topics of particular interest to PC"

"Not the newsletter as such. However, every time EMA release the appraisal/recommends a new indication (including extensions) for cancer medicines, the news is clearly communicated in the society website."



How useful do they find the newsletter?



(If answered neutral or not useful):

"Not everything is relevant to our audience"

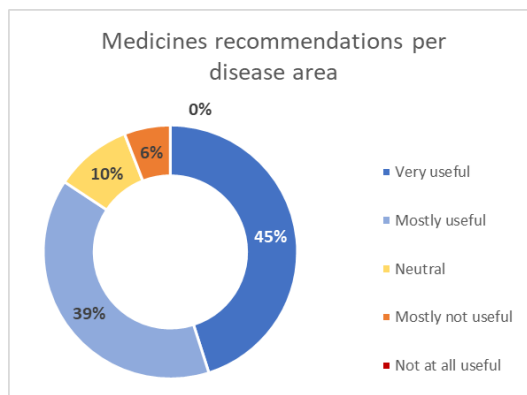
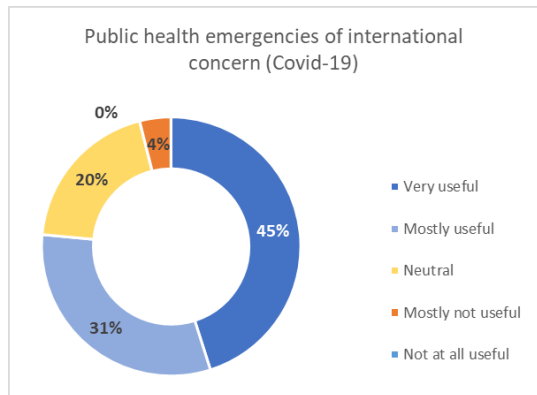
"Too long to read and not relevant"

"Not very patient-friendly"

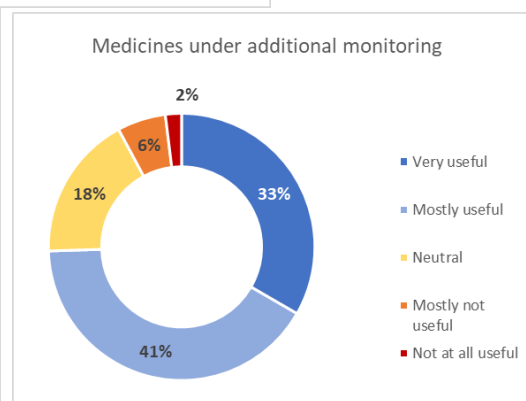
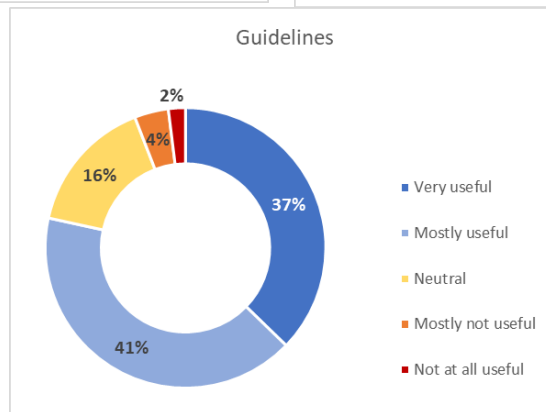
"There is no information about my interest"



How useful are the different sections of the newsletter?

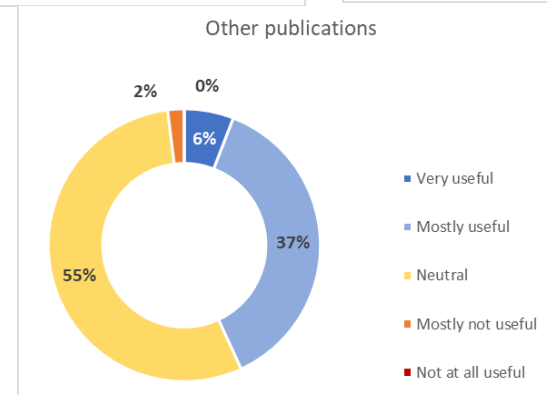
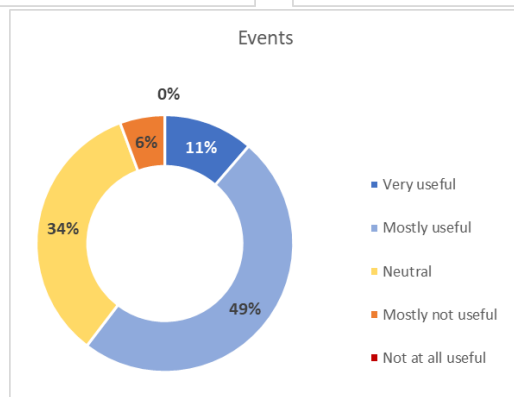
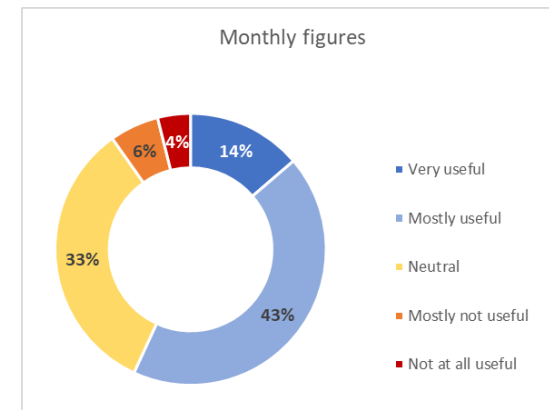
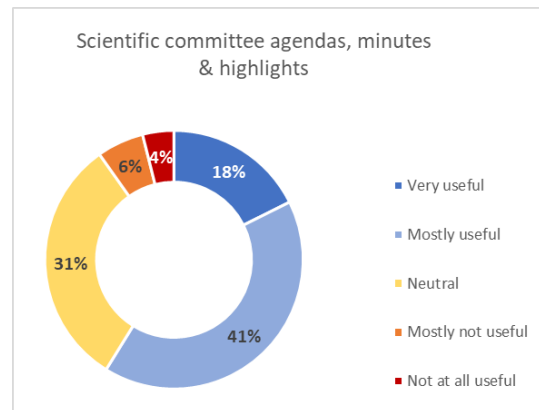
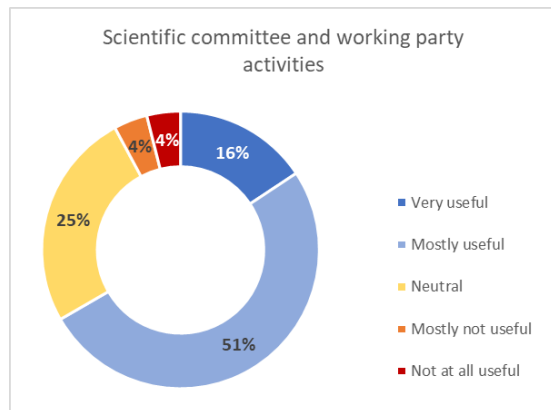


Areas most frequently mentioned as “very useful”





How useful are the different sections of the newsletter?





Comments

“The newsletter is broad, while my interest is small.”

“A lot of items can sometimes be useful, although often they are not.”

“It is sometimes difficult to understand and focus on the information I need.”

“It’s a definite go-to for information”

“The impression is that the newsletter reports on work done, not on future projects ... public consultations, workshops/meetings of wider interests can be highlighted in advance.”



Presentation of content

Presentation by disease-area (as now) most favoured option

Comments:

- In these days it must be possible to add the possibility to select different presentations [by disease-area or otherwise]
- When reading the newsletter, I found easier to have the medicines of my interest nicely grouped by disease area. However, it could also be of interest to have another way, which should not necessarily be an alternative, rather an addition ... for specific topics, e.g., biosimilars and shortages.
- Now it is hard for me to find information about specific diseases not disease areas.



Topics

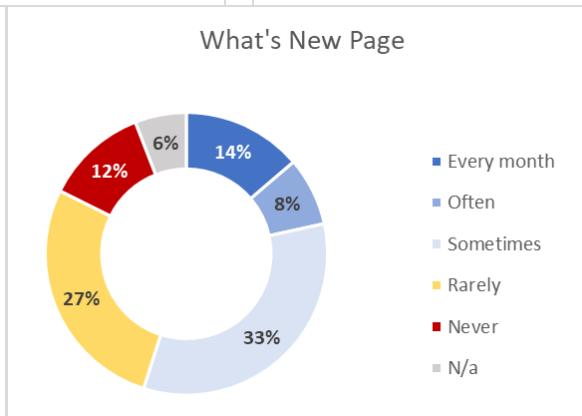
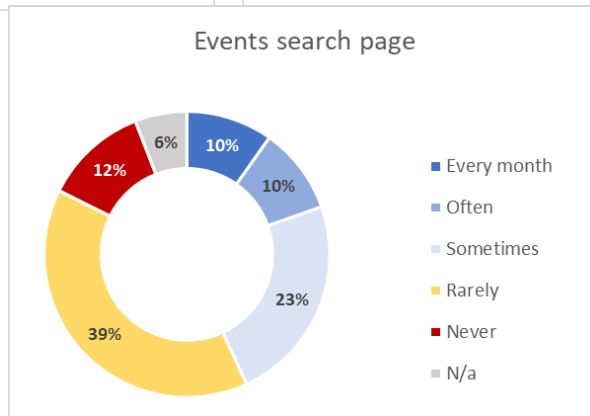
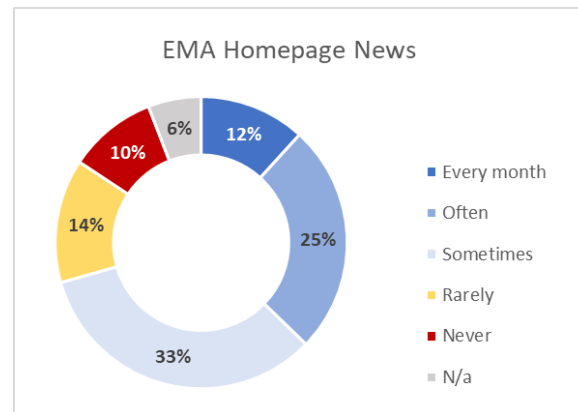
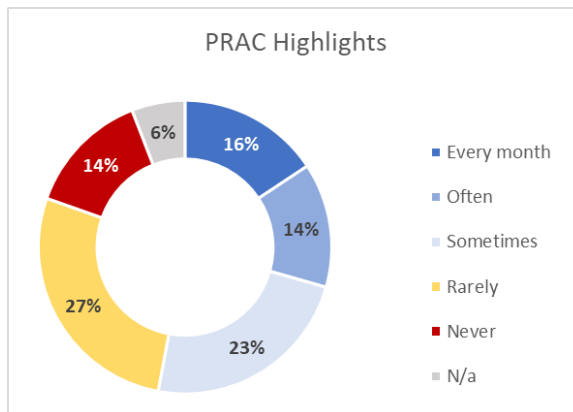
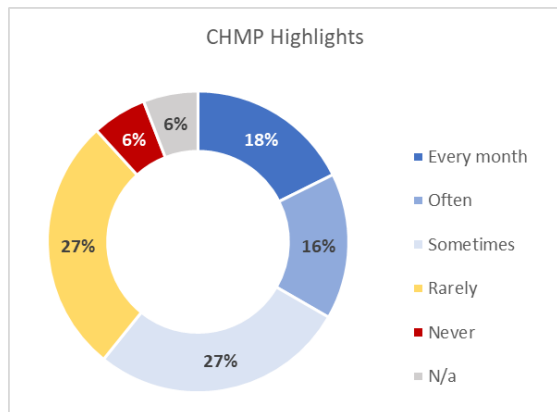
Most respondents (71%) did not think new topics need to be added.

Suggestions for additional topics :

- Frailty and multimorbidity
- Psychiatric medicines
- Side effects
- Older people
- Shortages
- Reasons why authorisation is withdrawn
- Who takes decisions on what
- Patient involvement, are patients and their organisations involved in decision-making, guidelines etc.
- replacement of animal use in risk assessment

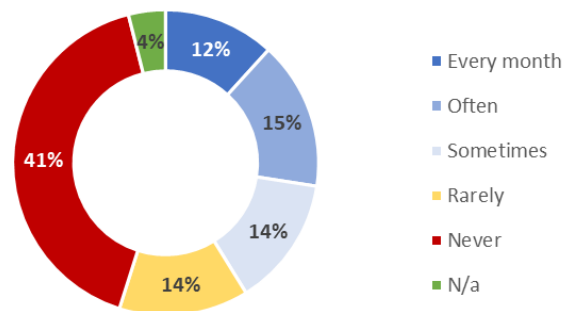


Which of the other EMA information resources do you use?

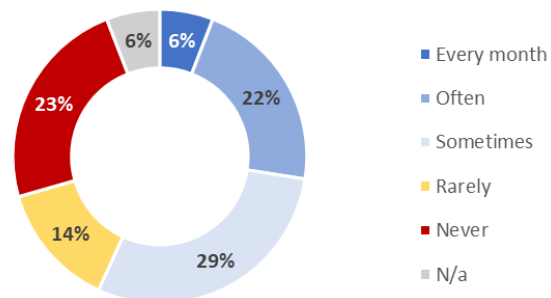


Which EMA social media do you use?

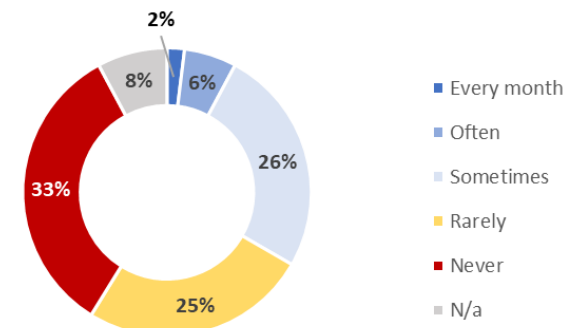
Twitter



LinkedIn



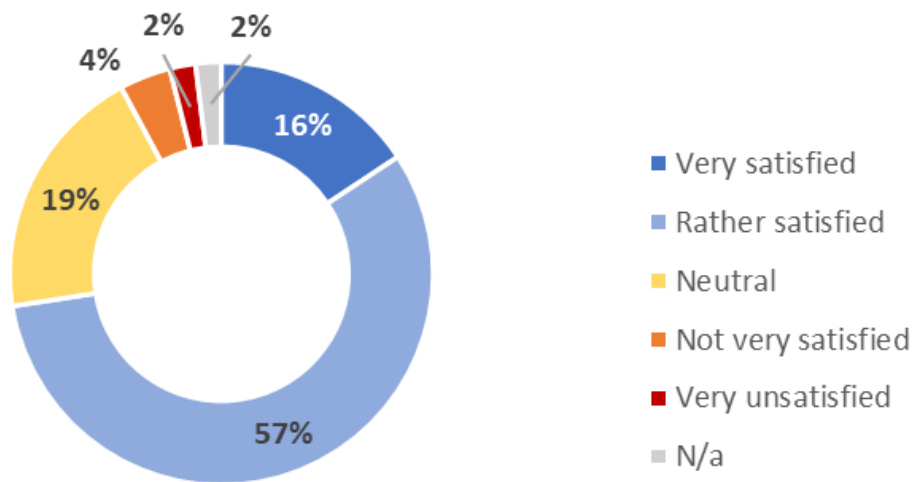
YouTube



- Social media use varies greatly

Design and timing of the newsletter

How satisfied are you with the design of the newsletter?



Level of satisfaction relatively high

- 73% are very or rather satisfied with the design
- 29% say they would like to improve some aspect

Timing:

- Majority (67%) prefer to keep it monthly rather than reduce frequency



General comments (selection)

"A section about **future activities, topics of wider interest** e.g. future or ongoing public consultations, workshops, transversal activities"

"Many of the topics listed under the section "other publication" are truly interesting, but reported in the list, **may not be noticed**. It would be nice to have an additional section, e.g. 'Spotlight on...' "

"The newsletter could start with an **interesting editorial** on this month work of EMA, instead of the present technical mishmash"

"However, keep in mind that it should still be **crisp and straight to the point**"

"Better explanation of what each section is about"

"Less text and more infographics perhaps **so you can immediately see what's relevant to you**. We get so many news bulletins and just don't have time to wade through endless text."

"The newsletter has a friendly user structure, but it is not very attractive."

"I am not convinced that patient experts are being (sufficiently) consulted by the EMA."



Initial reflections & next steps

- The results confirm that the newsletter is useful with some areas for improvement
- Some aspects comments on will be improved with the new design (e.g. grouping topics, using visuals, adding intros and making the newsletter more navigable)
- Requests for more news on topics of general interest, highlights on special themes
- Some comments indicate a need for more information on how EMA involves patients in its work

- Do the results resonate, anything surprising? Thoughts for improvement

Next steps: small number of interviews to look more in depth – timing after the summer holidays



Any questions?

Further information

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