

DISSEMINATION OF EMA INFORMATION

SUSANNA PALKONEN
EPF VICE PRESIDENT
LAURÈNE SOUCHET

“ A STRONG PATIENTS’ VOICE
TO DRIVE BETTER HEALTH IN EUROPE ”

1. What information

During a first phase EPF attempted to disseminate all news sent by EMA through our mailing list:

➡ **After member's feedback (too much information, most of it not relevant) it was decided to filter and send only specific news with a relevance to patient groups:**

- Calls for patient representatives, calls for participation to meetings, relevant surveys
- Information about EMA events and events in which EPF participated
- We do not disseminate announcements on specific medicinal products anymore
- We proactively navigate the EMA website to provide information or complement the information received.

2. Communication channels

- EPF disseminates EMA information through e-mail to our database of 54 members
- **We also have an events section in our monthly Newsletter which provides information on all future events including EMA meetings**
- Our Newsletter also provides reports on events attended by EPF Secretariat or Board, including EMA meetings
- We disseminated links to EMA information on pharmacovigilance through our toolkit, which is accessible on our website and blog
- We usually distribute the information in a few days to take the **time to evaluate/discuss its interest for members**

3. Members' feedback

- We asked our full membership through an e-mail, and the members of the policy advisory group to give us feedback on the information disseminated. They indicated:
 - Members receive information from EPF, but they also tend to receive information directly from EMA as many belong to the PCWP
 - Some said there was an “information overload” from EMA –they wish for **better targeted information** from EMA, e.g. with a “tick box” system to choose areas of interest
 - They indicated that the EMA newsletter contains too much information on new product approvals, which they would like to be able to filter (e.g. by disease area)
 - They indicated that **video format** can be very useful for the patient community for understanding complex issues (e.g. pharmacovigilance video)

4. Planned improvements

- Members indicated that the best way for EPF to communicate EMA information better is to have an “EMA corner” with updates and relevant links **included in our Newsletter**
- EPF’s revised website will include links to EMA information resources in all relevant areas (i.e. specific policy areas + dedicated “EMA tab”)
- EPF will also reflect on posting information through other channels such as our Facebook and Twitter pages, and our Youtube channel
- We will continue to collect ad hoc feedback from our members and follow up with our Policy Advisory Group
- One key question EPF is also reflecting on is **the question of language** – we will continue to provide information in “plain English” as far as possible; but we do not have resources to translate EMA info into other languages. The more info available from EMA in other languages, the better.

THANK YOU FOR YOUR ATTENTION!

More information:

www.eu-patient.eu

info@eu-patient.eu

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