

## Disseminating EMA information

Patients and Consumers Working Party (PCWP) and Healthcare Professionals Working Group (HCP WG) Joint Meeting

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### Overview

- How we disseminate our communication documents
- Results of survey on our press releases and Q&As
- Results of an audit of syndication of our communications on your websites
- What we would like to do in the future



# How we disseminate news, press releases and Q&As

- EMA website (around 165,000 unique visitors monthly: 500,000 visits)
- Publish through Twitter account (more than 3,500 followers)
- Publish on 'News and events' RSS feed (more than 6,000 subscribers)
- Press distribution list: core list of more than 300 journalists (newspapers, magazines, broadcast, special interest, trade, business) and extended press list of over 2,300
- Send to patient representative groups
- Send to healthcare professional representative groups
- Send to national competent authorities
- Include in human medicines highlights newsletter



suspected or confirmed as the cause of infection. In some of these patients, doctors should consider initiating concomitant treatment with an aminoglycoside antibiotic.



## Survey on our press releases and Q&As

Are you a patient or a healthcare professional?

Survey sent out to all patient, consumer and healthcareprofessional organisations in May 2012

38 respondents in total:

- 27 representatives of patient groups
- 11 representatives of healthcare professional groups





# What you think about our press releases and Q&As

33 organisations (87%) think that press releases and Q&As are written in **appropriate language** 

33 (89%) consider the information to be sufficiently detailed

34 (92%) find the instructions for patients and healthcare providers contained in these documents **sufficiently clear** 

30 (81%) are content with the information provided on **benefits** and risks of the medicine



# What you think about our press releases and Q&As

#### Some comments:

- Too much medical terminology, too technical
- Information only available in English
- Sometimes too much emphasis on benefits, too little on risks
- Include reference to further information where possible
- Sometimes clearer instructions needed
- More details, particularly regarding the elderly
- Statistical information needs translating into individual risk



# What you think about our press releases and Q&As

#### Your proposals for improvement:

- Better links to background information and more information
- Better customisation options to select relevant information
- Format should allow easy transfer of data
- Balanced approach to information (covering both benefits and harms)
- Information in national languages.
- Itemised search function, dated archive



## What you do with the information

10 organisations (27%) have never disseminated information to members, because:

- It's not relevant for your members
- You don't have the resources to do it
- The format makes dissemination difficult
- It is not clear who in your organisation receives the information



## How you disseminate our information

8% through social media channels
30% publish EMA press releases or Q&As on your website
43% link to the EMA press release or Q&A on your website











### Review of PCWP member websites

- In March 2012 we carried out a high-level review of the websites of the organisations represented in the PCWP
- PCWP websites are a key channel for reaching patients we wanted to understand how we were being referenced
- Some websites referenced the Agency a lot, described our role, linked to key news, some did not, 7 cases where no mention of EMA/EMEA
- We would like to work together to ensure that we reference Agency information to its full potential



## Next steps

- Provide you with the audit document so you can see where the main issues are on each website
- Provide each organisation with a list of relevant information that they could link to from their websites: special topic pages, therapeutic area pages, EPAR searches etc.
- Create links with the web editors at your organisation so we can directly provide interesting content to them as it appears
- Work on syndication initiatives to provide content such as medicine information direct to your website, for example



### What we would like to do in the future

Continue to listen to feedback and improve our outputs

More audiovisual content

#### Social media:

- Increase activity on Twitter
- Investigate using other channels (Facebook, LinkedIn, Google+ etc.)



### **Conclusions**

In general, you are **satisfied** with our outputs, but there is room for improvement

**We need you** to help us get our information and messages out to patients, consumers and healthcare professionals

We are looking at **increasing our outputs** and **engaging more** with patients, consumers and healthcare professionals over the coming years