



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Patient Engagement and Social Media

European Federation of Allergy and Airways Diseases Patients' Associations

Presented by Marie-Agnes Heine on 22 May 2017
Head of Communication Department, European Medicines Agency

An agency of the European Union





The European Medicines Agency (EMA)

EMA is the EU regulatory body responsible for the scientific evaluation and supervision of medicines developed by pharmaceutical companies for use in the European Union

(Human and Veterinary)

One application, one assessment, one authorization for medicines in Europe



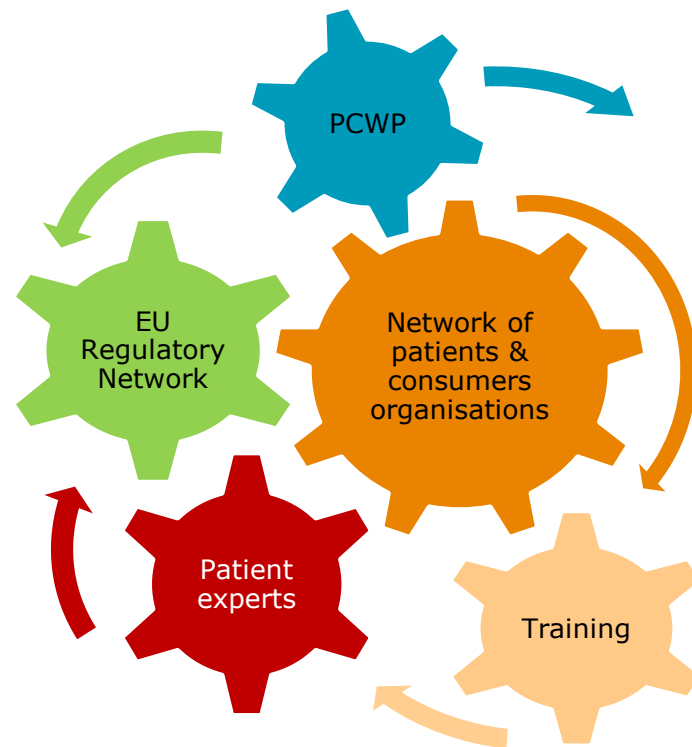


Patient/consumer engagement at EMA



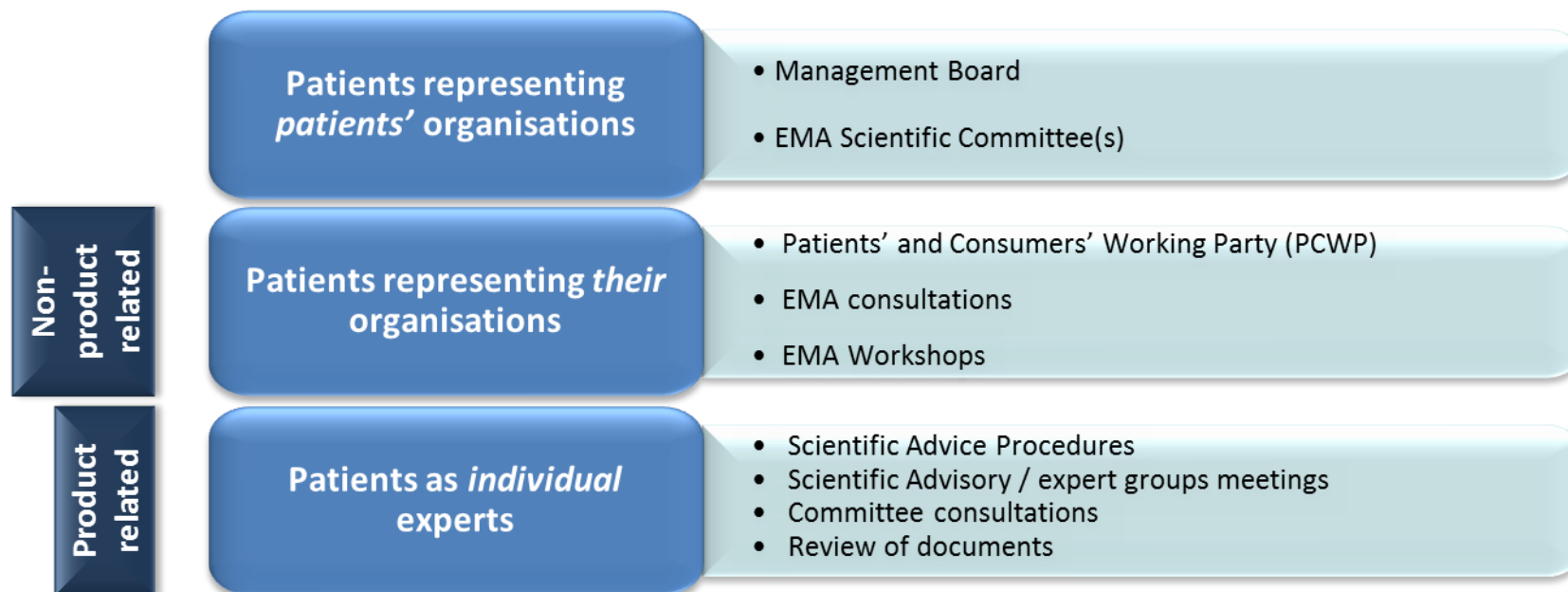
EMA Framework of interaction based on 5 essential elements:

1. A network of European patients and consumers organisations
2. A forum of exchange: EMA Working Party with Patients and Consumers' organisations (PCWP)
3. A pool of patients acting as experts in their disease and its management
4. Interaction with the EU Regulatory Network
5. Capacity-building focusing on training and raising awareness about EU regulatory system





How do patients participate:



Patients and Consumers Working Party (PCWP)

- Platform for dialogue and exchange between the EMA and patient organisations
- Representation from 20 organisations, EMA committees & Management Board
- Four plenary meetings per year, and consulted as and when needed

2016 - 10th
Anniversary!





Who do we work with in the Patient and Consumer Working Party?

- Any organisation representing EU patients or consumers that meets our [eligibility criteria](#)
- List of eligible organisations published on EMA website
- 'Individual stakeholder database' includes individual patients/consumers/carers ([application form](#))
- Large network of EU organisations and individuals

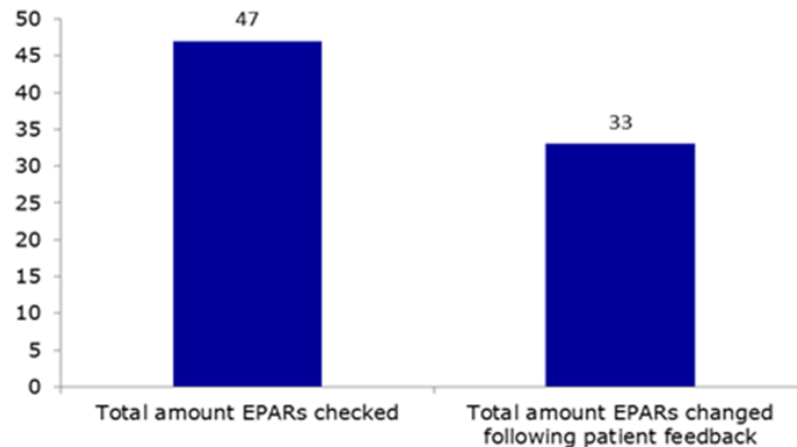
Patients review of EMA information for lay people

- Ensures key messages are understood

70% of comments led to changes



Review of EPAR summaries





Challenges

- Finding suitable patients (e.g. language barrier, availability)
- Ensuring comprehensive, tailored training and support
- Providing a clear definition of patients role in the different activities
- Managing potential conflicts of interest
- Representation
- CONTACT: PCWPsecretariat@ema.europa.eu





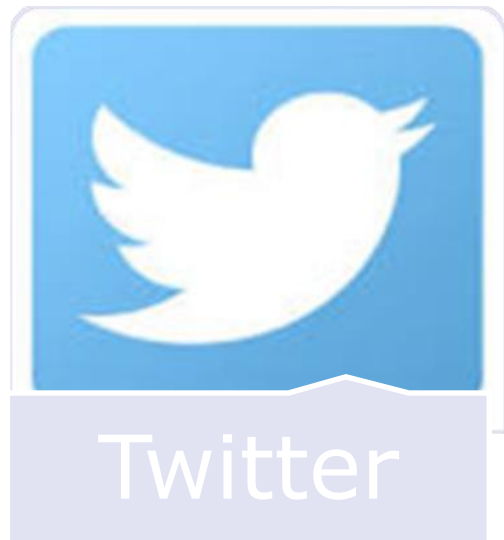
Value of involving patients in EMA's activities

- Patients' involvement :
 - ✓ Brings patients personal experience into the scientific discussions
 - ✓ Contributes to more meaningful regulatory outcomes
 - ✓ Improves quality of information and communication to patients

- Patients are a recognised and integral part of the Agency's work

- Participation has been refined for optimal involvement of mutual benefit.

EMA and Social Media



Twitter: **@EMA_news**

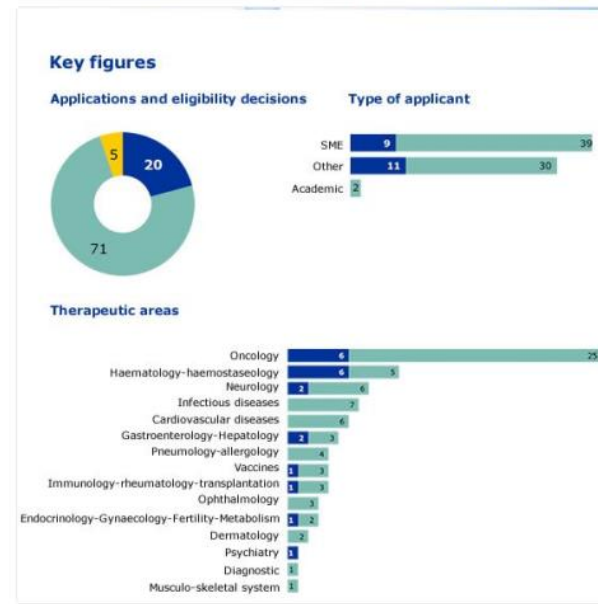
Launched: February 2010

Today (May 2017) we have: 27.3K followers, 239 following, 18.6K tweets

We tweet about: press releases, new guidelines, reports and more

 **EU Medicines Agency**
@EMA_News Follow

Find out about the [#medicines](#) accepted in our [#PRIME](#) scheme in April: bit.ly/2q825yY



RETWEETS 14 LIKES 16



9:24 am - 26 Apr 2017

  14  16



Twitter: Example of online campaign

European Immunization Week – 24/30 April 2017

Objective: Encourage people to vaccinate their children and themselves.


Results:

- Impressions: 41,746
- Retweets: 171
- Clicks on links: 61

Tweet Activity



EU Medicines Agency @EMA_News
We support the European Immunization Week 2017
[#vaccineswork](#) [#ImmunizeEurope](#)
<http://bit.ly/2q9RX5h>
pic.twitter.com/vBTfBUAb9J



Reach a bigger audience
Get more engagements by promoting this Tweet!


Get started

Impressions	8,084
Total engagements	364
Detail expands	238
Retweets	38
Media engagements	31
Likes	29
Link clicks	16
Hashtag clicks	6
Profile clicks	6

Tweet Activity



EU Medicines Agency @EMA_News
Let's not forget: some major human diseases are under control thanks to immunisation [#vaccineswork](#) [#ImmunizeEurope](#)
<http://bit.ly/2q9RX5h>
pic.twitter.com/bKgDCT3bD9

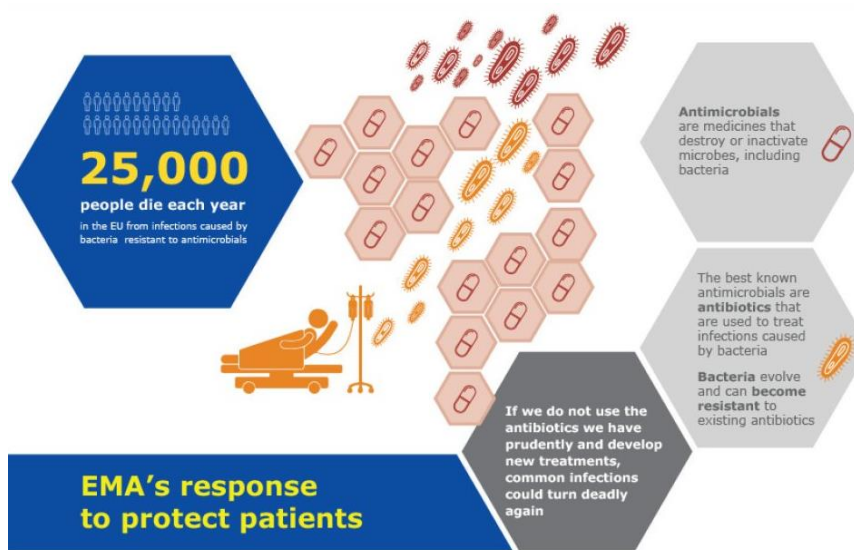


Reach a bigger audience
Get more engagements by promoting this Tweet!

Get started

Impressions	9,190
Total engagements	385
Detail expands	246
Retweets	55
Likes	50
Media engagements	14
Link clicks	8
Hashtag clicks	6
Profile clicks	6

Twitter: More examples



EU Medicines Agency @EMA_News Follow

The latest issue of our human #medicines highlights newsletter is now available: bit.ly/2a1FCD3



RETWEETS 5 LIKES 5

5:34 am - 9 Aug 2016

- Medicines are authorised for all EU citizens at the same time
 - Single evaluation by European experts
 - Product information available in all EU languages at the same time
- 

EU Medicines Agency @EMA_News · 16 Aug 2016

Centralised marketing authorisation for #medicines – why does it matter for #EU citizens? bit.ly/18P5cgv pic.twitter.com/ztaVSASNaD

RETWEETS 22 LIKES 18



LinkedIn and YouTube

LinkedIn: 17,665 followers



European Medicines Agency

Government Administration • 501-1,000 employees • London, London

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Following

17,665 followers

About us

The European Medicines Agency (EMA) is a decentralised body of the European Union with headquarters in London. Its main responsibility is the protection and promotion of public and animal health, through the evaluation and supervision of medicines for human and veterinary use.

Headquarters

London, London

Company Size

501-1,000 employees

Website

<http://www.ema.europa.eu>

Industry

Government Administration

Founded

1995

Featured Groups




European Medicines Agency

2,028 members

14 Patient Engagement and Social Media


YouTube: 2,455 subscribers and 368,362 views



emainfo [Subscribe](#) 2,437

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Welcome to the European Medicines Agency



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

0:04 / 0:15

Welcome to the European Medicines Agency
6,069 views 4 years ago

The European Medicines Agency is a decentralised agency of the European Union, located in London. The Agency is responsible for the scientific evaluation of medicines developed by pharmaceutical companies for use in the European Union.

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Recently published

Workshop on the implementation of ISO standard for individual case safety reports (ICSRs)
emainfo

1. Session 1: Documentation, Resources & Implementation milestones	1:59:06
2. Session 2: ISO ICSR Implementation Technical Aspects - Part 1	44:23

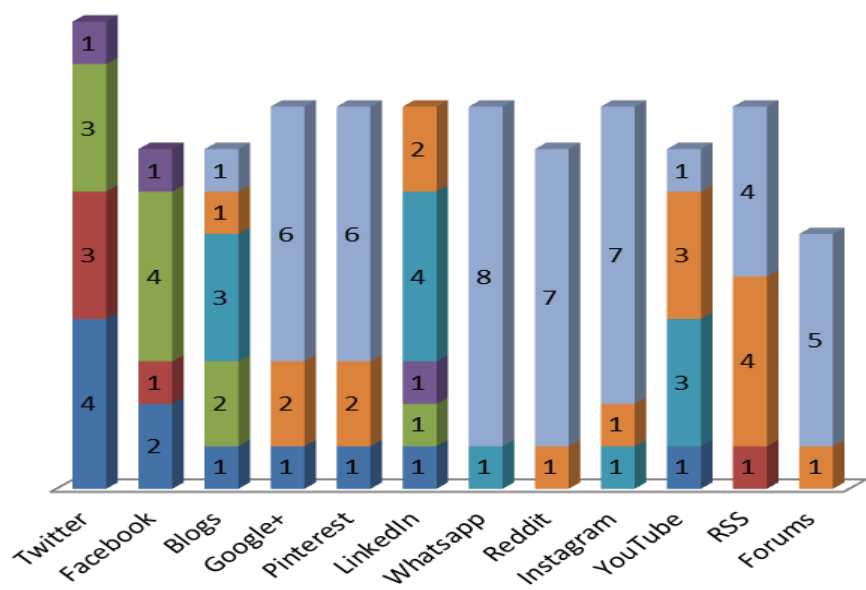
[View full playlist \(4 videos\)](#)

Patients' organisation that follow EMA's Social Media

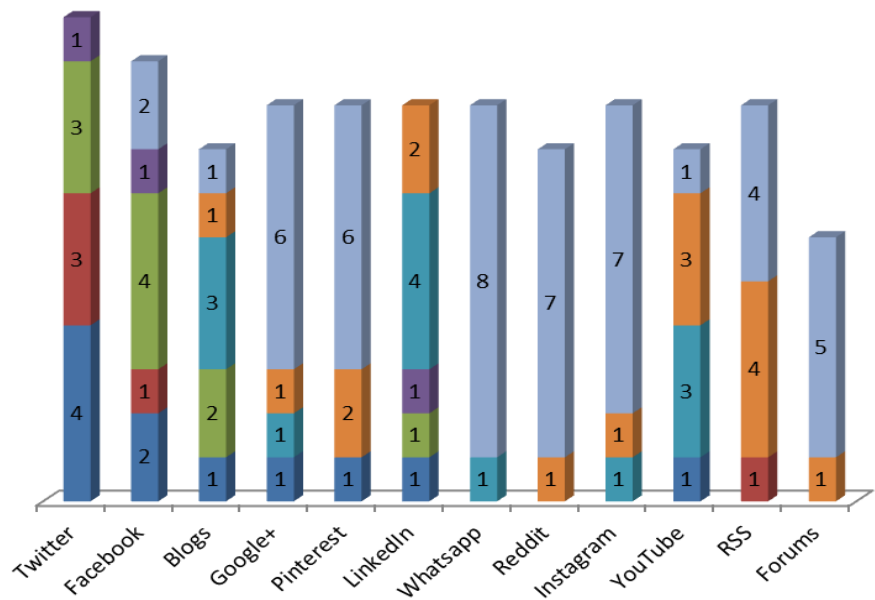


Social Media survey I - What social media do you use to...

... find information?



...communicate information?



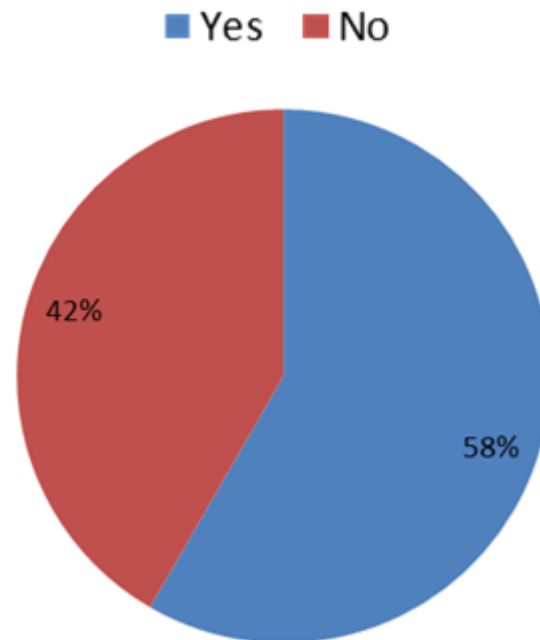
Social Media Survey II

Concerns: Personal information; vulnerability and anonymity; and the accuracy of information and its (mis)interpretation

Recommendations to EMA Social Media:

- Use Facebook and Storify
- Develop more engaging content

Do you have any concerns regarding posting information on social media?





Challenges I

Social Media facilitates **engagement and dialogue** with patients.



Vaccines are one of the most effective public health interventions of the past century that reduced considerably the burden of infectious diseases.



#ImmunizeEurope #VaccinesWork

BUT,

Social media also multiplies **fake news** information that is **not evidence-based**.



Polly Tommey: #Vaccine #Injury Destroys Lives So Listen To Parents

youtu.be/LMcO4PHnFWs
#LearnTheRisk #VAXXED



RETWEETS 5 LIKES 9



Challenges II

Artificial intelligence and big data

New trends and developments in these areas revolutionise healthcare.

BUT,

what about patients' data privacy?

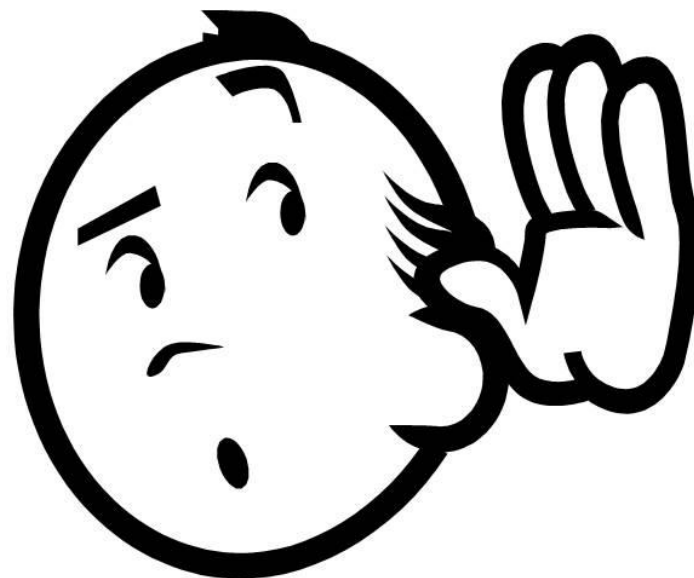


Challenges III

How to communicate on social media?

#H2H – Human to human

- Put ourselves in the mindset of the people we want to reach
- Explain complex issues in a simple way
- Use common language





Challenges IV

Tracking social media and follow-up

- Metrics that matter: impressions, reach, engagement
- Listen and adapt





Questions?

Further information

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