Sharing health information in the digital age: potential and challenges of social media

Report from a workshop on the impact of social media on patients, healthcare professionals and regulators

Introduction

Social media[1] is a group of electronic communication tools that allow users to view, create and share information, ideas, and other forms of expression via virtual communities and networks. In the health setting, social media has the potential to change how healthcare professionals, researchers, patients and consumers manage and share health-related data, and may impact on how information on medicines and their use is generated, shared and discussed.

EMA's Patients' and Consumers' Organisations Working Party (PCWP) and Healthcare Professionals' Organisations Working Party (HCPWP) discussed challenges and practical applications of social media and their impact on regulators, patients and healthcare professionals during a workshop held on 19 September 2016.

This workshop was the first in a series of meetings that will cover linked topics related to advances in digital health including social media, 'big data' analysis and IMI (Innovative Medicines Initiatives) projects such as WEB-RADR[2], where EMA will provide a platform for discussion and an opportunity for mutual learning.

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[1] Definition of social media: forms of electronic communication (as Web sites for social networking and microblogging) through which users create online communities to share information, ideas, personal messages, and other content (as videos) (source: Merriam-Webster's Learner's Dictionary)
[2] https://web-radr.eu/

Meeting outline

The workshop began with an [overview](#) of which social media tools are available and how they are used in relation to health, with a particular focus on medicine-related uses. Regulators, patients and healthcare professionals [shared their practices](#) on how social media are used to amplify communication on medicines, and discussed how these new tools are or can be used to gather medicine-related data.

[Breakout sessions](#) allowed participants the opportunity to discuss how medicine-related communication and data-gathering through social media may influence behaviours and attitudes, impact regulatory decisions and shape interactions with stakeholders. Keynote speakers from regulatory agencies and academia stimulated further discussion on how social media can enable [medicine-related data gathering](#).

The meeting ended with ['take home' messages](#) from EMA's Heads of Public Engagement, Communication, and Pharmacovigilance and Epidemiology departments.

Social media and its use in medicines communication

Mun-Keat Looi, keynote speaker from the **Wellcome Trust London**, gave an overview of the major social media tools that exist today, who uses them and how, providing a platform for discussion over the rest of the day.

Donald Singer of the **European Association for Clinical Pharmacology and Therapeutics (EACPT)** presented the findings from the PCWP/HCPWP topic group on social media. Results from two surveys on social media use conducted in 2015 and 2016 among members of PCWP and HCPWP and other organisations eligible for interaction with EMA showed what are the perceived strengths and weaknesses, opportunities and challenges emerging from the use of social media.

Sophie Labbe of **EMA** presented the Agency's current approach to social media, which focuses mainly on the use of Twitter as a tool to disseminate the main news from the Agency. EMA also outlined its efforts towards increased public engagement and the development of a social media strategy to further strengthen interactions with its stakeholders.

Catherine Chew and **Kimberly Chiu** presented the **United States FDA**'s experience with medicines communication using social media. Two case studies were presented to illustrate real-life implementation of 'best practices', and the way social media is integrated into FDA's health communications plan was described.

To close the session, the perspective of patients' organisations was illustrated by **Alessia Daturi** of **Fondazione Telethon**, who presented how the organisation uses social media to raise awareness about rare diseases, to support fundraising activities and to create a 'patient community' by means of virtual interaction with real patients.

Impact of social media on medicines use, stakeholders' interactions and decision-making

Participants took part in **breakout sessions** and discussed different aspects of the use of social media in health-related settings, and the way these are influenced by differences in geographical and cultural

uptake of social media and the current legislative framework. Several groups reflected on how communication and data gathering through social media may:

- ## Influence medicine-related behaviours and attitudes

Are you aware of any concrete example/study of behaviour change caused by social media campaigns?

Social media influence could be 'intended', as a result of dedicated campaigns and targeted interventions, or 'unintended', arising from public debate or issues 'going viral'. There is anecdotal proof of the potential of social media, but little research has been done to review and evaluate broader evidence. While health campaigning may have its limitations, successful examples such as the ALS (amyotrophic lateral sclerosis) campaign ('ice bucket challenge'), which raised awareness of the condition and increased research funding, were cited. On the other hand, the negative impact of the HPV vaccines controversy on medicines-related behaviour was mentioned.

Health care professionals (HCPs) should be encouraged to participate in social media because their opinion is still very influential. While social media is no substitute for personal interaction with HCPs, it may complement it and be used proactively to provide focused, tailored and personally relevant information. It may also facilitate healthcare-seeking behaviour or referrals, support health literacy and encourage healthy behaviours.

Do you have particular age groups/geographical subgroup in your organisations that are using social media in different ways? What learnings could you share?

When it comes to social media and other communication tools, the existence of a generational divide is clear: digital natives, digital immigrants[3] and non-digitals differ in their choice of communication tools. More research needs to be done on gender-based differences. Another finding was that social status as well as location can have an effect on the use of social media; also, there seems to be more interaction through social media in those countries where not a great deal of information is made available to patient groups by national competent authorities.

Several organisations shared their current social media practices: some reach a wider audience through Facebook and Twitter, and then follow up via WhatsApp; other use Twitter regularly to communicate, along with targeted campaigns on YouTube. It was observed that 'regionalisation' seems to increase the impact of campaigns.

Where do you see the major threats?

There are threats linked to communication in general and these may be amplified through the use of social media. The quality of information can be sometimes questionable and its authority could be put into question depending on its source. There is also the danger of 'misinformation amplification' and reinforcement of existing attitudes or behaviours. Data from social media is not representative of the public as a whole, and this should be kept in mind when analysing evidence. Language barriers can also lead to misinterpretation of data.

Organisations can control the information from their own campaign, but in some cases false information could be leaked in from other sources, or debates could be stirred into unintended

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[3] A 'digital native' is a person born or brought up during the age of digital technology and so familiar with computers and the Internet from an early age. A 'digital immigrant' is a person born or brought up before the widespread use of digital technology (source: Oxford Dictionaries (online)).

directions. For this reason, moderators should be in place to safeguard the quality of information. It could be difficult to identify the line between information and advertising, and social media debate about access to medicines could be used by industry as a tool to influence patient groups and regulators.

Data confidentiality and privacy concerns are seen as important issues that need to be adequately addressed.

Finally, the development and implementation of a social media strategy is considered a resource-intense endeavour which not all organisations have the capacity to undertake.

- ### Impact regulatory decisions

Should regulators elaborate a "new jargon" more fit for social media communication while keeping accuracy?

The need to understand the new jargon of social media is acknowledged. However, regulators should keep to clear, neutral language and not sound too friendly or informal: it is be important to use the correct technical language while speaking to a specialist audience. Regulators should try to engage with patients and consumers to get feedback on the language used. The use of aids such as infographics and videos to educate on complex issues is recommended.

Social media introduced new dynamics in communication. How can regulators make the most of and profit from these new tools?

Regulators should use patients' and HCPs' organisations as main channels to amplify their message, and should encourage and help organisations to use social media in the best way to reach the concerned audience. Having effective ways to measure the impact would be ideal. Opportunities may arise to fill in knowledge gaps and to clear up misunderstandings; also, to research how best to 'get the message out' and for messages to be more effective.

How can data gathered from social media inform regulatory decisions?

These data may provide an opportunity for detection of new signals, however a robust assessment would still be needed. Although the need for validated scientific data in regulatory decision-making cannot be replaced, current systems could be adapted to include 'big data' sources so that information gathered through non-traditional channels can help such decision-making. In addition, social media can provide an insight into what is important for patients, and this could, for example, help defining more meaningful endpoints for clinical trials.

Where do you see major threats for negative impact of social media on regulatory decisions?

Major perceived threats were the risk of regulators being lobbied on social media which could undermine independence of scientific decisions, and the risk of deliberate or inadvertent bias. Also, if there is too much 'noise', conversations might not be representative or accurate. Another sensitive area is data protection, since patients might expose their personal issues in too much

detail; strong processes to protect sensitive data are needed (such as the EU GPRD[4] and the FDA's Sentinel Initiative[5]).

- ## Have an effect on stakeholders' interactions

Are social media favouring a 'herd mentality'? If so, how should this be dealt with in relation to medicines information?

The way information is communicated may influence the opinion of the audience, and regulators can supply much needed balance in addressing this issue. Regulators should facilitate a baseline understanding of the regulatory system using 'smart techniques' and tools such as videos and infographics, and try to differentiate the message according to different audiences. Regulators could also take note of how patients and the general public talk about medicines, paying attention for example to which key words are being searched (including medical terms, brand names etc.), and from this listening exercise decisions could be made about the most appropriate tone for communication. The use of lay language is important when communicating to patients (the NHS choices[6] website was cited as an example), as is the availability of information in different formats, including digital. Also, the power of storytelling should not be underestimated: videos illustrating case studies with real patients were mentioned as possible communication tools. In this regard, it was felt that more research needs to be done on the approach to be taken and on the potential impact of different communication styles.

How can we address the impact of social media and move towards a constructive and meaningful evolution of stakeholder interactions?

The group also felt that patients and HCPs should be involved in the early stages of product development and approval, and through the medicines' lifecycle, and that this could lead to a positive change in the perception of the role of regulators. EMA could also help to raise awareness about the role of patients' and HCPs' organisations and the part they play in helping to improve the health of EU citizens.

It was acknowledged that when it comes to social media, it's about society and not technology, and one approach does not fit all: different methods and tools should be combined to maximise the potential of communication. Regulators should combine their efforts with those of their stakeholders to minimise the rise of biased information: HCPs are still recognised as central and trusted figures in the field of health and medicines communication. Aspects of data protection, ownership and confidentiality impose different modalities of interaction when using social media compared to traditional methods

Social media as health-data gathering enabler

The final speakers of the day stimulated and encouraged further discussion on how social media can enable medicine-related data gathering. **Ciro Cattuto** of **ISI Foundation** illustrated how information shared through social media is starting to be used, both at individual and at population level, to extract

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[4] http://ec.europa.eu/justice/data-protection/
[5] http://www.fda.gov/Safety/FDAsSentinelInitiative/ucm2007250.htm
[6] http://www.nhs.uk/pages/home.aspx

health-related signals and to inform policy-making, and highlighted future challenges and opportunities.

June Raine of the **United Kingdom MHRA (Medicines and Healthcare products Regulatory Agency),** also Chair of EMA's Pharmacovigilance and Risk Assessment Committee (PRAC), further reflected on how data gathered through social media could be relevant to regulatory decision-making. The current scale of use of social media offers regulators an unprecedented opportunity to listen to the voice of patients and the public; however key questions remain unanswered about which are the areas in which social media might contribute most to regulatory decision-making and in what way this might be undertaken.

To conclude the meeting, **Philip Tregunno (MHRA)** presented recent findings from **WEB-RADR**, a project funded by the European Commission's Innovative Medicines Initiative. This project is aimed at investigating the public health value of social media data to determine how it might supplement information related to pharmacovigilance collected through traditional means. The discussion focused on where social media data can add value to traditional pharmacovigilance activities.

Closing remarks

Isabelle Moulon, **Head of Public Engagement at EMA** and Chair of the workshop, together with co-Chairs **Marie-Agnes Heine (EMA Head of Communication)** and **Peter Arlett (EMA Head of Pharmacovigilance and Epidemiology)**, wrapped up the meeting by highlighting some of the main points that emerged from the discussion:

- The use of social media when searching for and communicating about health-related issues is a fact that regulatory agencies, who communicate on the benefits and risks of medicines, cannot ignore: indeed, they should understand such use and employ it to better communicate with the general public.

- Social media is more about society than technology, and temporal, geographical and social context should be taken into account when analysing data extracted from it.

- As there are many differences in social media uptake depending on age, location and social circumstances, the use of social media still needs to be complemented with traditional means of communication.

- The notion that 'one size does not fit all' was considered very appropriate in the context of social media, both when pushing out messages and when gathering data. The need to be very clear and specific about the target audience and to use the relevant social media tool according to audience preferences was also mentioned as an essential aspect of a successful social media strategy.

- The style of communication is fundamental, and a different impact can be also expected depending on the tool used; for this reason it is necessary to identify user needs and feed them into content strategies.

- Much research in the fields of data-mining and health computing is currently ongoing: analysis of social media data in healthcare is a reality, and regulators should not only use the data emerging from this research, but also trigger research, for example on the impact of their messages on different audiences.

- In the field of data gathering, an effort should be made to identify where social media may add value, rather than noise: social media can help to generate hypotheses, but these need to be then supported by robust data.

- Social media can provide an insight into how medicines are used in real life; the existence of knowledge gaps, for example with regard to adverse events reporting, was recognised.

- The role of HCPs in delivering and amplifying the right and validated message, and in minimising biased information when discussing with their patients, was highlighted and confirmed.

- Social media can ultimately be seen as an enabler of EMA's key goal, which is to put the patient at the center of its activities.

- More work needs to be done on how best to use the tools of the digital world, and EMA will follow developments very closely through various means, including the dedicated focus group of the PCWP and HCPWP.

- EMA is currently developing a social media strategy with the aim of broadening stakeholders' engagement, and will take into account the main points that emerged from the workshop discussion when considering how to diversify and optimise its social media presence.