EMA Human Scientific Committees' Working Parties with Patients' and Consumers' Organisations (PCWP) and Healthcare Professionals' Organisations (HCPWP) joint meeting: Workshop on social media

Speakers' abstracts for their presentations

Mun-Keat Looi

Going viral: the state of play and potential of social media in 2016

Like it or not, social media is a part of everyday life for a majority of citizens in any major country. As a platform for dissemination and debate it has proved an invaluable democratic tool, as well as an amplifier of the information overload and confusion that comes with the Internet. Social media has turned the traditional media of newspapers, radio and television upside down, while opening up for wider communication opportunities than have ever been possible. And it is reinventing itself at every turn. This talk will give an brief overview of the major social media that exist today—Twitter, Facebook, LinkedIn and others—who uses them and how, providing a platform for discussions over the rest of the day.

Donald Singer

Findings from the PCWP/HCPWP topic group on Social media

Social media is a group of electronic communication tools that have the potential to change how healthcare professionals, researchers, patients and consumers manage and share information in the digital age, including on the safe and effective use of medicines.

In its 2015 survey, the Social Media topic group identified areas and patterns of use of social media by PCWP and HCPWP member organisations in relation to the EMA and to their other key professional areas of interest and activity.

In a new survey conducted over the summer of 2016, SWOT feedback has been obtained from 28 PCWP and HCPWP member organisations currently active in use of social media and a further 3 member organisations not currently active in use of social media.

There was a clear consensus that effective use of social media by professional organisations is not risk-free however offers major potential benefits for health professionals, patients and consumers. Respondents were in general more optimistic about return on investment from effective use of social media by their organisation than from social media in general. Organisations not currently active in use of social media tended to be more concerned about weaknesses and threats than impressed by strengths and opportunities.

Case studies will be summarised in relation to process for successful use of social media, and applications of social media for organising health awareness events and lobbying on health matters. Areas of agreement and uncertainty in use of social media will also be presented.

Sophie Labbe

Towards increased engagement through social media

This presents EMA's current approach to social media, which focuses mainly on Twitter and aims at disseminating the main news from the Agency, helping stakeholders keep track of what is going on at EMA. We will also present our perspective going forward, as EMA strives to go from 'broadcasting' of news via social media, to engaging with its stakeholders. EMA took note of the findings from its perception survey carried out in 2015, that stakeholders would welcome an increased use of social media from the Agency. As a result, EMA has already started to make improvements to its Twitter channel, and is working towards defining a new social media strategy.

Caroline Chew and Kimberly Chiu

The experience from US FDA

Part of the U.S. Food and Drug Administration's responsibilities include providing the American public with the information they need to safely use medicines to improve their health. FDA's Office of Communications within the Center for Drug Evaluation and Research, serves as the focal point for public communications and inquiries on human drug products.

Ensuring public health messages achieve optimal reach of target audience(s) requires the strategic use of all communication tools, including social media. Social media leads from the Division of Drug Information will:

- share best practices and learnings from their experiences in using these tools to communicate important messages to the public.

- describe two case studies to illustrate real-life implementation of these best practices and learnings.

- describe how social media is integrated into a health communications plan.

Alessia Daturi

Virtual interaction with real patients

The Telethon Foundation is a **major Italian charity focused on rare genetic diseases**. Founded in 1990 by a group of muscular dystrophy patients, its mission is to advance biomedical research towards the cure of all the rare genetic diseases, otherwise neglected by major public and private investments. The ultimate goal is to **make therapies available to all patients in need**. To achieve this goal the

Foundation funds mission-oriented research strictly selected through a **peer review evaluation process** and encourages collaborations between private and public institutions in order to develop therapies from the results obtained.

Telethon relies on donations from the general public through major fundraising events (such as the annual television marathon) and various fundraising initiatives held throughout the year. Accountable fund management and careful expense monitoring are performed to fulfill its promise to patients and to the donors who continue to support its mission.

Telethon Foundation has set an informal **network of more than 183 Patient Associations called** "Telethon friends", with the aim of sharing information about rare diseases, meetings, awareness initiatives and research highlights. Since 2009, Telethon has organized an annual meeting dedicated to these organizations in order to share updates on their research and discuss its future prospects. The initiatives are often developed in collaboration with Uniamo, the Italian federation of people living with a rare disease.

Besides its institutional activities, Telethon has invested many efforts in marketing and communication, especially in the *digital strategy* that integrates the website, the newsletter, digital PR and social media.

Three are the **main objectives**: raising awareness and brand positioning; supporting fundraising activities; creating a real patient community with Telethon's stakeholders.

People living with rare diseases are the core of all Telethon's activities, therefore the digital strategy is based on *user generated contents*: both photos and videos provided by patients are at the heart of Telethon's storytelling strategy. All the contents are planned trough a strong editorial plan alternating patients' stories, research updates, researchers' stories, patient organizations updates, volunteers' and donors' stories, fundraising call to actions.

The patients are aware that they can support Telethon's research by sharing their stories and experiences. The contents provided are an inexhaustible source of interactions between families, researchers and clinicians. Virtual relations have become real friendships between patient organizations and groups of volunteers located around the country. The participation in social media also allows sharing valuable information about research, quality of life, in order to empower the patients that are becoming more aware and informed.

Last but not least, Telethon social media are also linked to **Telethon's Infoline**, an information service that provides information on genetic diseases and the state of art of Telethon scientific research, as well as on appropriate Centres of Expertise, specialists and Patient Organisations.

Besides the daily work, Telethon organises **special digital campaigns**: the main annual fundraising campaign, the Christmas fundraising campaign; The Rare Disease day campaign, the Spring fundraising campaign; the Tax refund campaign; the Back to school campaign. The case history will examine the most popular campaign in 2015, that has hugely contributed in growing the Telethon fanbase on Facebook (+ 65% in two month) and in raising funds and awareness, connecting people living with the same disease, sharing valuable information about research and quality of life.

Telethon is on:

Facebook (240.000 fan, + 38% from June 2016)

Twitter (74.000 followers, + 38% from June 2016)

Youtube (717 videos, 2.521 subscribers, 3.200 millions views)

Intagram (8.818 followers, + 100% from February 2016)

And

newsletter subscribers: 39.448

telethon.it website:

1.246.860 unique visitors/year

Unique page views 2.837.591

Page views 3.831.866

Ciro Cattuto

From Social to Medical: how is digital information being used?

The widespread adoption of diverse social media platforms has recently prompted intense research on using real-time streams of user-generated content from social media to monitor health both at the population scale and at the individual level, to constrain mathematical models of health threats such as epidemics, to empower disease surveillance and inform policy making. This talk will give an overview of the state of the art in using digital information from social media sources to extract health-related signals, it will review some interesting use cases in specific domains and it will highlight future challenges and opportunities.

June Raine

How could this data be relevant to regulatory decision-making?

Regulatory decision-making in Europe has been enhanced by the contribution of patients and the public for the last decade or more. The opportunities for involvement of patients have broadened and regulatory systems have evolved to be more transparent and accessible. A particular focus for patient involvement has been in regulatory systems and structures responsible for prompt identification of harms associated with medicines, and for capturing the impact of adverse effects on patients' lives. There is growing appreciation that in today's world the scale of use of social media offers an unprecedented opportunity to listen to the voice of patients and the public. But how might social media contribute most to regulatory decision-making and in what way might this be undertaken? And how will we inform future strategies by evaluation of the value of such data? This presentation will aim to discuss the key questions and consider how we might move forward.

Philip Tregunno

Recent learnings from the IMI WEBrADR project

Reporting of side effects identified from press and social media data has been a hot topic for many years, historically driven by the desire of the pharmacovigilance network to ensure compliance with regulatory reporting obligations. It is only more recently that organisations have begun to consider the public health value of social media data, and where it might supplement information collected through traditional means. Until recently there has been limited information on the volume, breadth and quality of social media data, and consequently where it may add value from a pharmacovigilance perspective. The WEB-RADR project, funded by the European Commission's Innovative Medicines Initiative, it exploring this area in detail, and will make policy recommendations on the use of social media data in

2017 based upon research conducted within the project and wider. This presentation will explore the projects findings to date, and discuss current opinions on where social media data can add value to pharmacovigilance activities.