



**Social media:
is this the way for
pharmacovigilance?**

Lisa Stagi

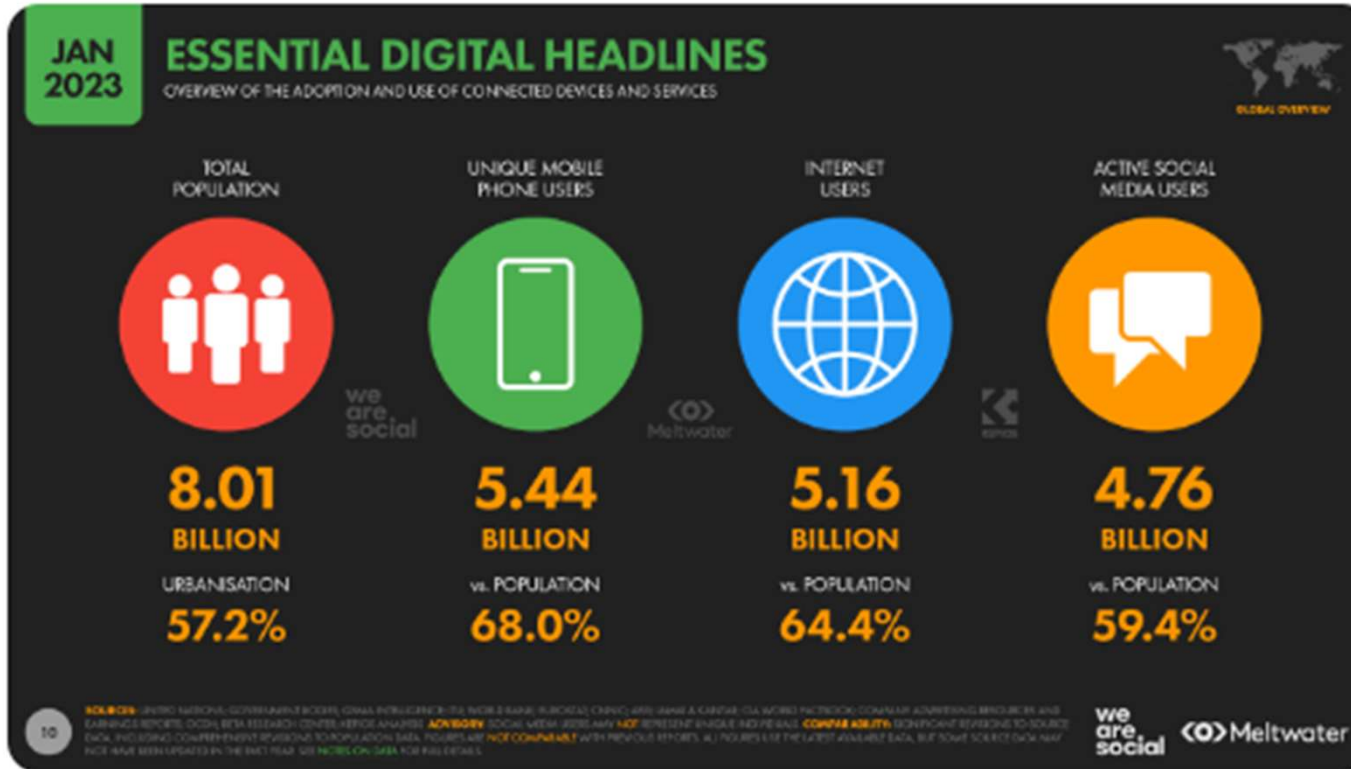
**Patient Safety Country Cluster Lead,
International Patient Safety, Roche**

May 30th, 2023

Social media and PV



Why we talk of social media?



<https://datareportal.com/reports/digital-2023-global-overview-report>

2030 PV perspectives: future trends

Pharmacovigilance 2030

Peter Arlett, Sabine Straus, Luca Pani

Clinical Pharmacology & Therapeutics 2019; 107:89-91



- *Smarter collection and reporting of ICSRs.*
- *Measurement of on-market performance of medicines*
- *Improved engagement of patients and healthcare professionals*

A case study: maturity of PV digital activities in Italy

Authors

Members of PV Working Group "Ernesto Montagna" of SIMeF*,
Italian Society of Pharmaceutical Medicine

Goal

Understanding current status and the PV role
in digital activities at Italian national level

Methods

CAWI interview to SIMeF members
(93 answers out of 297)
Period July-October 2019

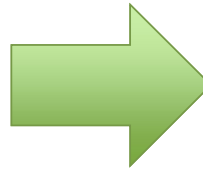
Topics

- Digital channels used by the healthcare/ pharmaceutical companies
- Governance tools in place
- Management of AE collected from digital channels and projects
- Impact of artificial intelligence on PV activities



Digital activities: the proposal from the case study

- **Early PV involvement** (e.g. project discussion or drafting of the project) occurred **in less than 40%** of the healthcare/pharmaceutical companies (even not at all in 12%)
- Despite **growing number of projects** based on digitalization and social media, **areas of uncertainty** are still observed at several steps (choice of the right tools to ensure effective PV governance, right moment for PV involvement...)
- Around **50% of the interviewed companies expressed the need** to further investigating aspects of management of AE reports collected from digital channels (i.e. poor follow-up, privacy).
- **Need for more guidance/clear regulation**



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- **2 An introduction to Digital Media**
- **3 PV and Digital Media: Regulatory framework**
- **4 General aspects**
 - 4.1 Governance aspects
 - 4.2 Open points and interactions with other departments
- **5 Internal PV processes for management of digital projects**
 - 5.1 Set up, risk assessment and approval processes
 - 5.2 Vendor due diligence
 - 5.3 Vendors management
 - 5.4 Maintenance activities during the program
- **6 AE report management**
 - 6.1 Collection of reports (considering also set-up of IT tools)
 - 6.2 Identification of the reporter
 - 6.3 Follow up and privacy

Listening: the role and challenges of PV

Reinforce awareness

Importance of PV assessment for digital projects in *an early phase* (best *before going live*)

Continuous Safety Partnership

Early awareness of new projects

Early evaluation for all PV relevant projects, (e.g. 2 way customer interaction)

Clear instructions /checklist points for business owner

Integration in the already existing processes and review boards

Can social media help detect AEs?



9 February 2017
EMA/70469/2017
Pharmacovigilance and Epidemiology

Innovative Medicines Initiative WEB-RADR Workshop Report: Mobile Technologies and Social Media as New Tools in Pharmacovigilance

International Journal of Data Science and Analytics
<https://doi.org/10.1007/s41060-019-00175-3>

REGULAR PAPER

Harnessing social media data for pharmacovigilance: a review of current state of the art, challenges and future directions

Dimitra Pappa¹ · Lampros K. Stergioulas¹

Received: 29 September 2017 / Accepted: 14 January 2019
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Abstract



[Drug Saf.](#) 2019; 42(12): 1393–1407.

Published online 2019 Aug 24. doi: [10.1007/s40264-019-00858-7](https://doi.org/10.1007/s40264-019-00858-7)

PMCID: PMC6858385

PMID: [31446567](https://pubmed.ncbi.nlm.nih.gov/31446567/)

Recommendations for the Use of Social Media in Pharmacovigilance: Lessons from IMI WEB-RADR

[John van Stekelenborg](#),¹ [Johan Ellenius](#),² [Simon Maskell](#),^{3,4} [Tomas Bergvall](#),² [Ola Caster](#),² [Nabarun Dasgupta](#),⁵ [Juergen Dietrich](#),⁶ [Sara Gama](#),⁷ [David Lewis](#),^{7,8} [Victoria Newbould](#),⁹ [Sabine Brosch](#),⁹ [Carrie E. Pierce](#),¹⁰ [Niska-Neophytou](#),¹² [Antoni F. Z. Wiśniewski](#),¹³ [Phil Tregunno](#),¹² [G. Niklas Norén](#),² and

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Preliminary work in this area shows pro & cons of social media for detecting new safety information

Open points

General topics

- Extent of MAH check on social media
- Are all population represented?
- Are new fragile population created?

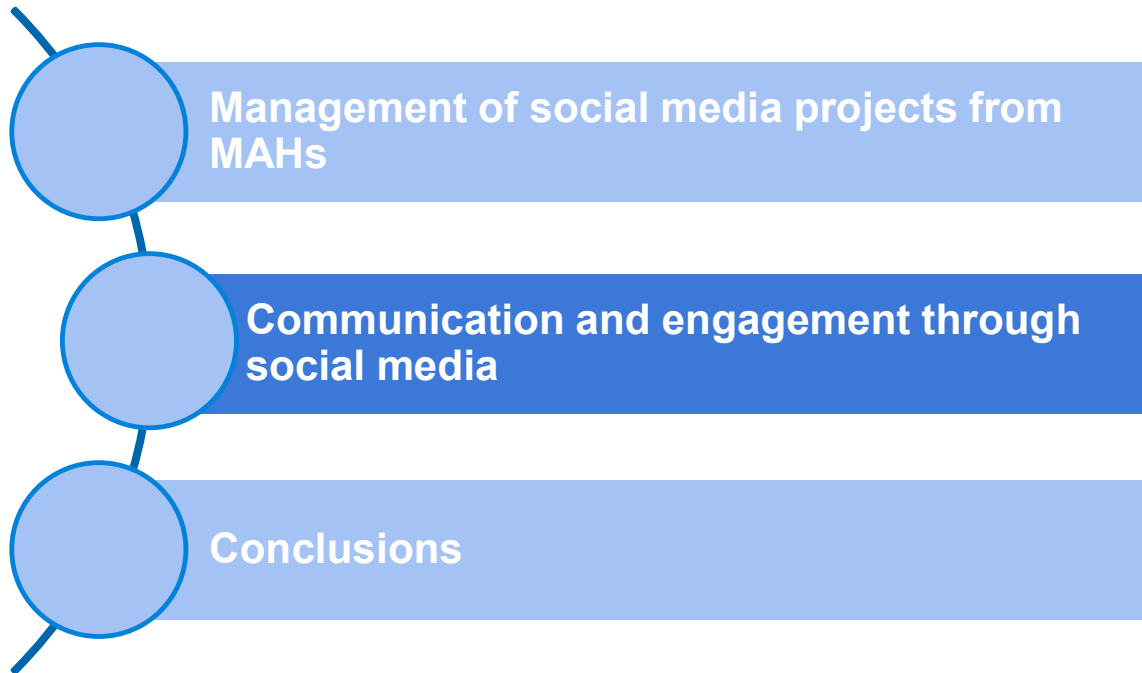
Quality of information & transparency

- Many duplications leading to problems with signals
- Is truthful?
- Potential misuse

Technical management of cases

- Absence of medical confirmation
- Privacy issues
- Low quality
- Follow up process
- Difficulties in identifying the reporter
-

Social media and PV



Pharmacovigilance: communication through social media

Create awareness on PV processes

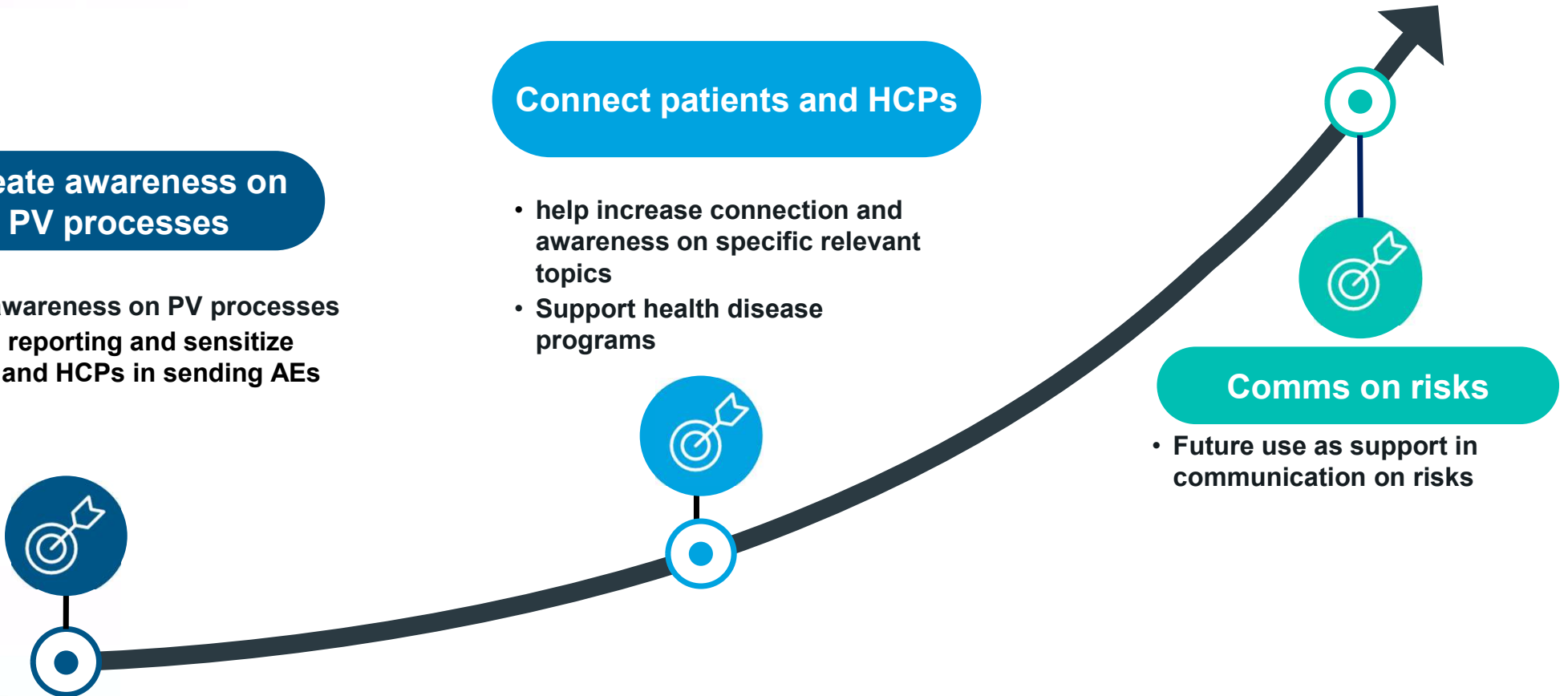
- Create awareness on PV processes
- Improve reporting and sensitize citizens and HCPs in sending AEs

Connect patients and HCPs

- help increase connection and awareness on specific relevant topics
- Support health disease programs

Comms on risks

- Future use as support in communication on risks



Social media campaigns to raise awareness on reporting



Home > Sicurezza dei farmaci

> Sicurezza dei medicinali: anche quest'anno AIFA aderisce alla campagna social europea sulla segn

Sicurezza dei medicinali: anche quest'anno AIFA aderisce alla campagna social europea sulla segnalazione delle sospette reazioni avverse

Dal 20 al 24 novembre 2017 l'Agenzia Italiana del Farmaco aderisce alla campagna social europea di sensibilizzazione sull'importanza della segnalazione delle sospette reazioni avverse ai medicinali.

Come la campagna social si inserisce nel contesto della settimana di sensibilizzazione europea...

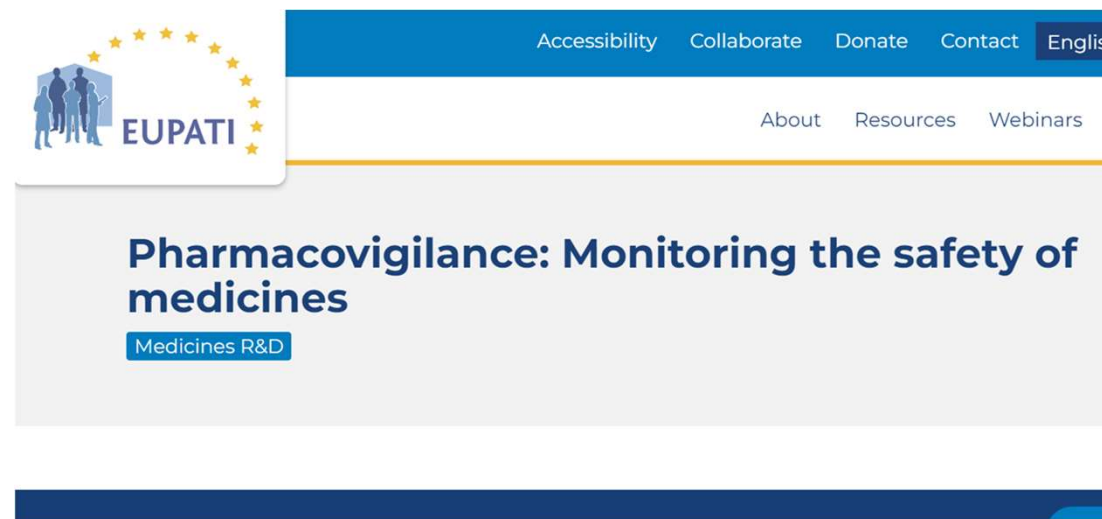


**Social media are important channels
to raise awareness on reporting or
on the importance of PV**

Patient are key for effective PV management

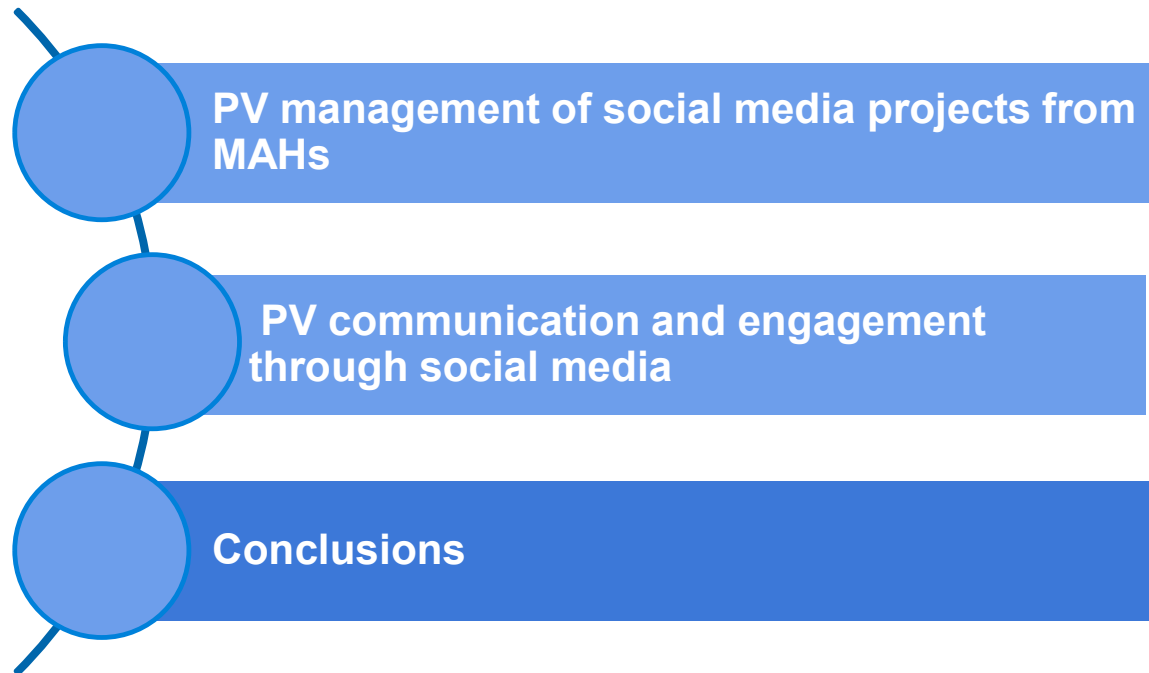


[video youtube](#)



See: <https://www.roche.it/it/per-un-uso-sicuro-dei-medicinali/patient-safety-council.html>

Social media and PV



Conclusions

Opportunities

- Increasing importance for everyone daily life
- Easy communication
- Large amount of users with growing numbers
- Can become source of PV information
- Large amount of data and information
- Can sustain awareness and better knowledge around PV
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Challenges

- More guidance required
- Many open points from more general and technical perspectives
- Medical significance of the information collected
- Transparency?
- Misuse?
- Privacy?
- Capabilities upskilling
- ...

Thank You

