Harnessing Data from Social Media and to Monitor the Safety of Medicines

Nabarun Dasgupta

Epidemico, Ltd.

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Background

Use of smartphones & social media
Evolution of technology

- What does personal computing look like in 2014?
- Personal and work devices have begun to merge together
- Handheld devices are more powerful than the desktop PCs of only a couple of years
- Social media is fully integrated and always on
Smartphones and mobile apps

- 1.75 billion smartphones in use worldwide
- 34.6 million in the UK
- 62% of UK adults and 53% of households have a smartphone (24% also have a tablet)
- 1.3 million apps available for android users (1.2 million for iOS)
- Around 6,000 health related apps
- NHS has its own app store
Social media

• 1.35 billion active Facebook users
• 680 million on mobile devices
• 48% log on every day
• 25-34 largest age group

• 284 million active Twitter users
• 80% active on mobile
• 500 million tweets per day worldwide
Introducing WEB-RADR

- Organisation
- Social media mining
- Mobile App
- Ethics
- Policy
WEB-RADR aims

**W**eb-Recognising Adverse Drug Reactions

**E**mbracing new technologies

**B**oth public and private partners involved

**R**eports via mobile app vs established reporting schemes

**A**lgorithms and analytics

**D**evelop a policy framework

**R**eshape the pharmacovigilance world
Our Vision

• New technology giving us tools to transform pharmacovigilance in the modern world
• Developing a policy framework to influence how they are used
• Using the best possible science to do this
• New tools everyone wants to use – patients, health professionals, industry and regulators

Shaping the pharmacovigilance world of the future
Project setup

WP1 – Governance and policy
EMA (Public lead)
Sanofi (EFPIA lead)

WP2a – Social media platform
Epidemico (Public lead)
J&J (EFPIA lead)

WP2b – Analytics
UMC (Public lead)
J&J (EFPIA lead)

WP3a – Mobile reporting platform
Epidemico (Public lead)
UCB (EFPIA lead)

WP3b – User based evaluation
Uni of Groningen (Public lead)
Amgen (EFPIA lead)

WP4 – Scientific impact evaluation
University of Liverpool (Public lead)
Novartis (EFPIA lead)

WP5 – Project Management and communication
MHRA (lead)
Novartis (EFPIA lead)
Acquire

Collect unstructured data from social media APIs, third-party authorized resellers, and automated scraping.
Data are passed through a series of apps, emerging as meaningful bits of information.
Export

Relevant data are passed to another series of apps in preparation for human interpretation and analysis.
Export

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Albuterol has me feeling all sorts of dizzy and weak this morning 😖 😊.
Signal analysis in social media?

- Case recognition?
- Signal detection?
- Signal strengthening?
- Duplicate detection?
Essential Aim:

To determine whether novel media applications (apps and social media) add value to existing pharmacovigilance methodologies

- Add information to the established safety profile of a medicine
- Enable earlier detection of new signals
- Reveal new patterns or trends in reporting
- Provide a means for geo-pharmacovigilance
Apps Launched

- Package under development for other MS by the end of the project
- Considering how utility of the tools might be expanded through APIs
- Evidence based evolution of tools
**Value**

**Patient evaluation**
- Patient focused studies to understand barriers and facilitators to the use of the app
- Most value in the news feeds and data streams that we can make available

**Scientific Value**
- Initial view indicates that the data are equivalent value to traditional data
- Quality & Value under formal evaluation but already contributing to signal detection

Meet patients where they’re at  
Protect their privacy  
Give them easy to-use tools
Legal & Ethical considerations

Ethics can only be considered when the legal position is clear

- Public data only?
  - Aggregated private data available as well

- Do people understand how their data can be used?
  - Consent vs responsibility

- When to engage?
  - Responsibility as an HCP vs lack of knowledge about the individuals circumstances
Objectives

• Develop a policy framework spanning all WEB-RADR WPs with recommendations to support further GVP development

• Focus on usage of mobile devices and social media in the context of the EU medicines and phv legislation for the purpose of:
  - Reporting
  - Monitoring and early detection of signals
  - Communication and interaction with healthcare professionals, patients and carers

• Areas to be addressed include ADRs, quality defects, medication errors, off-label use, misuse, abuse, overdose, occupational exposure and pregnancy exposure for medicines incl. delivery devices

Key Topics

1. Assessment of stakeholder needs and challenges

2. Provision of advice and guidance on all phv aspects to promote harmonisation and consistency across all WPs

3. Assessment of personal data protection requirements and ethical and societal aspects for the purpose of phv and public health protection

4. Development of a policy framework with recommendations towards utilisation of the new WEB-RADR technologies and methods

5. Development of recommendations to assist stakeholder communications by regulators, public health organisations and pharmaceutical and biotechnology companies to inform and alert on safety and public health issues
Thank you. Questions?

Email: nabarun@epidemico.com

Website: http://web-radr.eu

Twitter: @WEBRADR