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**FP7-ICT Strategic Targeted Research Project PHEME (No. 611233)**  
Computing Veracity Across Media, Languages, and Social Networks



**Annexe to D7.1 Requirements and design documents**

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## **Summary**

In this annexe, we are addressing the reviewers' recommendations from the Y1 report and will cover the following areas:

- 1) Use of social media by patients and caregivers – review of literature and relevance to mental healthcare use case study
- 2) Risk management – methodological considerations and results
- 3) Technical approach – integration of WP7 into main PHEME dashboard
- 4) Use cases – review of demonstration studies

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## **1 Use of social media by patients and caregivers**

### **1.1 Literature review**

We would like to thank the reviewers for highlighting this important research and we provide here a summary of the literature they suggested we utilised to better inform the value of social media data by Twitter user studies.

*Hamm et al, 2015 – Social media use among patients and caregivers: a scoping review*

This is a literature review evaluating social media use by patient and caregivers. Two-thirds (186/284) of the studies concluded that there was evidence for the utility of social media by patients and their caregivers particularly in terms of self-care (77.1%) with most social media user groups belonging to the lifestyle and weigh loss categories. However, the majority of the studies (189/284) evaluated discussion forums leaving a gap in evaluation of performance of other social media tools.

*Fisher and Clayton, 2012 – Who gives a tweet: assessing patients' interest in the use of social media for health care*

This paper describes a survey on the use of social media for health care by 111 outpatients of a family practice clinic. The majority of respondents (83%) had used at least one type of social media and half of them were in favour of healthcare providers using social media to communicate. Email (62%) and mobile (52%) communications were most preferable among those using social media. Patients who did not use social media reported they would consider doing so if their healthcare provider used it. Almost half of the patients (48%) were concerned with privacy and confidentiality issues when using social media for healthcare.

*Choudhury, 2013 – Role of social media in tackling challenges in mental health*

This position paper explores recent research investigating the potential of social media to serve as a new medium for mental health measurement and surveillance. Expressions in Twitter posts may characterize depression as manifested in everyday life and provide a rich source of information to capture sufferers' social context and help detect depression in populations. It's a naturalistic setting and not a response to

prompts about mental health but makes sense of people's behaviour over time and in heterogeneous samples. It is a great tool for treatment and diagnosis information as well as social and emotional support.

*Antheunis, Tates and Nieboer, 2013 – Patients' and health professionals' use of social media in health care: motives, barriers and expectations*

This online survey describes data from 139 patients and 153 health care professionals in obstetrics and gynaecology on the motives, barriers and expectations in using social media for healthcare. Almost all patients (99.3%) used one or more of 5 social media compared to half of the health professionals (59.3%). A third of patients (31.7%) and a quarter of the health professionals (26.8%) used social media for health-related reasons. Different social media were associated with different motives for use – Twitter was primarily used by patients for increasing knowledge whereas Facebook was used for social support. Health professionals were most likely to use LinkedIn and Twitter for communication with colleagues and marketing. Patients reported privacy and health professionals stated inefficiency of social media as the main barriers to using it. Both patients and professionals said that 'deciding for themselves when they use social media' was the main expectation on future use for health-related reasons.

## **1.2 Relevance of literature**

Research in the field of social media use in health care is still at early stages but it is already evident that the way we interact over this medium is changing rapidly. A growing number of patients and healthcare professionals are using social media to keep in contact with their peers or look for information. Widely accessible and instant exchange of healthcare information and sharing of experiences will be uniquely beneficial to the development of professional knowledge and improved health management.

The papers reviewed emphasise the ability of social media to be customised for different purposes as supported by the principles facilitating knowledge translation interventions (Graham et al, 2006). As Hamm et al (2015) report, Twitter is also additionally utilised to disseminate public health alerts. The importance of implementing social media use in health care is unquestionable.

Choudhury (2013) further discusses the inherent nature of social media such as Facebook and Twitter to be rich sources of thoughts, feelings and opinions and how these nuanced observations can be utilised over time to monitor and assess mental health. The dual advantage of analysing these user-generated data is to (i) facilitate wellness technologies and (ii) develop early warning systems for personalised alerts and information.

It is within the scope of the second functionality that WP7 is developing the PHEME-related case studies. Our focus is on the effectiveness of social media in signifying mental health issues and how we can use such occasions to develop public awareness, alert health care professionals and inform educational and training material. We will do so by analysing aggregated and anonymised patient data to explore how events in social media might correspond to aggregated occurrences in clinical records. It must be stressed that we do not attempt to link a specific social media account to a specific clinical record (which is anonymised in any case). Instead, data from both sources is first aggregated and only then observations and conclusions are drawn, e.g. whether similar trends and attitudes are observed in both kinds of data sources.

We are concentrating on social media and particularly, Twitter, as a representative medium of trending news and events. If a story or sentiment is prevalent on Twitter, it is certain that this will be circulating on other mainstream media where patients and healthcare professionals will be exposed to the event; actual use of Twitter is not a consideration for the development of the studies. Moreover, accessing patients' social media accounts would be unethical and in our case, impossible, as we are only analysing anonymised clinical records that would be impossible to link to personal accounts.

Making these comparisons at population rather than individual level has already produced positive findings: results from our legal high case study showed that mephedrone mentions in Twitter, including periods of increased or decreased chatter, follow a similar pattern to the number of times mephedrone was referenced in the clinical records between 2009 and 2014. These are further supported by the generalizability of clinical population characteristics; demographics of mephedrone users in the clinical records widely match those of users in the general population –

white ethnic background, male gender, in late 20s (Public Health England, 2013; Mixmag, 2013a).

## **2 Risk management**

As with any novel research approach, there are risks associated with the methodology of the case studies as well as with the expected findings. We have identified the following areas of concern and ways of overcoming risk:

### **1) Using Twitter as a data collection source for mental health research**

Mining information and trends in mental health from Twitter is an original approach that has not been performed before. However, studies have proved the utility of Twitter for public health surveillance, in particular for influenza trends (e.g. Broniatowski et al, 2013). Similarly to how Twitter data are mined for influenza surveillance, we are also using the Twitter Streaming API to collect an uncapped keyword stream. We are also collecting a keyword stream capped at 10% of public tweets between 2009 and 2014. This will ensure a comprehensive data collection schedule to also reflect changes in public attitudes towards mental health-related issues over time. We are following a vigorous methodological process that can be validated and generalised for use in future mental health research involving social media.

### **2) Finding no associations or negative results**

There is a risk that our analyses will reveal no association between occurrences in social media and events in patient records. Likewise, they might produce negative results. For example, mental health stigma might affect vulnerable populations over time rather than immediately and might be difficult to identify and measure. However, research in mental health depends on small samples that might not be representative of larger populations (Banerjee & Chaudhury, 2010). It also usually relies on retrospective self-reports that are subject to recall and assessment bias (Trull & Ebner-Priemer, 2009). In our study, continuous streams of Twitter data will limit the temporal gaps along which assessments are made and facilitate collection of comprehensive, longitudinal data. The large, heterogeneous sample will also reinforce generalizability of results. If there is absence of an association or the data produce

negative results, we will have tested our hypotheses robustly enough to be certain of their reliability.

### **3 Technical approach**

As specified in the DoW, the social media data collected for this case study will be analysed with the content analytics tools developed in WP2, WP3 and WP4, and visualised using the PHEME visualisation dashboard (WP5).

#### **3.1 Data Collection**

Following the recommendations from the review, work was carried out on identifying sources other than Twitter. Specifically, the focus has been on patient forums, as these are a key social media platform used by patients (Coulson and Shaw, 2013). We have now shortlisted as relevant the following fora:

<http://www.patientslikeme.com/>

<http://www.addforums.com/forums/>

<http://www.patient.co.uk/forums>

<http://www.medhelp.org/forums/list>

<http://www.mentalhealthforum.net/>

[http://www.sane.org.uk/what\\_we\\_do/support/supportforum/support\\_rooms](http://www.sane.org.uk/what_we_do/support/supportforum/support_rooms)

<http://www.psychforums.com/>

<http://www.depressionforums.org/forums/>

<http://forum.psychlinks.ca/>

<http://www.healthyplace.com/forum/>

<https://forums.psychcentral.com/>

<http://www.recoveryourlife.com/forum/>

<http://www.medschat.com/forums.asp>

<http://www.takethislife.com/prescription-medication/>

<http://www.drugs.com/forum/>

<http://www.drugbuyersguide.net/>

<http://www.iddb.org/forums/>

<http://www.crazyboards.org/forums/>

<http://www.beatingthebeast.com/forum/index.php?s=60b0a285c86c93e3bdc990f34c2efa9d&showforum=15>

<http://www.healthboards.com/boards/#mental-health-board>

[http://ehealthforum.com/health/health\\_forums.html](http://ehealthforum.com/health/health_forums.html)

<http://www.minddisorders.com/forum/viewforum.php?f=1>

A special priority will be given to PatientsLikeMe as they have a DataForGood policy.

In addition to the datasets already mentioned in D7.2.1, we are also working on rumour annotation of the Germanwings tweet-set, which has been collected in cooperation with WP8, alongside annotations for stigmatising comments and attitudes from WP7. Conversational threads and source tweets are being considered, following the rumour annotation methodology established in WP2. This dataset will enable us to get a more complete and in-depth analysis of stigma and relate that to controversies, mis/disinformation, and speculations in social media. The work will also build on USH's experience of analysing hate speech.

From the four use cases considered in WP4, self-harm and suicide are the ones most open to controversies and speculations and reflect into news stories too, thus forming a natural interface with WP8. Another distinguishing and challenging factor here, unlike in the news case study in WP8, is that there can be no ground truth and facts as such. In some cases, there is potentially a professional viewpoint, but even that can be disputed by certain professionals, e.g. whether train suicides should get reported in the media or not (as it could initiate a wave of more suicides). Thus the qualitative and automatic analysis in PHEME could have effect on policies of agencies, such as the Samaritans.

### **3.2 Analysis**

As can be seen from the manually annotated tweets in D7.2.1, the type of information that needs to be detected as well as topics differ from those in the WP8 news case study. Consequently, the WP3 and WP4 algorithms, which are primarily being trained on the London riots and parts of the recent WP8 datasets (D8.2), will need to be adapted to the specifics of this use case. In particular, healthcare professionals are interested also in opinions expressed, not just whether a tweet is about, e.g. mephedrone.

Therefore, experiments will be run on adapting the WP2 pre-processing algorithms, as well as the rumour and trustworthiness detection algorithms from WP3 and WP4 to the specific requirements of this case study. One important avenue to be pursued is

making use of Life Science linked data and the reasoning component developed in WP4 (including ONTO's Linked Life Data resource of close to 10 billion triples).

WP7 also presents a challenge for the analysis algorithms in that they need to run on the anonymised CRIS patient record database, which is only accessible on servers inside the South London and Maudsley NHS Trust firewall. Therefore, we are pursuing the deployment of CAPTURE and the Kafka-based software integration framework onto their servers. Since the focus in PHEME is on developing new scientific methods for veracity intelligence, software integration with CRIS will be kept as lightweight as possible via services, and initially focus on data exchange. Due to the confidential nature of CRIS, public demonstrators from WP7 and the healthcare-oriented PHEME dashboard will not refer to individual patient records or show such data.

### **3.3 Visualisation and the PHEME dashboard**

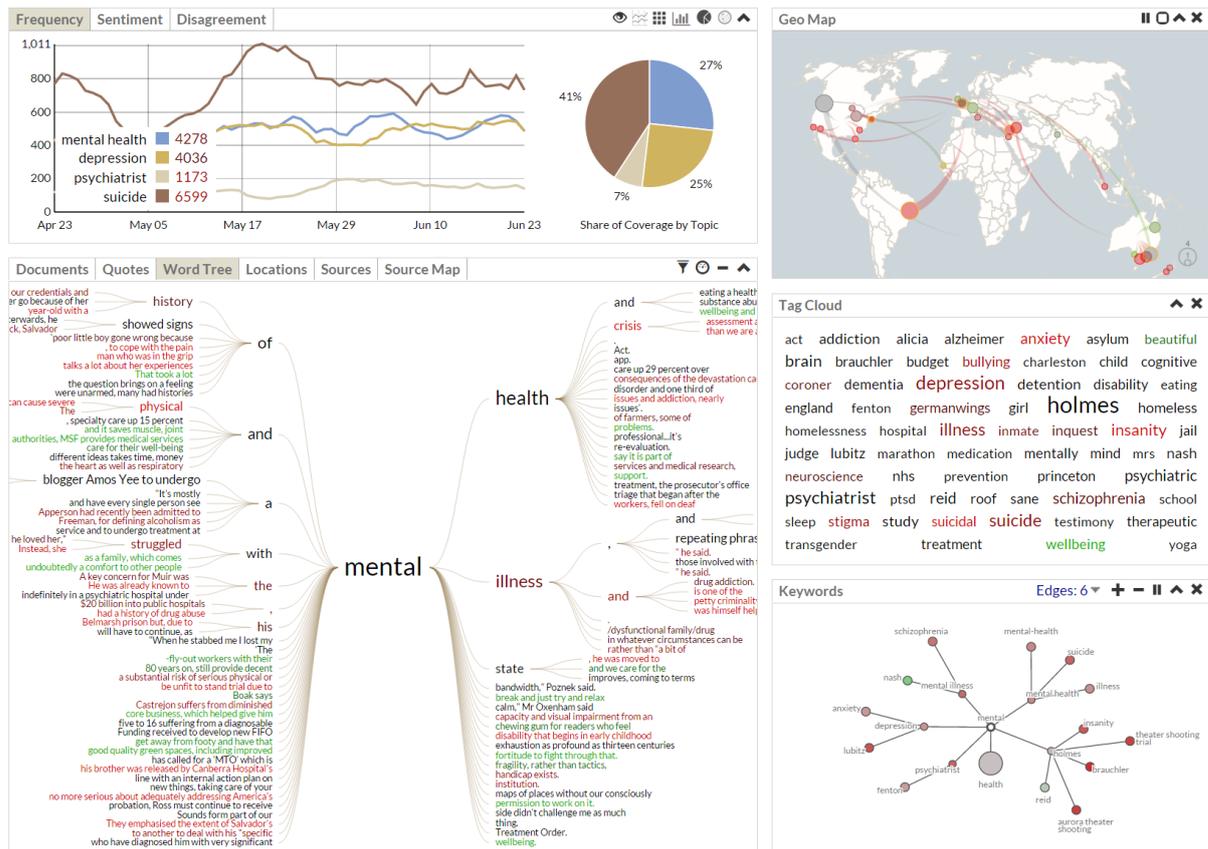
The PHEME visualisation dashboard (Task 5.4) supports the visualization of trends over time, showing query results in their geographic and semantic context. The Web-based application design will allow for delivery to users anywhere and across a range of devices and platforms.

For effective data interchange, WP5 will provide an API for data upload into the dashboard, fully or partially annotated, as well as APIs for (i) querying the domain-specific knowledge repository, and (ii) integrating individual visualisation components into bespoke Web applications via iFrame technology. WP5 will also deliver a mobile-friendly HTML5 version of the dashboard, which we hope will help with adoption by healthcare professionals.

The screenshot in Figure 1 contains a screenshot of the dashboard prototype. It shows the results of a query for *mental health* based on international news media coverage between April and June 2015, with various visualizations including a *trend chart* in the upper left corner to show temporal context, a *word tree* to show the lexical content, a *geographic map* to show the regional context, as well as a *tag cloud* and *keyword graph* to depict associated terms. The colour depicts document sentiment, ranging from red (negative) to grey (neutral) to green (positive). These sentiment

colours also vary in saturation, depending on the degree of polarity – vivid colours indicate emotionally charged issues, less saturated shades a more restrained coverage.

Given that one of the aims of WP7 is to understand and track public discourse and misconceptions around mental health, the word tree visualisation is of particular interest.



**Figure 1** Screenshot of the user interface prototype, showing the results of a query for mental health based on international news media coverage between April and June 2015

In particular, we envisage testing and, as needed, adapting the PHEME dashboard to the specifics of the stigma use case. For instance, based on their automatic analysis by the use case specific algorithms, tweets and other content will be shown as stigmatising versus not, as an alternative categorisation of tweets/forums/news media. Such a “stigma dashboard” is of potential use for clinicians, charities and other such bodies.

Such a bespoke dashboard can be enhanced with customised visualisations, such as overall stigma indicators shown as charts, similar to those currently used for visualising aggregated sentiment.

The availability of the PHEME dashboard as a mobile phone application will hopefully help with adoption by such specialist users, who will also be provided with targeted training in how best to make use of the technology. We will aim to gather a focus group to test some ideas and possible visualisation alternatives, as part of a workshop to be held around April 2016. The workshop will target healthcare professionals from the above mentioned categories.

#### **4 Case Study Prioritisation**

At the reviewers' suggestion, we have reviewed the four case studies currently being undertaken in WP7; legal highs, medication, mental health stigma and self-harm/suicide. We appreciate that this is a great undertaking especially since it explores new territory in social media and clinical research. We are confident in completing the data collection and analysis for all case studies but we have taken the reviewers' concerns into thoughtful consideration and decided to prioritise the legal highs, medication and mental health stigma case studies. However, we will continue to collect historical and streaming API data from Twitter for the self-harm/suicide case study and will endeavour to complete it if the other case studies have been successfully concluded.

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