DELIVERABLE SUBMISSION SHEET

To: Susan Fraser   (Project
                                                        Officer)

                EUROPEAN COMMISSION
                Directorate-General Information Society and Media
                EUFO 1165A
                L-2920 Luxembourg

From:

Project acronym:	PHEME	Project number:	611233
Project manager:	Kalina Bontcheva		
Project coordinator	The University of Sheffield (USFD)		

The following deliverable:

Deliverable title:	Requirements and design documents
Deliverable number:	D7.1
Deliverable date:	30 April 2014
Partners responsible:	King's College London (KCL)
Status:	☒ Public ☐ Restricted ☐ Confidential

is now complete.

☒ It is available for your inspection.

☒ Relevant descriptive documents are attached.

The deliverable is:

☒ a document

☐ a Website (URL: ....)

☐ software (..........................)

☐ an event

☐ other (..........................)

Sent to Project Officer:	Sent to functional mail box:	On date:
Susan.Fraser@ec-europa.eu	CNECT-ICT-611233@ec.europa.eu	7 May 2014

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

D7.1 Requirements and design documents
_____

Anna Kolliakou, King's College London
Rob Stewart, King's College London

Abstract
FP7-ICT Strategic Targeted Research Project PHEME (No. 611233)
Deliverable D7.1 (WP 7)

This deliverable describes the development of four demonstration studies to monitor and inter-link social media and patient records. It provides an introduction to PHEME and a background to the CRIS system– the tool used to extract anonymised data from clinical records. A structured description of the case studies is presented together with social media resources already identified for each one. An outline of the technical requirements necessary for providing rumour intelligence for direct use by clinical and public health practitioners as well as linking social media to and correlating it with aggregated patient records, is provided. The aim of this deliverable is to describe the structure for testing the utility of PHEME as a primary source of data and in combination with electronic patient records.

Keyword list: electronic health records, CRIS system, novel psychoactive substance, self-harm, suicide, mental health stigma, healthcare rumour intelligence.

PHEME Consortium

University of Sheffield
Department of Computer Science
Regent Court, 211 Portobello St.
Sheffield S1 4DP, UK
Tel: +44 114 222 1930
Fax: +44 114 222 1810
Contact person: KalinaBontcheva
E-mail: K.Bontcheva@dcs.shef.ac.uk

Universitaet des Saarlandes
Universitaet des Saarlandes
Language Technology Lab
Campus
D-66041 Saarbrücken
Germany
Contact person: Thierry Declerck
E-mail: declerck@dfki.de

MODUL University Vienna GMBH
Am Kahlenberg1
1190 Wien
Austria
Contact person: Arno Scharl
E-mail: scharl@modul.ac.at

Ontotext AD
Polygraphia Office Center fl.4,
47A Tsarigradsko Shosse,
Sofia 1504, Bulgaria
Contact person: Georgi Georgiev
E-mail: georgiev@ontotext.com

ATOS Spain SA
Calle de Albarracin 25
28037 Madrid
Spain
Contact person: TomásPariente Lobo
E-mail: tomas.parientelobo@atos.net

King'sCollege London
Strand
WC2R 2LS London
United Kingdom
Contact person: Robert Stewart
E-mail: robert.stewart@kcl.ac.uk

iHub Ltd.
NGONG, Road Bishop Magua Building
4th floor
00200 Nairobi
Kenya
Contact person: Rob Baker
E-mail: robbaker@ushahidi.com

SwissInfo.ch
Giacomettistrasse 3
3000 Bern
Switzerland
Contact person: Peter Schibli
E-mail: Peter.Schibli@swissinfo.ch

The University ofWarwick
Kirby Corner Road
University House
CV4 8UW Coventry
United Kingdom
Contact person: Rob Procter
E-mail: Rob.Procter@warwick.ac.uk

Executive Summary

This deliverable provides an introduction to PHEME and a background to the CRIS system– the tool used to extract anonymised data from clinical records. A structured description of the case studies is presented together with social media resources already identified for each one. An outline of the technical requirements necessary for providing rumour intelligence for direct use by clinical and public health practitioners as well as linking social media to and correlating it with aggregated patient records, is provided. The aim of this deliverable is to describe the structure for testing the utility of PHEME as a primary source of data and in combination with electronic patient records.

Our first demonstration study on social media and healthcare choices will focus on the effects discussions about controversial medications and treatments might have on the presentation of clinical populations and clinicians' prescribing practices. The monitoring of controversial novel psychoactive substances in social media and their appearance in clinical records is the focus of the second study. The development of the study on social media and stigma aims to address the vulnerability of particular clinical groups to the peaks of stigmatising chatter on social media platforms. Lastly, our last demonstration study will seek to explore whether social media might influence young people at risk of self-harming behaviour and suicide.

Data extraction from patient and physician blogs and forums as well as Twitter using queries containing keywords and hashtags will be carried out. A system to monitor news stories relating to the demonstration studies will be developed. Another essential requirement will be to connect social media occurrences to clinical records by enabling the easy integration of the PHEME rumour intelligence algorithms with the CRIS system analysis infrastructure. The PHEME veracity intelligence tools and visual dashboard will support the identification and quality assessment of the mis/disinformation source, detection of new trends and sentiment on the topics of interest and cross-referencing to news stories.

Our next focus will be in addressing individual elements of each case study for collection and annotation of corpora as well as identifying events and groups of interest in the clinical records.

Contents

1 Introduction

1.1 PHEME – Project rationale and vision

From a business and government point of view there is an increasing need to interpret and act upon information from large-volume media, such as Twitter, Facebook, and newswire. However, knowledge gathered from online sources and social media comes with a major caveat – it cannot always be trusted. Rumours, in particular, tend to spread rapidly through social networks, especially in circumstances where their veracity if hard to establish. Researchers have found that people read untrusted sources for various reasons, the main ones being their interestingness, entertainment value, a friend's online recommendation, or a search engine result (Ennals et al, 2010).

A 2012 report by Pew Internet Research on the future of big data (Anderson and Rainie, 2012) argues that, even though by 2020 big data are likely to have transformational effect on our knowledge and understanding of the world, there is also a danger arising from inaccurate or false information (termed "distribution of harms").

Social media poses three major computational challenges, dubbed by Gartner the 3Vs of big data: volume, velocity, and variety. Content analytics methods, in particular, face further difficulties arising from the short, noisy, and strongly contextualised nature of social media. To address the 3Vs of social media, novel language technologies have emerged, e.g. using locality sensitive hashing to detect new stories in media streams (volume), predicting stock market movements from tweet sentiment (velocity), and recommending blogs and news articles based on users' own comments (variety). PHEME focuses on a fourth crucial, but hitherto largely unstudied, big data challenge: veracity.

More specifically, PHEME will investigate models and algorithms for automatic extraction and verification of four kinds of rumours and their textual expressions (which we refer to as phemes):

- uncertain information or speculation
- disputed information or controversy

- misinformation
- disinformation

In other words, veracity intelligence is an inherently multi-disciplinary problem, which can only be addressed successfully by bringing together currently disjoint research on language technologies, web science, social network analysis, and information visualisation. Therefore, to meet the need for automatic veracity intelligence, now is the time to develop novel, cross-disciplinary social semantic methods for veracity intelligence, drawing on the strengths of these four disciplines.

1.2 WP7 – Veracity intelligence for patient care

The relationship between clinicians and their patients has already been changed by the internet in three waves. First, the provision of pharmaceutical data, diagnostic information and advice from drug companies and health care providers, have created new sources for self-directed diagnosis. Second, co-creation sites like Wikipedia and patient support forums (e.g. PatientsLikeMe) have more recently added a discursive element to the didactic material of the first wave. Finally, the social media revolution has acted as an accelerant and magnifier to the second wave. It is now possible, under the right circumstances, for groups of patients to move from the appearance of a symptom to world-wide dissemination of their experience as a meme (or pheme!). A suspected new 'legal high' (i.e. psychoactive substance created for recreational use and not yet subject to legislation), for example, might be trending on Twitter within hours of its first suggestion and long before the veracity of the appearance has any chance of proper examination by specialists.

PHEME's first use case (WP7) will therefore start the process of re-tooling medical information systems to operate in this new context. Two complementary uses of PHEME in the health care domain will be investigated: first, as a primary source of data and, second, in combination with electronic patient records. In the first use, PHEME will provide rumour intelligence for direct use by clinical and public health practitioners. The ability to spot rumours as they appear (e.g. monitored at a national level for different areas of medical care) could provide daily alerts of problematic cases that are likely to be raised by patients. Timely national media interventions could therefore be facilitated. In the second complementary use of PHEME, social

media analysis will be combined with analysis of the structured data and free text from patients' records thus linking social media to and correlating it with aggregated patient records. This seeks to enable health care practitioners to (i) examine the veracity of social media health topics in the light of clinician-recorded patient encounters and (ii) access information on a social dimension, alongside the usual clinical dimension.

Public health professionals have started to undertake social media surveillance for various purposes, e.g. real-time tracking of flu epidemics, syndromatic classification of Twitter messages, or examining attitudes towards vaccination. In this context, veracity, rumours and spam are a major challenge. For example, PatientsLikeMe.com contains a wealth of discursive information and personal patient data but veracity and the influence of rumour are major problems, not least because pharmaceutical lobbying organisations are assumed to be active in such social media. Given the volume and velocity of content, however, there is a strong need for automated algorithms for rumour detection, to help public health researchers with aggregating and monitoring patient forums, Twitter etc.

This deliverable is structured as follows: Chapter 1 presents the rationale for the wider PHEME project within which WP7 operates. Chapter 2 describes the development of the CRIS system used to search anonymised clinical records. Chapters 3 to 6 summarise the four demonstration case studies that are in development. Chapter 7 presents an overview of the technical requirements necessary for completing the case studies. Chapter 8 gives a short summary of the relevance of WP7 to PHEME and the other work packages. References and appendices follow, lastly.

2   Background

2.1 The SLAM Case Register and CRIS application

The longitudinal nature of case registers- a 'patient-centred longitudinal record of contacts with a defined set of psychiatric services originating from a defined population' (World Health Organisation 1983)- their size and coverage of defined populations make them an important research asset, providing large numbers of subjects and measurement points, and the potential for data linkage (Alleback et al, 2009). Electronic health records (EHR) based registers have been proposed as a possible 'new generation' (Perera et al, 2009). Through technological advances in both the daily updating and validation of registers, large and complex projects can be carried out with a particular strength of these data resources being their ability to cover all types of psychiatric services thereby providing a more comprehensive picture of mental health within a catchment area.

The South London and Maudsley (SLAM) NHS Foundation Trust provides comprehensive mental health services to a geographic catchment of over 1.2 million residents in four south London boroughs – Croydon, Lambeth, Lewisham and Southwark – as well as some regional/national specialist services. Clinical records have been fully electronic (i.e. paperless) across all SLAM services since April 2006 using the bespoke Patient Journey System (PJS). The Clinical Record Interactive Search (CRIS) application was developed in 2007-08 and consists of a series of data-processing pipelines which both structure and de-identify PJS fields, rendering effectively anonymised data from the full clinical record available at the researcher interface, with search and database assembly functionality, thus forming the SLAM Case Register. Ethical approval as an anonymised database for secondary analysis was granted in 2008 (Oxford C Research Ethics Committee 08/H0606/71) and this was renewed for a further 5 years in 2013 (Oxford C Research Ethics Committee 08/H0606/71+5). CRIS set-up and development have been funded as a data infrastructure resource by the British National Institute for Health Research (NIHR) Biomedical Research Centre for Mental Health (BRC-MH) awarded to SLAM/KCL and by local Trustees support.

Although, the SLAM Case Register conforms to the World Health Organisation's formal description of a psychiatric case register, the way in which data in the BRC Case Register are generated (by automated 'extract, transform and load' processes from a transactional database underpinning the comprehensive electronic patient record operated by a large secondary mental health care provider), the comprehensive nature of the data that are imported (covering all documented clinical encounters) and the inclusion of both structured and unstructured (open text) data in de-identified form, variously distinguish the BRC Case Register from other local, regional and national case registries, including those extracted from EHRs such as the disease registries maintained by the United States Veteran's Administration (see for example (Backus et al. 2009) and (Morden et al. 2010)), and also from routinely collected datasets such as the Mental Health Minimum Dataset and Hospital Episode Statistics for England and Wales.

Over the years, the SLAM Case Register has evolved in response to the need for greater flexibility in querying and retrieving data by, firstly, creating a second, relational database version of the SLAM Case Register to operate alongside the original CRIS interface—SQLCRIS. Using a suitable programming language, usually some form of Structured Query Language (SQL), database users may perform operations upon these relations. Another priority for progress has been to develop more efficient ways of using open text data. Beyond the efficiencies in manual coding gained by extracting only those records required for coding through keyword searches and post-search processing, further gains may be made by displaying text in ways that make text of interest easier to see, and by displaying data that are required to be reviewed together in close proximity, and away from other data. Furthermore, natural language processing (NLP) techniques have been evaluated and applied for extracting knowledge from unstructured text data. For our purposes, the key NLP technique has been information extraction (IE) where unstructured text is converted into structured tables (Cunningham 2005). Such methods promise massive reductions in the time resource required by researchers to unlock information held in clinical notes that in turn may be connected to other parts of the structured record. It was therefore decided to implement a text mining capability in CRIS. This was to be generic, in that information to be extracted could not necessarily be foreseen in advance of the design of individual research studies. It was also decided to implement a capability rather

than just technology, so that methodologies and skills would need to be developed to deploy NLP for specific research studies. As such, General Architecture for Text Engineering (GATE; http://gate.ac.uk; Cunningham 2002) was chosen as the core NLP infrastructure for CRIS and this has been developed through a longstanding collaboration between SLAM/KCL and the Department of Computer Science at the University of Sheffield.

SLAM comprises one part of the King's Health Partners (KHP) Academic Health Sciences Centre (AHSC; established with King's College London, Guy's and St Thomas' and King's College Hospitals NHS Foundation Trusts) and, through NIHR funding, set up a service to meet the growing demand from SLAM & KHP researchers whose projects require linked data extracts. SLAM consequently established the Clinical Data Linkage Service (CDLS) as a Trusted Third Party safe haven set up to enable safe and secure data processing services (linkage, and/or storage, and/or extraction) on distinct data sets for secondary research use. The two main methods of linkage have involved either 1) CDLS performing a secure linkage using probabilistic matching if/as required or 2) CDLS supporting another trusted third party service to perform the linkage outside of the SLAM electronic firewall followed by CDLS receiving the linked data afterwards (e.g. CRIS-HES linkage). To date, linkages have been successfully carried out between CRIS and the a) Thames Cancer Registry, b) Hospital Episode Statistics (HES) and c) Death certification. Figure 1 provides a schematic representation of the CRIS system.

Figure 1 Diagram of CRIS technical architecture including NLP and data linkage
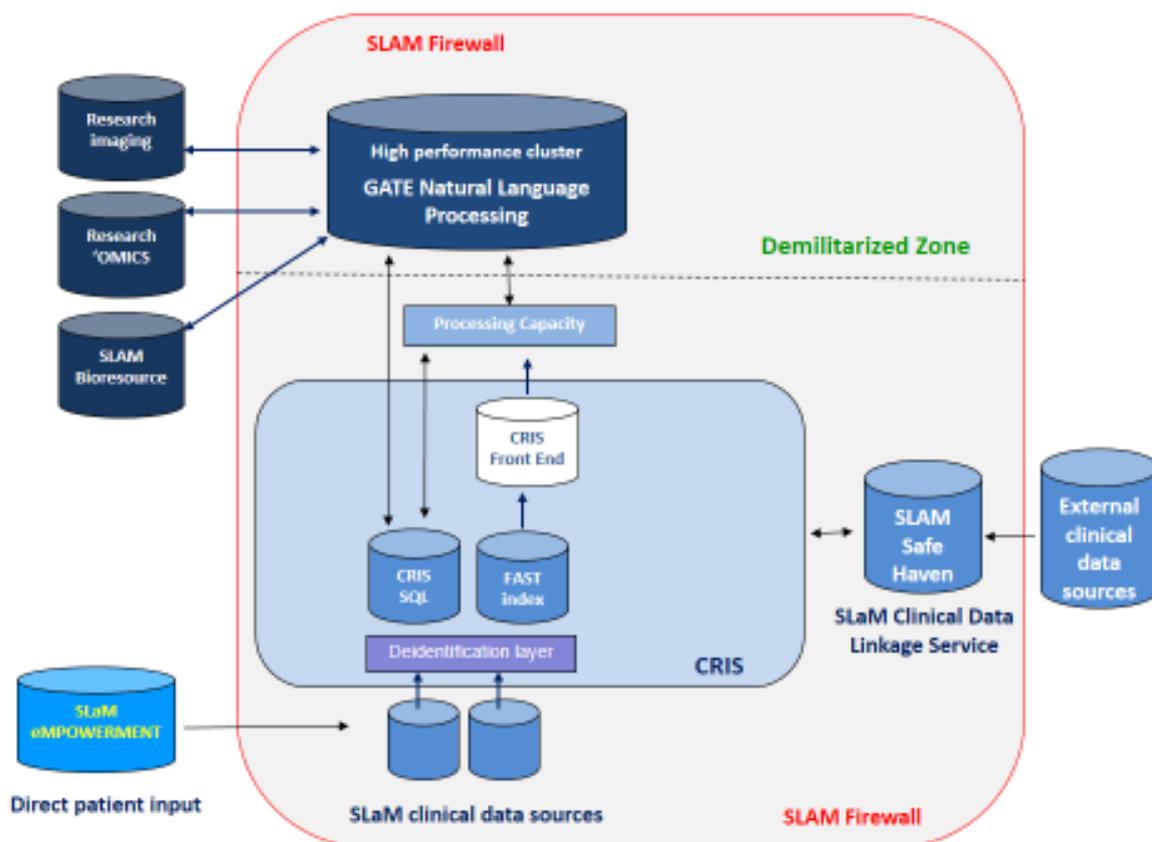
Currently, the SLAM Case Register contains around 250,000 patient records with nearly 40,000 'active' cases (i.e. currently receiving care from SLAM services) at any one time with the largest numbers receiving care from Psychosis or Child and Adolescent Mental Health Services (Table 1). Almost two thirds of patients are aged between 21 and 60 years old from a white background with equal proportions of males and females (Table 2).

Table 1 Numbers of active and inactive cases on 1st October 2013 by SLAM service

SLAM service	Number of cases		
	Active	Inactive	Total
Psychosis	7184	13995	21179
Child and Adolescent Mental Health Services	6904	24092	30996
Mood, Anxiety and Personality	6556	26559	33115
Psychological Medicine	5669	48758	54427
Mental Health of Older Adults and Dementia	4776	20508	25284
Behavioural and Developmental Psychiatry	3309	6736	10045
Addictions	3302	9890	13192
Not recorded	1810	71533	73343
	39510	222071	261581

Table 2 Descriptive summary of SLAM Case Register records at 1st October 2013

Total	Number (%)
Age (years)	
≤ 20	38,181 (17.3)
21–40	74,684 (33.8)
41–60	64,535 (29.2)
61–80	23,879 (10.8)
>80	19,649 (8.9)
Gender	
Male	110,052 (49.9)
Female	110,517 (50.1)
Ethnicity	
British, Irish or any other white ethnic groups	109,798 (66.8)
Mixed	2,107 (1.3)
Indian, Pakistani, Bangladeshi or 'other Asian'	7,391 (4.5)
Caribbean, African or any 'other Black'	32,533 (19.8)
Other	12,613 (7.7)

PHEME's spatio-temporal focus complements current developments in the KCL/SLAM BRC Clinical and Population Informatics theme to harness geospatial expertise in order to characterise better SLAM's multicultural and socially diverse catchment area – not only to link with secondary care statistics provided by CRIS, but also to make use of micro-level characterisation through a large BRC-MH funded survey of mental health and environmental stressors: the SELCOH project (Hatch et al, 2011).

Supported by further NIHR funding, the CRIS application has been enabled at four other sites, creating a substantially larger academic network as a result from health services covering Oxford, Cambridge, north and west London services. This generates not only substantially greater sample sizes for analyses, but also much greater sample heterogeneity. Finally, covered by current NIHR BRC funding, a shared electronic record is currently being piloted, having been developed in collaboration with Microsoft. This will bring in valuable patient-generated data of potential relevance in the later stages of PHEME.

2.2 Aims and objectives

The broad aims of WP7 are to turn the project technologies toward practical applications in the healthcare domain, to enable clinicians, public health professionals and health policy makers to analyse the high-volume, high-variety, and high-velocity internet content for emerging medically-related patterns, rumours, and other health-related issues. This analysis may in turn be used (i) to develop educational materials for patients and the public, by addressing concerns and misconceptions, and (ii) to link to analysis of the EHR.

The objective of WP7 is therefore to carry out research towards a PHEME-based platform for the medical domain for multi-channel media monitoring, extraction, verification, and visualisation of automatically extracted knowledge across media and languages. PHEME will create the application and resources needed to monitor and inter-link social media and patient records, specifically targeted at health professionals and meeting the quality required by both the profession and its regulators. This case study provides the integration of PHEME's technology into a (hospital-based) health records application and methodological and user verification

for the ultimate goals of monitoring health related rumours and misinformation in social media.

To this end, there are 4 main demonstration studies being considereddeveloped in WP7. These studies are under examination for feasibility and it might not be practical to fully develop all of them. The aims of these studies will be to:

1) Identify social media preferences and dislikes about certain medication and treatment options and how these present in clinical records
2) Monitor the emergence of novel psychoactive substances in social media and identify if and how promptly they appear in clinical records
3) Explore how mental health stigma arises in social media and presents in clinical records.
4) Ascertain the type of influence social media might have on young people at risk of self-harm or suicide.

3 Demonstration study 1 – Social media and healthcare choices

3.1 Background

In the healthcare industry, face-to-face contact had until recently been the main medium for information exchange. People are now increasingly using the web to obtain information and, as such, social media have become a vital part of healthcare by providing unofficial channels for communication between patients and also clinicians. In May 2011, the PewResearch Internet Project reported that 80% of internet users (59% of 3,001US adults surveyed) used social media to access healthcare information. Similarly in India, 39% of 1,004 adults surveyed reported using the internet for material related to healthcare (Max Bupa Health, 2011).

Technology advances have also transformed one-to-one communication into one-to-many conversations, in which patients interact with one another or with clinicians to obtain rapid information on health conditions. Healthcare portals such as PatientsLikeMe (http://www.patientslikeme.com; refer to Appendix 1.1 for full list of portals) facilitate the interaction between patients with similar conditions by enabling discussions and informed choices with regards to clinician and treatment options. A survey of 1,323 PatientsLikeMe members found that 12% changed their choice of physician based on information accessed on the website. Similarly, 22% of mood disorder patients surveyed needed reduced inpatient care as a result of online interactions on the site (HPM Institute, 2010). Social media also provide a unique platform for clinicians to share ideas and experiences with each other. Websites such as Ozmosis (https://ozmosis.org/home; refer to Appendix 1.1 for full list of portals) ensure online information exchange between healthcare providers to enable better knowledge and improved practice.

Web data mining is playing an increasingly prominent role in health research with analysis of data generated by social media platforms already shown to be integral to health improvements. By examining data on Flu Trends, a site that scans millions of Google searches worldwide to track patterns of activity, flu outbreaks were detected nearly two weeks before these appeared in official CDC reports (Ginsberg et al, 2007).

At the same time, use of social media for healthcare choices raises particular concerns. Inaccurate or misleading information may cause harm. Misinformation about symptoms and treatment options as well as lack of source verification are major concerns for both patients and clinicians. According to a recent study, only 25% of online health information users challenged the reliability of the source (Health Dialog, 2011). This could lead to ignoring serious symptoms, refusing care or choosing inappropriate treatments.

In summary, social media have transformed the way information is filtered relating to medication and treatment, symptom recognition and even choice of physician. Being able to relate personal experiences to a wide audience has made gathering knowledge vital to health and medical care instantly accessible through the internet. Even health professionals have created online communities to consult with peers (i.e. Doximity; https://www.doximity.com/). Undoubtedly, patients feel more enabled and clinicians are more confident in their practice but how does online exchange and uncertain credibility of information affect the mental healthcare choices of particular patient groups?

3.2 Aims and objectives

The main aim of this study will be to identify social media preferences and dislikes about certain medication and other treatment options (e.g. psychotherapy) in mental healthcare and how these related to outcomes derived from clinical records. Its objective will be to describe the interaction between online medication and treatment discussions and occurrences (such as comments around treatment adherence) in clinical records as well as to investigate the effects of processing healthcare information from untrustworthy sources on particular patient groups.

3.2.1 Specific aims

The particular aims of this demonstration study will be to:

1) Determine the attitude towards pre-specified medications and other treatment options in social media

2) Establish whether this social media sentiment is reflected in the clinical records

3) Investigate the extent to which patients' choice of and adherence to medication and other treatment may be influenced by how favourably these are discussed in social media

4) Examine whether clinicians' prescribing practices are affected by social media responses to certain medications and other treatments

5) Explore the impact of information around controversial treatments, such as Electro-convulsive Therapy (ECT) for treatment of depression or amphetamine-like agents for treatment of attention-deficit disorder (ADD) in children, on patient healthcare choices.

3.3 Methods

3.3.1 Clinical setting and samples

As described in Chapter 2, the study will use anonymised electronic health records data from the SLAM Case register through the CRIS application. Data will be extracted from all available clinical records (all demographic and diagnostic groups) to ensure a comprehensive range of medication and treatments are explored.

3.3.2 Data source identification

In order to identify discussion forums relevant to diverse psychotropic medication and treatment regimes, exploratory online searches have been conducted using the Google search engine with generic query terms such as 'patient forum', 'mental health patient forum', 'mental health forum', 'medication forum', 'prescription drug forum', 'anxiety disorder forum', 'depression forum', 'bipolar disorder forum', 'eating disorders forum', 'personality disorder forum', 'mood disorder forum', ' schizophrenia forum', 'psychosis support forum', 'addiction forum' . For each query term, the results in the first 20 pages were searched for any information/discussion related to medication and treatment. The related/suggested links of selected websites were also searched. One-hundred and eight forums were identified: 102 from primary and 6 from secondary searches (through a primary internet resource) (Appendix 1.1).

A gazetteer of medication has been created (Appendix 1.2) which comprises over 100 generic and brand names of psychotropic medication as well as their common uses. This was developed by cross-checking the lists produced by the National Alliance on Mental Illness, the Metro Crisis Services, the DHS of Wisconsin-USA and the National Institute of Mental Health to ensure comprehensive coverage. An inventory of slang terms used to describe common psychotropic medication was also produced for use in searching Twitter hashtags (Appendix 1.3).

3.3.3 Expectations and results

The first step in setting up this study will involve identifying appropriate medications and other treatments and determine prevailing social media comments relating to these. Choice of treatments will be determined by their frequency in the records (i.e. identifying the most commonly used agents for different key disorder groups) and their frequency in social media (which may be more likely to identify relatively controversial treatments such as ECT, or amphetamine-like agents for ADD in children). We should then be able to establish differences in positive and negative expressions relating to certain medications/treatments and whether these are reflected in the clinical records by either patients and/or clinicians. As with other case studies, having identified the key relationships (between social media and the health record) by their temporal relationship, we will go on to define characteristics of social media (e.g. nationality, type of site) associated with most influence, and the clinical sub-groups most influenced (e.g. by diagnosis, demographic status).

4   Demonstration study 2 – Social media and the 'legal highs' market

4.1 Background

Novel psychoactive substances (NPSs), commonly referred to as 'legal highs' and also known as 'designer drugs', 'herbal highs' and 'research chemicals', are synthetic compounds which are designed to mimic the properties and effects of traditional and illegal substances of abuse (Corazza et al., 2011a, 2011b, 2011c). In the last two decades more than 200 NPSs have been detected: 41 in 2010, 49 in 2011 (EMCDDA-Europol, 2010; EMCDDA, 2011b; EMCDDA, 2011a; EMCDDA, 2012) and 57 in 2012 (Deluca et al, 2012). With one new NPS, on average, appearing on the drug market every week, it is becoming increasingly urgent to monitor emergent substances and establish new diffusion trends.

The rapid advancement of this recreational drug market has caused information from traditional sources such as early warning and monitoring systems to be often inaccurate or outdated (Mounteney, 2010). Information from drug-related websites and vendors is increasingly regarded as key to complementing data from other sources in promptly identifying new substances and trends. Drug-related forums where users, protected by anonymity, share personal experiences with regard to drug use can provide wide-ranging information about previously unknown psychoactive compounds and their effects. Online user-generated content is increasingly becoming essential to generating an informed and up-to-minute portrayal of positive and negative effects, subjective experiences and availability of NPSs (Davey et al, 2012). To this end, two European Commission-funded projects, the Psychonaut Web Mapping System (www.psychonautproject.eu) and the ReDNet (www.rednetproject.eu) were developed to (i) explore the emergence of novel psychoactive substances by monitoring the Internet, and (ii) improve the information available to young people and healthcare professionals about the potential effects and risks of NPS, respectively.

The growing prevalence of NPSs and the rapid rate with which they appear, places healthcare providers at a great disadvantage. These substances are marketed through hundreds of unregulated online shops and clinicians are often unaware of recently-

appearing compounds. Furthermore, the 'branding' of these drugs and the actual composition of the substance render effects difficult to predict both by the user and by the healthcare professional (Advisory Council on the Misuse of Drugs. Consideration of the novel psychoactive substances ('Legal Highs'). Home Office, 2011.), which increases the risk of adverse consequences.

In summary, the Internet is occupying an increasingly dominant role in expanding the drugs market with a large number of NPSs appearing rapidly and emerging trends in drug use becoming increasingly difficult to identify and monitor. Misinformation on the actual compound and effects of novel psychoactive substances places users in potential danger. Predictably, clinicians are also frequently unaware of these novel compounds, which poses a major challenge in accurately assessing their physical and mental health effects.

4.2 Aims and objectives

The main objective of this study will be to monitor the emergence of novel psychoactive substances in social media, the controversies surrounding them and identify if and how promptly they appear in mental health clinical records.

4.2.1 Specific aims

The particular aims of this demonstration study will be to:

1) Determine the incidence of references to novel psychoactive substances in clinical records.
2) Establish the time lag between the emergence of a novel psychoactive substance in social media and how controversial user information and changes in legal status might affect its appearance in clinical records.
3) Utilize sentiment-bearing expressions (positive and negative references) in describing experiences referring to novel psychoactive substances in clinical records.
4) Describe the characteristics of mental health records in which NPSs appear – for example, by service context, diagnosis, or demographic profile.

4.3 Methods

4.3.1 Clinical setting and groups

As described in Chapter 2, section 2.1, the study will use anonymised electronic health records from the SLAM Case Register using the CRIS system. Data will be extracted from all available clinical records (all demographic and diagnostic groups) to ensure that a comprehensive range of clinical groups are included.

4.3.2 Data source identification

Exploratory online searches have been conducted so far using the Google search engine with generic query terms such as 'legal highs', 'new legal drugs', 'new psychoactive substances', 'drug forum' and 'buy legal highs'. For each query term, the results in the first 20 pages were searched for any information/discussion related to legal or illegal drug use. Online drug vendors and sites with user-generated content were included as well as harm-minimization and government sites. Worldwide sites were selected as long as English was their main language.

Twenty-three websites/forums/blogs were identified: 18 from primary and 5 from secondary searches (through a primary internet resource). Thirty-eight online shops and vendors were selected: 32 from primary and 6 from secondary searches. Of the 22 Twitter accounts of interest, only 5 were identified from primary searches. The majority of the Twitter accounts belonged to sites already selected in earlier searches (Appendix 2.1).

The most frequently detected and controversial NPSs will first be explored. These include: M-Cat or mephedrone, Spice, MXE – methoxetamine and DMAA or dimethylamylamine. A list of slang/street names commonly associated with these substances has been produced for searching social media and clinical records (Appendix 2.2).

In addition to monitoring the above mentioned sources for the emergence of new psychoactive substances, 'Google Insights for Search' (Google, 2012) will also be used. Google insight reports will provide an additional measure of the popularity of psychoactive substances by summarising the relative frequency of search terms

(psychoactive compounds) entered by Google users and how this varies over time and according to location.

4.3.3 Expectations and results

Through this study we aim to determine the incidence of references to NPSs in clinical records and establish a time-frame between their emergence in social media and appearance in the records. We will also explore how controversies surrounding particular NPSs and changes in legal status might affect their presence in patient records. We will be also able to ascertain if the location of new NPSs or the source of user-generated experience will affect their appearance in the clinical records. We anticipate that references to NPSs in the clinical records will be relatively low in comparison to well-established illicit substances of abuse such as cannabis and cocaine. We will also distinguish between positive and negative statements surrounding NPSs in how users describe their experiences/attitudes. Most importantly, we will investigate the trajectories that NPSs follow, in order to explore their level of online popularity and real-world interest based on location. Lastly, in cases where NPS are mentioned in the clinical records, we will be able to establish the wider context within which they appear and identify characteristics specific to the case notes where they are reported such as group demographics, diagnosis or service type among other clinical features.

5 Demonstration study 3 – Social media and mental health stigma

5.1 Background

Stigma, meaning any discriminatory, discrediting or insulting attitude, related to mental illness has profound effects on people suffering from mental health problems. Social scientists believe stigma, which existed long before psychiatry, is a result of stereotyping and discriminatory practices which may have been further fuelled by labelling from Psychiatry. Byrne (2000) further comments on the surprising absence of a word to describe mental health stigma, contrasting with other 'named' prejudicial beliefs/behaviours such as racism, sexism and ageism, attributing the enduring nature of mental health related stigma to its ubiquity and lack of description.

Mental health related stigma can have a huge impact on confidence, social functioning and interpersonal relationships. This potentially covers a wide range of disadvantages, such as missing out on employment or accommodation, being viewed as ineligible to provide childcare, or not being invited to social occasions (Corrigan et al, 2001; Corrigan, 2004). Self-stigmatisation, the process of directing publically-adopted stereotypes towards oneself by internalising the negative attitudes projected onto sufferers, often leads to low self-esteem, feelings of being undervalued and social exclusion (Livingston and Boyd, 2010).

Stigma can undoubtedly affect different aspects of people's lives. Even a short period of mental health problems can have effects on welfare, personal and professional life, and social interactions, with far-reaching effects on friends and family. These may in turn lead to further problems such as isolation, anxiety and depression. Stigma may prevent people from accessing early intervention for mental health problems, delaying the seeking of professional help until their symptoms have become very serious (Clement et al, 2014). For those with an already established disorder, stigma can be a deterrent against engaging with services or adhering to treatment, which in turn can lead to relapse and impede recovery (Parle, 2012).

The media have been accused of perpetuating stigma by portraying mental illness inaccurately to boost ratings. News stories focused on stereotypes tend to fuel public prejudice and fear. People may feel stigmatised as soon as they are diagnosed with a

mental health illness and may attribute their feelings to how their illness has been represented in the media (Dinos et al, 2004). Violence was found to be a key element in television representations, incorporated in 66% of items about mental illness (Philo, 1996), or else people with mental illness are pictured as victims or 'the deserving mad' (Byrne, 1997). In the current age of instant and far-reaching online interactions, social media have the potential to both propagate stereotypes related to mental illness in a way which is less easy to control than 'official' media outlets. On the other hand, they present a potentially valuable opportunity to disseminate positive messages, reduce discrimination and promote social inclusion.

In summary, many mental disorders are associated with stigma – a sign of discredit which sets someone apart from others. Despite awareness campaigns and educational initiatives, mental illness continues to receive negative attention, primarily because of fear and prejudice. Social media risk playing a significant role in diffusing inaccurate portrayals of mental illness and are still powerful instruments for the perpetuation of stereotypes and discrimination against mental health disorders. Failure to identify and deal with this stigma – societal or self-directed – may hinder prospects of recovery and rehabilitation.

5.2 Aims and objectives

The main aim of this study will be to identify how mental health stigma arises in social media, the role mis- and disinformation plays in stigmatising behaviour, and how it is reflected in clinical records.

5.2.1 Specific aims

The particular aims of this demonstration study will be to:

1) Determine the incidence of references to mental health stigma in social media
2) Explore how mis- and disinformation affect stigmatising chatter in social media
3) Establish whether patterns in this environmental context affect the clinical presentation of people who may identify with the diagnosis and/or behaviour that is being stigmatised.

5.3 Methods

5.3.1 Clinical setting and groups

As described in Chapter 2, section 2.1, the study will use anonymised electronic health records from the SLAM Case Register through the CRIS system. Data will be extracted from all vulnerable patient groups most likely to identify with the mental disorders discriminated against in social media to ensure the focused assessment of the effect of stigma on pre-defined, potentially vulnerable clinical populations.

5.3.2 Data source identification

Words and phrases associated with discriminatory and stereotypical attitudes towards mental disorders will be searched for in social media sources, through the development of a methodology allowing the identification of a given word/phrase (e.g. a diagnosis such as schizophrenia) and the quantification of positive/negative terminology occurring in the text relating to it, as well as common mis- and disinformation attached to mental health disorders. Temporal patterns of the intensity of negative phrasing in relation to a given disorder will thus be identified.

In addition to monitoring social media for stigma-bearing expressions, 'Google Insights for Search' (Google, 2012) will also be used. Google insight reports will provide an additional measure of interest in stigmatising expressions by summarising the relative frequency of search terms entered by Google users and how this varies over time and according to location. In addition, this function will enable us to relate periods of increased online activity with news stories more likely to provoke prejudice.

5.3.3 Expectations and results

The first step towards achieving the aims of this study will be to identify stigmatising statements as they appear in social media, to classify positive and negative sentiments surrounding particular mental disorder diagnoses, and identify common mis- and disinformation in this context. We should be able to distinguish between differences in stigmatising chatter based on location and source, establish a time-frame from the appearance of stigmatising statements to changes in clinical events and determine

their effect on the clinical groups of interest. It is very likely that peaks of stigmatising chatter will coincide with news stories such as those related to acts of violence or criminality by people suffering from mental illness. This will variably influence clinical events based on location and source. Clinical populations who relate to the behaviour discriminated against are expected to be most affected, with a moderate time-lag of the stigmatising statements appearing in social media. The broad aim will be to develop a dashboard which can identify risk periods as they emerge, ascertained from social media, the groups likely to be most vulnerable to these influences, and the outcomes of which they are most likely to be at risk.

6   Demonstration study 4 – Social media and self-harm/suicidal behaviour

6.1 Background

Self-harm, defined as the deliberate, self-inflicted destruction of tissues (ISSS, 2010) has increasingly been the focus of research and clinical exploration, seen as a behaviour transcending clinical barriers, most commonly observed in patient groups, but also with a high prevalence in certain demographic groups in community samples, such as young adults (Walsh, 2006; Welch, 2004). Lifetime prevalence in non-clinical groups ranges from 12% to 37% among adolescents. Studies have shown that 1 in 12 adolescents – 1 in 10 girls – self-harm, but most will stop by early adulthood (Moran et al, 2012). Although self-harm is distinct from suicide, many people practising self-harm are at increased risk of suicide-related behaviours (Whitlock and Knox, 2007). Suicide is the second most common cause of death for young people and the most common cause in girls aged 15–19 years (Patton et al, 2009).

Mass media have attracted scrutiny in the past in relation to their possible role in promoting self-harm and suicidal behaviours through contagion (Becker et al, 2004), and the Internet has received increasing attention in recent years. Anxieties about the Internet are particularly extensive in relation to younger people and the spread of problematic or harmful content such as that promoting self-harming and suicidal behaviours. The use of pro-self-harm forums, exchange of images, promotion of such behaviours and encouragement of others to engage in similar activities present multiple challenges for vulnerable young people. Some studies have shown that such content may encourage people to engage in self-harm practices (Jett et al, 2010).

Adolescence can be a turbulent time and considerable numbers of teenagers seek escape through self-harm, even if no fatal outcome is envisaged or desired. With the majority of adolescents accessing the Internet daily (Lenhart, 2010), it comes as no surprise that social media have received considerable attention for their possible role in contributing to self-harm and self-inflicted mortality as well as glamourizing and at times promoting these behaviours. The risk arising from unsupervised contact, with vast information and exposure to upsetting messages, particularly for young people already engaged in self-harming and suicidal behaviours, is very high.

6.2 Aims and objectives

The main objective of this study will be to describe the interaction between online 'chatter' around themes of self-harm and suicide, disinformation, and how this affects the clinical presentations of vulnerable patient groups.

6.2.1 Specific aims

The particular aims of this demonstration study will be to:

1) Determine the nature of online discussions on self-harm and suicide
2) Establish whether social media affect the clinical presentation of people vulnerable to self-harming behaviour and suicide

6.3 Methods

6.3.1 Clinical setting and groups

As described in Chapter 2, section 2.1, the study will use anonymised electronic health records from the SLAM Case register through the CRIS system. Data will be extracted from the records of a pre-defined sample of adolescents and young adults most at risk of self-harm and suicide.

6.3.2 Data source identification

In order to identify discussion forums relevant to pro self-harm or suicide chatter, exploratory online searches were conducted using the Google search engine with generic query terms such as 'pro self-harm', 'pro suicide', 'self-harm tips', 'pro self-harm forum', 'pro-suicide forum', 'suicide methods', 'suicide pacts', 'suicide buddies', 'pro-choice' . For each query term, the results in the first 20 pages were searched for any information/discussion related to pro self-harming behaviour and suicide. The related/suggested links of selected websites were also searched. The slang terms 'cat' and 'sue' will also be used for searching Twitter hashtags.

Thirteen forums were identified: 11 from primary and 2 from secondary searches (through a primary internet resource) (Appendix 3).

In addition to monitoring the above mentioned forums for self-harm/suicide discussions, 'Google Insights for Search' (Google, 2012) will also be used. Google insight reports provided an additional measure of interest in pro self-harm and suicide by summarising the relative frequency of search terms entered by Google users and how this varied over time and according to location.

6.3.3 Expectations and results

Through this study we should be able to identify periods of increased chatter about self-harm and suicide and determine the nature of attitudes towards this (positive or negative). It is anticipated that peak times of increased discussions about these behaviours will coincide with news stories of relevant content. We aim to distinguish between positive and negative attitudes towards self-harming and suicidal behaviour on social media and establish how the clinical presentation of vulnerable groups is potentially affected. The broad aim will be to develop a dashboard which can identify risk periods as they emerge, ascertained from social media, and the groups likely to be most vulnerable to these influences.

7 Requirements

The following section will address a series of cross-case requirements, in order of importance, that are considered key to the development of WP7 and the wider aims of PHEME. These may get refined as work progresses, in an agile manner, and we experiment with and evaluate the PHEME technology.

7.1 Data collection

Data will be collected from patient and, where appropriate, physician forums and blogs (as listed in the Appendices to this deliverable) using queries containing keywords. Currently, 100s of relevant sites have been identified from initial searches but this number is likely to vary because of (i) closure and replacement of websites (particularly relevant to the 'legal highs' demonstration case) and (ii) privacy and accessibility issues (most likely to be the case with patient forums). New lists will be generated in regular intervals to ensure we are up to date with new websites and forums. In the case of private forums, contact with the administrator will be sought in the first instance to request creation of account for ease of access. A record will be kept of this process, which will provide additional information to the methodological procedures for data collection followed by WP7.

Twitter is becoming an increasingly important resource for information, particularly among young people, and this has expanded to include patient groups and clinicians. A large variety of user-generated input can be utilised especially in the 'legal highs', 'medication and treatment' and 'stigma' demonstration studies. Beyond specific tweets identified from hashtags (as listed in the Appendices to this deliverable), it will be valuable to examine trends, re-tweeted tweets as well as tweets from prolific users. Since we aim to monitor over 100 search terms in some use cases, it might be challenging to combine this requirement with Twitter's API restrictions.

7.2 Following news stories

Monitoring of related news stories, in addition to social media, will enable us to cross-reference information between the two sources as well as establish the effects such stories have on social media trends. Health-related news about controversial therapies,

incidents of violence by mental health patients and teenage suicides are expected to be trending subjects in social media within minutes of being publicised. We expect, for these three case studies, that news stories will effect rapid peaks in social media trends. These trends will tail off gradually with smaller peaks generated based on how long and frequently developments from the same story will reappear in the news. This will in turn have an impact on the presentation of vulnerable patient groups in clinical records.

7.3 Connecting social media with clinical records

In order to relate social media occurrences with clinical presentations, we will define and implement data exchange formats and protocols to enable the correlation of results extracted from social and news media with patient records. We will also develop the PHEME rumour intelligence algorithms as easy-to-combine web services and/or GATE text processing pipelines for easy integration with the CRIS analysis infrastructure. WP7 will be in ongoing consultation during the interface design of the PHEME dashboard in WP5 in order to ensure customisation to the needs of the use cases.

7.4 CRIS-GATE interface

The BRC uses the GATE language engineering toolkit (http://gate.ac.uk) for all information extraction over records in the CRIS case register. All applications written to process CRIS records within PHEME will be required to operate within the CRIS GATE interface.

GATE pipelines are run on the BRC'S 96 node compute cluster. Pipelines are deployed on the compute cluster as standard GATE application. Documents to be processed are described as a virtual table in the CRIS database. The GATE application is then parallelised and run over these documents using a bespoke GATE CRIS harness for Grid Engine running on the cluster. The GATE-CRIS harness retrieves documents from the CRIS database and distributes to GATE threads running on Grid Engine. Each application thread returns extracted results back to the CRIS database. This process is shown in the figure below:
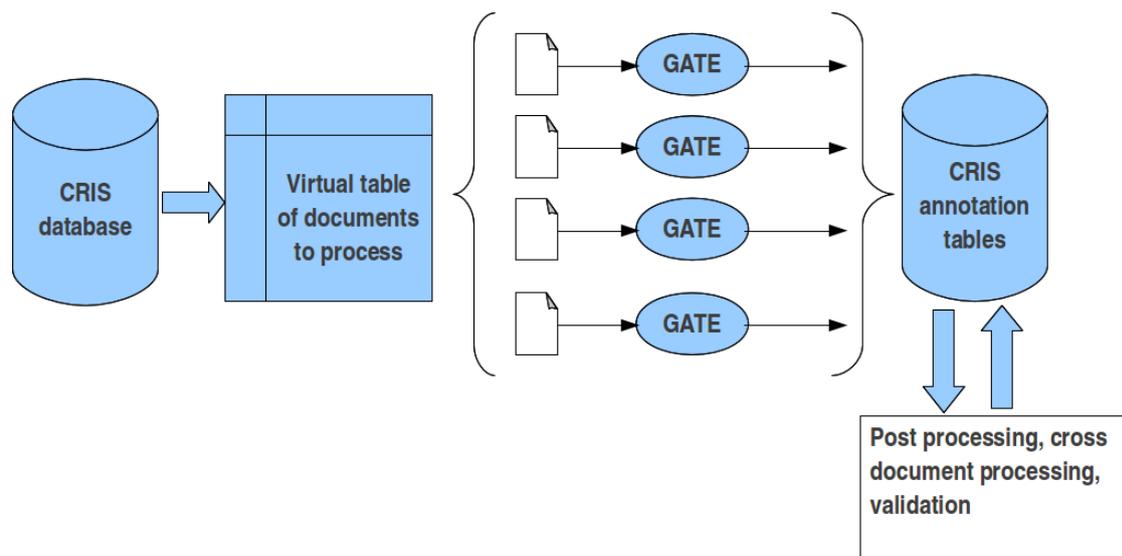
7.4 Veracity intelligence tools and visual dashboard

We will define and implement data exchange formats and protocols, in order to enable correlation of results extracted from social and news media against the patient records. For the purpose of the current use cases, near-real time analysis would be sufficient to start with, although in year 3, it would be useful if the monitoring dashboard gave early warnings as quickly as possible.

The PHEME veracity intelligence tools and visual dashboard will make the following provisions for:

1) Ways of rapidly identifying the origins and spread of suspected mis- and disinformation or controversy relevant to any of the demonstration studies (e.g. medication/treatment, legal highs).

2) Supporting the detection of unusual spikes/new trends on any of the four topics monitored by WP7.

3) Rapid assessment of emerging social media content, cross-referenced to news sources, where applicable.

4) Showing all available information regarding a source's trustworthiness and profile, as well as any previous relevant controversies or mis/disinformation spread by the same source.

5) Tracking and visualising aggregated opinions and sentiments towards any of the four topics of interest, as well as allow for drilling down into details at a site/user level (e.g. does this site/social media user regularly support self-harm).

6) Automatically identifying spam bots and flagging social media content created by these as untrustworthy.

7.5 Interface mock-up

The designing of the interface mock-up is not relevant in WP7 since the application will be built on the PHEME visual dashboard, to be designed in WP5. This report focused on the functionality of the application as detailed in each of the demonstration studies. In the near future, the requirements of WP7 will be assessed individually to establish the needs for data extraction and integration with the clinical records. The PHEME visual dashboard will therefore evolve based on ongoing processing and analysis.

8   Steps to Deliverable 7.2

The following tasks will be completed leading up to the development and submission of D7.2 in year 2.

8.1 Healthcare choices

1) Identification of controversial medication and treatments
2) Classification of social attitudes towards those treatments and statements of compliance/adherence and prescribing practices
3) Detection of news stories related to medication/treatment of interest
4) Establishment of clinical events and groups to explore

8.2 Legal Highs

1) Trial in detection of popular/controversial NPSs
2) Classification of positive and negative references with regards to use
3) Identification of clinical events and groups to explore

8.2 Mental health stigma

1) Identification of stigmatising statements
2) Classification of positive and negative sentiments surrounding particular diagnoses
3) Detection of news stories likely to facilitate stigmatising chatter in social media
4) Identification of clinical events and groups to explore

8.3 Self-harming and suicidal behaviour

1) Establishment of pro/against self-harm/suicide statements
2) Identification of news stories related to these behaviours
3) Definition of vulnerable clinical groups and clinical events of interest

Bibliography and references

Advisory Council on the Misuse of Drugs (ACMD). Consideration of the novel psychoactive substances ('legal highs') 2011.

Allebeck, P. The use of population based registers in psychiatric research. Acta Psychiatr Scand 2009; 120: 386–391.

Anderson, J. and Rainie, L. The Future of Big Data. Pew Internet Research (2012). http://www.pewinternet.org/Reports/2012/Future-of-Big-Data. Accessed on January 11th, 2013.

Backus, L.I. et al. Clinical Case Registries: Simultaneous Local and National Disease Registries for Population Quality Management J Am Med Inform Assoc 2009; 16(6): 775–783.

Becker, K.et al. Parasuicide online: Can suicide websites trigger suicidal behaviour in predisposed adolescents? Nord J Psychiatry 2004; 58: 111–114.

Byrne, P. Psychiatric stigma: past, passing and to come. J R Soc Med 1997;90: 618–620.

Byrne, P. Stigma of mental illness and ways of diminishing it. Adv Psychiatr Treat 2000; 6: 65-72.

Centres for Disease Control and Prevention (CDC). H1N1 Web and Social Media Metrics (2010). http://www.cdc.gov/metrics/campaigns/reports/h1n1-cumulative_report_01-31-10.pdf. Accessed on April 10th, 2014.

Clement, S. et al. What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. Psychol Med 2014; http://dx.doi.org/10.1017/S0033291714000129. Accessed on April 11th, 2014.

Corazza, O. et al. Designer drugs on the Internet: a phenomenon out-of-control? The emergence of hallucinogenic drug bromo-dragonfly. Curr Clin Pharmacol 2011; 6(2): 125-129.

Corrigan, P. et al. Prejudice, social distance, and familiarity with mental illness. SchizophrBull 2001; 27: 219-226.

Corrigan, P. How stigma interferes with mental health care. Am Psychol 2004; 59(7): 614-625.

Cunningham, H. GATE, a general architecture for text engineering. Comput Hum 2002; 36(2): 223–254.

Cunningham, H. Information Extraction, Automatic. In K. Brown, (Ed.) Encyclopedia of Language and Linguistics, 2nd Edition. Oxford: Elsevier. (2005).

Daine, K. The Power of the Web: A Systematic Review of Studies of the Influence of the Internet on Self-Harm and Suicide in Young People. PLoS One 2013; 8(10): 1-6. doi:10.1371/journal.pone.0077555. Accessed on April 11th 2014.

Davey, A. et al. e-Psychonauts: Conducting research in online drug forum communities. J Ment Health 2012; 21: 386-394.

Deluca, P. et al. Identifying emerging trends in recreational drug use; outcomes from the Psychonaut Web mapping Project. Prog Neuropsychopharmacol Biol Psychiatry 2012; 39: 221-226.

Dinos, S. et al. Stigma: the feelings and experiences of 46 people with mental illness. Br J Psych 2004; 184: 176-181.

EMCDDA. The state of the drugs problem in Europe- Annual report 2011. Lisbon, Portual: European Monitoring Centre for Drugs and Drug Addiction; 2011a.

EMCDDA. Report on the risk assessment of mephedrone in the framework of the Council decision on new psychoactive substances. Luxembourg: Publications Office of the European Union; 2011b.

EMCDDA. Europol 2011 Annual Report on the implementation of Council Decision 2005/387/JHA. Lisbon; April, 2012.

D7.1 / Requirements and design documents

Ennals, R. Trushkovsky, B. Agosta, J.M. Highlighting Disputed Claims on the Web (2010).

Hatch, S. et al. Identifying socio-demographic and socioeconomic determinants of health inequalities in a diverse London community: the South East London Community Health (SELCoH) study. BMC Public Health 2011; 11: 861.

Fox, S. The Social Life of Health Information, Pew Research Center (2011). http://www.pewinternet.org/2011/05/12/the-social-life-of-health-information-2011/. Accessed on April 10th, 2014.

Ginsberg, J. et al. Detecting influenza epidemics using search engine query data. Nature 2009; 457: 1012-1014.

Health Dialog. Know Your Source: Online Health Information Can Empower or Mislead (2011). http://www.healthdialog.com/Utility/News/PressRelease/11-01-11/Know_Your_Source_Online_Health_Information_Can_Empower_or_Mislead. Accessed on April 10th, 2014.

HPM Institute. Healthcare Performance Management in the Era of "Twitter", 2010.http://www.hpminstitute.org/documents/HPM_in_the_Era_of_Twitter.pdf. Accessed April 10th, 2014.

International Society for the Study of Self-injury (ISSS). About self-injury. http://www.isssweb.org/aboutnssi.php. Accessed on April 11th, 2014.

Jett, S. et al. Impact of exposure to pro-eating disorder websites on eating behaviour in college women. Eur Eat Disord Rev 2010; 18(5): 410-416.

Lenhart, A. Social media & young adults. Pew Internet Research (2010).

http://www.pewInternet.org/presentations/2010/Feb/Department-of-Commerce.aspx. Accessed on April 11th 2014.

Livingston, J.D. and Boyd, J. Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. Soc Sci Med 2010; 7: 2150-2161.

Max Bupa Health. Health on the internet, The Hindustan Times (2011). http://www.hindustantimes.com/business-news/businessbankinginsurance/health-on-the-internet/article1-653848.aspx. Accessed on April 11th, 2014.

Moran, P. et al. The natural history of self-harm from adolescence to young adulthood: a population-based cohort study. Lancet 2012; 379: 236–243.

Morden, N.E. et al. Quality of Care for Cardiometabolic Disease. Med Care 2010; 48(1): 72–78.

Mounteney, J. et al. Challenges of reliability and validity in the identification and monitoring of emerging drug trends. Subst Use Misuse 2010; 45(1-2): 266-287.

Parle, S. How does stigma affect people with mental illness. Nurs Times 2012; 108(28): 12-14.

Patton, G.C. et al. Global patterns of mortality in young people: a systematic analysis of population health data. Lancet 2009; 374: 881–892.

Perera, G. et al. The psychiatric case register: noble past, challenging present, but exciting future. Br J Psychiatry 2009; 195(3): 191–193.

Philo, G. Media and Mental Distress. New York: Addison Wesley Longman; 1996.

Walsh, B.W. Treating self-injury: A practical guide. New York, NY: GuilfordPress; 2006.

Welch, E.T. Self-injury: When pain feels good. Phillipsburg, NJ: P&R Publishing; 2004.

Whitlock, J. et al. The Internet and self-injury: What psychotherapists should know. J Clin Psychol. 2007; 63(11):1135-1143.

World Health Organisation: Psychiatric case registers. Report on a Working Group.Copenhagen: WHO Regional Office for Europe; 1983.

Appendices

Appendix 1.1   List of healthcare-related social media resources

Website/ Forum/ Blog	Primary search	Secondary search	Keyword search	Twitter/ FB
General/ All issues				
http://www.patient.co.uk/forums	Yes		patient forum	
http://www.patientslikeme.com/	Yes		patient forum	patientslikeme
http://www.thepatientforum.com/	Yes		patient forum	
http://www.medhelp.org/forums/list	Yes		patient forum	
http://www.mentalhealthforum.net/	Yes		mental health patient forum	
http://www.mentalhealth-world.org.uk/forums/	Yes		mental health patient forum	
http://www.sane.org.uk/what_we_do/support/supportforum/support_rooms	Yes		mental health patient forum	
http://www.psychforums.com/	Yes		mental health patient forum	
http://www.depressionforums.org/forums/	Yes		mental health patient forum	
http://forum.psychlinks.ca/	Yes		mental health patient forum	
http://www.healthyplace.com/forum/	Yes		mental health forum	
https://forums.psychcentral.com/	Yes		mental health forum	
http://www.recoveryourlife.com/forum/	Yes		mental health forum	
http://www.rethink.org/talk	Yes		mental health forum	
http://www.healthfulchat.org/all-chat-rooms.html	Yes		mental health forum	
http://www.medschat.com/forums.asp	Yes		medication forum	
http://www.takethislife.com/prescription-medication/	Yes		medication forum	
http://www.drugs.com/forum/	Yes		prescription drug forum	

Website/ Forum/ Blog	Primary search	Secondary search	Keyword search	Twitter/ FB
http://www.drugbuyersguide.net/	Yes		prescription drug forum	
http://www.iddb.org/forums/	Yes		prescription drug forum	
http://www.crazyboards.org/forums/	Yes		anxiety disorder forum	
http://www.mentalearth.com/	Yes		anxiety disorder forum	
http://www.beatingthebeast.com/forum/index.php?s=60b0a285c86c93e3bdc990f34c2efa9d&showforum=15	Yes		depression forum	
http://www.healthboards.com/boards/#mental-health-board	Yes		depression forum	
http://www.bluepeople.com/forumdisplay.php?f=222	Yes		depression forum	
http://www.mytherapycouch.com/forums/	Yes		bipolar disorder forum	
http://ehealthforum.com/health/health_forums.html	Yes		mental health patient forum	
http://www.christianforums.com/	Yes		mental health patient forum	
http://www.dailystrength.org/support-groups	Yes		mental health patient forum	
http://www.talkhealthpartnership.com/forum/viewforum.php?f=111	Yes		mental health patient forum	
http://www.caringonline.com/discussion/	Yes		eating disorders forum	
http://www.addforums.com/forums/	Yes		anxiety disorder forum	
http://www.minddisorders.com/forum/viewforum.php?f=1	Yes		personality disorder forum	
http://forum.psychlinks.ca/	Yes		personality disorder forum	

Anxiety disorders

Website/ Forum/ Blog	Primary search	Secondary search	Keyword search	Twitter/ FB
http://www.anxietyzone.com/	Yes		anxiety disorder forum	
http://anxietyforum.net/forum/forum.php?s=ef1b77247f332dc1f74eba89ce777c04	Yes		anxiety disorder forum	
http://www.socialanxietysupport.com/forum/	Yes		anxiety disorder forum	
http://www.nomorepanic.co.uk/forum/	Yes		anxiety disorder forum	

Website/ Forum/ Blog	Primary search	Secondary search	Keyword search	Twitter/ FB
http://www.gadforum.com/	Yes		anxiety disorder forum	
http://www.mdjunction.com/forums/anxiety-disorders-discussions	Yes		anxiety disorder forum	
http://www.socialphobiaworld.com/social-anxiety-disorder-forums/	Yes		anxiety disorder forum	
http://www.reddit.com/r/Anxiety	Yes		anxiety disorder forum	
http://www.social-anxiety-community.org/db/	Yes		anxiety disorder forum	
http://anxiety-panic-attacks-phobias.co.uk/index.php	Yes		anxiety disorder forum	
http://www.phobiasupport.org/forum/	Yes		anxiety disorder forum	
Mood disorders				
http://www.moodgarden.org/forum/	Yes		mood disorder forum	
http://mdao.v-cc.com/support/default.aspx	Yes		mood disorder forum	
http://www.dealingwithdepression.co.uk/forum.php	Yes		depression forum	
http://talk-depression.org/	Yes		depression forum	
http://www.depression-understood.org/forum/	Yes		depression forum	
http://www.reddit.com/r/depression	Yes		depression forum	
http://www.healingwell.com/community/?f=19	Yes		depression forum	
http://forum.discussdepression.org/	Yes		depression forum	
http://www.depressioncenter.net/	No	http://www.goodtherapy.org/blog/best-depression-resources-depression-websites-2012-0118137		
http://www.depression-understood.org/mainchat/mainchat.htm	No	http://www.goodtherapy.org/blog/best-depression-resources-depression-websites-2012-0118137		
http://www.dailystrength.org/c/Bipolar-Disorder/forum/Treatments	Yes		bipolar disorder forum	
http://www.bipolaruk.org.uk/e-community/	Yes		bipolar disorder forum	
http://forums.about.com/n/pfx/forum.aspx?folderId=4&listMode=13&nav=messages&webtag=ab-bipolar	Yes		bipolar disorder forum	
http://www.mdjunction.com/forums/bipolar-support-forums/medicine-treatments	Yes		bipolar disorder forum	

Website/ Forum/ Blog	Primary search	Secondary search	Keyword search	Twitter/ FB
http://www.bipolarsupport.org/modules.php?name=Forums&file=viewforum&f=24	Yes		bipolar disorder forum	
http://www.healingwell.com/community/?f=13	Yes		bipolar disorder forum	
http://www.pendulum.org/penduforum/	Yes		bipolar disorder forum	
http://www.reddit.com/r/bipolar/	Yes		bipolar disorder forum	
Psychotic disorders				
http://www.schizophrenia.com:8080/jiveforums/index.jspa?categoryID=1	Yes		schizophrenia forum	
http://schizophrenia-support.com/forum/index.php?PHPSESSID=b0d84737f5f5dc11160da73b3bfa13a8;board%3D6.0	Yes		schizophrenia forum	
http://mytherapy.com/discussion/forum.asp?FORUM_ID=179	Yes		psychosis support forum	
http://www.reddit.com/r/psychoticreddit	Yes		psychosis support forum	
Eating disorders				
http://www.b-eat.co.uk/get-help/online-community/young-people/forum/	Yes		eating disorders forum	
http://www.nationaleatingdisorders.org/forum	Yes		eating disorders forum	
http://www.nbp-eating-disorders.co.uk/forum/	Yes		eating disorders forum	
http://whyeat.net/forum/forum.php?s=c57861311ffe775a32b24a2d488c4030	Yes		eating disorders forum	
http://fishyvb.something-fishy.org/	Yes		eating disorders forum	
http://www.smartrecovery.org/community/forumdisplay.php?f=23#.Ux78-nBSi7I	Yes		eating disorders forum	
http://webiteback.com/forum/	Yes		eating disorders forum	
http://www.recoveryboat.com/forum/	Yes		eating disorders forum	@TheRecoveryBoat
http://www.uncommonforum.com/viewforum.php?f=29	Yes		eating disorders forum	

Website/ Forum/ Blog	Primary search	Secondary search	Keyword search	Twitter/ FB
http://www.healthyplace.com/forum/eating-disorders/	Yes		eating disorders forum	
http://eatingdisorder.org/forum/	Yes		eating disorders forum	
http://forum.bodybuilding.com/showthread.php?t=70778	Yes		eating disorders forum	
http://www.anad.org/forum/?phpMyAdmin=l7u%2CfyGNW2GDyPbCtffKcIuWeae	Yes		eating disorders forum	
http://www.virtualteen.org/forums/forumdisplay.php?f=15	Yes		eating disorders forum	
http://www.teenhelp.org/forums/f15-eating-disorders/	Yes		eating disorders forum	
https://healthunlocked.com/anorexiabulimiacare	Yes		eating disorders forum	
http://www.reddit.com/r/EatingDisorders	Yes		eating disorders forum	
http://mindsupport.co.uk/forumdisplay.php?f=26	Yes		eating disorders forum	
https://teenlineonline.org/boards/viewforum.php?f=12	Yes		eating disorders forum	
http://180degreehealth.com/180forums/forum/eating-disorders/	Yes		eating disorders forum	
http://www.soberrecovery.com/forums/eating-disorders/	Yes		eating disorders forum	
http://mengetedstoo.co.uk/community/go-to-forum	Yes		eating disorders forum	
http://www.cyberrecovery.net/forums/forumdisplay.php?f=13	Yes		eating disorders forum	
http://www.youreatopia.com/forums	Yes		eating disorders forum	
http://anorexics.net/forum/	Yes		eating disorders forum	
http://scaredeatingdisorders.yuku.com/	Yes		eating disorders forum	
http://blahtherapy.com/user-groups/eating-disorders/forum/	Yes		eating disorders forum	

Personality Disorders

http://outofthefog.net/forum/	Yes		personality disorder forum	

Website/ Forum/ Blog	Primary search	Secondary search	Keyword search	Twitter/ FB
http://ocpd.freeforums.org/	Yes		personality disorder forum	
http://schizotypal.freeforums.org/portal.php	Yes		personality disorder forum	
http://www.socialphobiaworld.com/avoidant-personality-disorder-forum/	Yes		personality disorder forum	
http://www.mdjunction.com/forums/obsessive-compulsive-personality-disorder-discussions	Yes		personality disorder forum	
http://www.anxietyzone.com/index.php?action=register	Yes		personality disorder forum	
Addictions				
http://www.drugs-forum.com/forum/forumdisplay.php?f=56	Yes		addiction forum	
http://www.addictionforum.co.uk/	Yes		addiction forum	
http://www.addictiontribe.com/member/_/P/L2ZvcnVtLw==	No	http://www.addictionforum.co.uk/	addiction forum	
http://www.addictionrecoveryguide.org/message_board/	No	http://www.addictionforum.co.uk/	addiction forum	
http://www.addictionsurvivors.org/vbulletin/	No	http://www.addictionforum.co.uk/	addiction forum	
http://www.cyberrecovery.net/forums/	No	http://www.addictionforum.co.uk/	addiction forum	
http://www.drugs.com/forum/general-discussion-boards/	Yes		addiction forum	
http://www.recoverynation.com/phpBB3/ucp.php?mode=login	Yes		addiction forum	
Physician-only networks				
http://www.medscape.com/connect	Yes		physician only network	
https://www.sermo.com/	Yes		physician only network	
http://doc2doc.bmj.com/	Yes		physician social network	
http://www.doctorshangout.com/	Yes		physician social network	
http://www.clinician1.com/	Yes		physician social network	
https://www.physpro.net/	Yes		physician professional network	

Website/ Forum/ Blog	Primary search	Secondary search	Keyword search	Twitter/ FB
https://www.doximity.com/	Yes		physician professional network	
http://about.doctors.net.uk/	Yes		physician professional network	
https://ozmosis.org/home	Yes		physician professional network	
https://www.doclynk.com/	Yes		doctors professional network	
http://www.doctorsrepublic.com/	Yes		doctors professional network	
http://www.newmediamedicine.com/forum/content/	No	http://digito.me/physician-social-networks/		
http://medicalnetwork.medicspeak.com/home.php	No	http://digito.me/physician-social-networks/		
http://www.imedexchange.com/	No	http://www.fiercehealthit.com/special-reports/6-physician-social-networks-glance		
http://www.orthomind.com/login	No	http://www.fiercehealthit.com/special-reports/6-physician-social-networks-glance		
http://www.themedicalpro.com/?utm_campaign=Listly&utm_medium=list&utm_source=listly	No	http://list.ly/list/11z-social-networking-sites-for-medical-professionals		
http://medicalnetwork.medicspeak.com/home.php	No	http://list.ly/list/11z-social-networking-sites-for-medical-professionals		
http://docglobal.com/home/	No	http://list.ly/list/11z-social-networking-sites-for-medical-professionals		
http://www.doctalkpanel.com/	No	http://list.ly/list/11z-social-networking-sites-for-medical-professionals		
https://secure.quantiamd.com/	No	http://www.healthecareers.com/article/top-5-social-media-sites-for-physicians/168490		

Appendix 1.2 List of psychotropic medication

Generic Name	Brand Name	Current Uses
acetophenazine	Tindal	schizophrenia (typical)
alprazolam	Xanax	anxiety, panic
amitriptyline	Elavil, Endep	depression (tricyclic)
amobarbital	Amytal	sleep agent
amoxapine	Asendin	psychotic depression
amphetamine	Adderall	ADD
amphetamine (extended release)	Adderall XR	ADD
aripiprazole	Abilify	schizophrenia (atypical)
atomoxetine	Strattera	ADD
buprenorphine	Butrans, Subutex	opiate dependence
buprenorphine and naloxone	Subutex, Suboxone	opiate dependence
bupropion	Wellbutrin, Aplezin, Zyban	depression, ADD
buspirone	BuSpar	anxiety
butabarbital	Butisol	sleep agent
carbamazepine	Tegretol	bipolar disorder
chloral hydrate	Chloral Hydrate	sleep agent
chlordiazepoxide	Librium	alcohol dependence, anxiety
chlorpromazine	Thorazine	schizophrenia (typical)
chlorprothixene	Taractin	schizophrenia (typical)
citalopram hydrobromide	Celexa	depression (SSRI)
clomipramine	Anafranil	OCD, depression (tricyclic)
clonazepam	Klonopin	anxiety
clorazepate dipotassium	Tranxene	anxiety
clozapine	Clozaril	schizophrenia (atypical)

Generic Name	Brand Name	Current Uses
desipramine	Norpramin	depression (tricyclic)
desvenlafaxine	Pristiq	depression (SNRI)
dexmethylphenidate	Focalin	ADD
dexmethylphenidate (extended release)	Focalin (XR)	ADD
dextroamphetamine	Dexedrine, Dexstrotat	ADD
diazepam	Valium	anxiety
diphenhydramine	Benadryl	sleep agent
disulfiram	Antabuse	alcohol abuse/dependence
divalproex sodium (valproic acid)	Depakote	bipolar disorder
donepezil	Aricept	dementia
doxepin	Adapin, Sinequan	depression (tricyclic)
duloxetine	Cymbalta	depression (SNRI)
escitalopram	Lexapro	depression (SSRI), anxiety
estazolam	Prosom	anxiety
eszopiclone	Lunesta	sleep agent
ethchlorvynol	Placidyl	sleep agent
fluoxetine	Prozac, Sarafem	depression (SSRI), OCD, panic
fluphenazine	Prolixin, Prolixin Decanoate	schizophrenia (typical)
flurazepam	Dalmane	anxiety
fluvoxamine	Luvox	OCD, depression (SSRI)
gabapentin	Neurontin	epilepsy
galantamine	Reminyl, Razadine	dementia
glutethimide	Doriden	sleep agent
guanfacine	Intuniv	ADD
halazepam	Paxipam	anxiety
haloperidol	Haldol, Haldol Decanoate	schizophrenia (typical)

Generic Name	Brand Name	Current Uses
hydroxyzine	Atarax, Vistaril	anxiety
iloperidone	Fanapt	schizophrenia (atypical)
imipramine	Tofranil	depression (tricyclic), panic
imipramine pamoate	Tofranil-PM	depression (tricyclic), panic
isocarboxazid	Marplan	depression (MAOI)
lamotrigine	Lamictal	epilepsy
lisdexamfetamine dimesylate	Vyanse	ADD
lithium carbonate	Eskalith, Lithobid	bipolar disorder
lithium citrate	Cibalith S	bipolar disorder
lorazepam	Ativan	anxiety
loxapine	Loxitane	schizophrenia (typical)
lurasidone	Latuda	schizophrenia (atypical)
maprotiline	Ludiomil	depression (tricyclic)
memantine	Namenda	dementia
meprobamate	Miltown	sleep agent
mesoridazine	Serentil	schizophrenia (typical)
methadone	Dolophine	opiate dependence
methamphetamine	Desoxyn	ADD
methprylon	Noludar	sleep agent
methylphenidate	Ritalin, Concerta	ADD
methylphenidate (extended release)	Metadate CD, Metadate ER, Ritalin SE	ADD
methylphenidate (long acting)	Ritalin LA, Concerta	ADD
methylphenidate (oral solution and chewable tablets)	Methylin	ADD
methylphenidate patch	Daytrana	ADD
mirtazapine	Remeron	depression
molindone	Moban	schizophrenia (typical)

Generic Name	Brand Name	Current Uses
naloxone	Narcan	opiate dependence
naltrexone	Vivitrol	opiate dependence
nefazodone	Serzone	depression
nortriptyline	Pamelor, Aventyl	depression (tricyclic)
olanzapine	Zyprexa	schizophrenia (atypical)
olanzapine and fluoxetine	Symbyax	schizophrenia and depression
oxazepam	Serax	anxiety
oxcarbazepine	Trileptal	epilepsy
paliperidone	Invega	schizophrenia (atypical)
paroxetine	Paxil	depression (SSRI), OCD, panic
paroxetine mesylate	Pexeva	depression (SSRI), OCD, panic
pemoline	Cylert	ADD
pentobarbital	Nembutal	sleep agent
perphenazine	Trilafon	schizophrenia (typical)
phenelzine	Nardil	depression (MAOI)
phenobarbital	Phenobarbital	sleep agent
pimozide	Orap	Tourette's syndrome
prazepam	Centrax	anxiety
prochlorperazine	Compazine	schizophrenia (typical)
promazine	Sparine	schizophrenia (typical)
propanolol	Inderal	anxiety, panic
protriptyline	Vivactil	depression (tricyclic)
quazepam	Doral	anxiety
quetiapine	Seroquel	schizophrenia (atypical)
quetiapine (extended release)	Seroquel XR	schizophrenia (atypical)
ramelteon	Rozerem	sleep agent

Generic Name	Brand Name	Current Uses
risperidone	Risperdal	schizophrenia (atypical)
rivastigmite	Exelon	dementia
secobarbital	Tuinal	sleep agent
selegiline transdermal	Emsam (patch)	depression, dementia
selegiline	Anipryl, L-deprenyl, Eldepryl, Emsam, Zelapar	depression, dementia
sertraline	Zoloft	depression (SSRI), OCD, panic
tacrine	Cognex	dementia
temazepam	Restoril	sleep agent
thioridazine	Mellaril	schizophrenia (typical)
thiothixene	Navane	schizophrenia (typical)
tiagabine	Gabitril	epilepsy
topiramate	Topimax	epilepsy
tranylcypromine sulfate	Parnate, Jatrosom	depression (MAOI)
trazodone	Desyrel	depression (tricyclic)
triazolam	Halcion	sleep agent
trifluoperazine	Stelazine, Vesprin	schizophrenia (typical)
triflupromazine	Vesprin	schizophrenia (typical)
trimipramine	Surmontil	depression (tricyclic)
venlafaxine	Effexor	depression (SNRI)
zaleplon	Sonata	sleep agent
ziprasidone	Geodon	schizophrenia (atypical), bipolar
zolpidem	Ambien	sleep agent

Appendix 1.3   Slang terms for common psychotropic medication

Barbiturates: Barbs, reds, redbirds, phennies, tooies, yellows, yellowjackets

Benzodiazepines: Candy, downers, sleepingpills, tranks, totempoles, chillpills, french-fries, tranqs, blues, z-bar, bricks, benzos

Sleep agents: a-minus, zombiepills

Stimulants: Skippy, thesmartdrug, vitamin, bennies, blackbeauties, roses, hearts, speed, uppers, kiddycocaine, westcoast, crosses, laturnaround, truckdrivers, beans, christmastrees, doubletrouble, rid, jif, r-ball, rittys, rits

Appendix 2.2   List of NPS-related social media resources

Website/ Forum/ Blog	Primary search	Secondary search	Keyword search	Twitter/ FB
http://www.drugscience.org.uk/	Yes		new legal drugs	@ProfDavidNutt
http://www.talktofrank.com/	Yes		new legal drugs	No
http://www.legalhighsforum.com/index.php	Yes		new legal drugs	No
http://www.legaldrugreviews.com/	Yes		new legal drugs	No
http://knowthescore.info/	Yes		new legal drugs	No
http://www.legalhighslethallows.co.uk/	Yes		new legal drugs	No
http://www.whynotfindout.org/	No	http://www.legalhighslethallows.co.uk/		@whynotfindout
http://www.substance.org.uk/Default.aspx	Yes		new legal drugs	No
http://www.drugs-forum.com/forum/index.php	Yes		new legal drugs	@drugsforum
http://drinkanddrugsnews.com/	Yes		new legal drugs	@DDNMagazine
http://legalhighsblog.net/	Yes		legal highs	@legalhighsblog/ https://en-gb.facebook.com/legalhighsblog
http://www.ukresearchchemicals.co.uk/	Yes		new psychoactive substances	@Ukresearchchems/ https://www.facebook.com/ukresearchchemicals
http://novelpsychs.wordpress.com/	Yes		new psychoactive substances	No
http://www.partyvibe.org/forums/drugs/	Yes		drug forum	No
http://www.reddit.com/r/Drugs	Yes		drug forum	No
http://www.bluelight.org/vb/forum.php	Yes		drug forum	@BluelightForum
https://www.erowid.org/	No	http://motherboard.vice.com/blog/in-a-world-of-opiate-addicts-the-internet-plays-doctor-and-therapist		@vaultsoferowid @Erowid

Website/ Forum/ Blog	Primary search	Secondary search	Keyword search	Twitter/ FB
http://www.uklegalhighs.co.uk/	Yes		where to buy legal highs	@UKLegalHighs / https://www.facebook.com/uklegalhighs
http://www.chemsrus.com	Yes		where to buy legal highs	@ChemsRUs
http://www.neorganics.net/	No	Psychonaut		No
http://www.wedinos.org/	No	Twitter		@WEDINOSproject
http://www.ukchemicalresearch.org/	No	Twitter		@UKCRofficial
http://www.angelusfoundation.com/	Yes		legal highs	@Angelustweets
Vendors				
http://www.iceheadshop.co.uk/	Yes		where to buy legal highs	No
http://www.iamlegallyhigh.com/	Yes		where to buy legal highs	No
http://www.buymadcat.com/	Yes		where to buy legal highs	No
http://www.coffeesh0p.com/legal-highs/	Yes		where to buy legal highs	No
http://am-hi-co.co.uk/	Yes		where to buy legal highs	No
http://www.herbalhighs.co.uk/	Yes		where to buy legal highs	No
http://www.alternativemind.co.uk/	Yes		where to buy legal highs	No
http://www.smokeysams.co.uk/	Yes		where to buy legal highs	No
http://www.alibongo.co.uk/catalog/index.php?area=home	Yes		where to buy legal highs	@AliBongoNorwich
http://www.ukhighs.com/shopping/mall/ukhighs/Webpage/551	Yes		where to buy legal highs	No
http://www.buychargepowder.com/	Yes		where to buy legal highs	No
http://www.sensibleseeds.com/legal-highs/	Yes		where to buy legal highs	No
http://cactuscandy.co/	Yes		where to buy legal highs	No
http://www.herbaleye.co.uk/	Yes		where to buy legal highs	No
http://www.herbal-highs.com/	Yes		where to buy legal highs	No

Website/ Forum/ Blog	Primary search	Secondary search	Keyword search	Twitter/ FB
http://herbalaromas.co.uk/	Yes		where to buy legal highs	No
http://www.essencegifts.co.uk/	Yes		where to buy legal highs	No
http://www.mysteriousplants.com/	Yes		where to buy legal highs	No
http://www.eurostarhigh.net/	Yes		where to buy legal highs	No
http://www.officialbenzofury.com/	No	http://www.chemsrus.com		No
http://www.cloud9chemicals.com/	No	http://www.chemsrus.com		@cloud9chemicals
http://www.purechemicals.net/	No	http://www.chemsrus.com		No
http://www.buyanychem.com/	No	http://www.chemsrus.com		No
http://vip-legals.com/	No	http://www.chemsrus.com		No
http://tkkchems.com/	No	http://www.chemsrus.com		No
http://www.herbal-spice-666.co.uk/	Yes		where to buy legal highs	No
http://www.londonundergroundpills.com/	Yes		where to buy legal highs	https://www.facebook.com/LULegalHighs
http://www.legalhighsstore.co.uk/	Yes		where to buy legal highs	No
http://salviaonline.co.uk/	Yes		where to buy legal highs	No
http://www.legalhighs-4u.com	Yes		where to buy legal highs	No
http://www.smokersheavenshop.co.uk/home.php	Yes		where to buy legal highs	No
http://www.redeyefrog.co.uk/	Yes		where to buy legal highs	No
http://www.legal-highs.co.uk/	Yes		legal drug shop	No
http://legaldrugshop.com/en/	Yes		legal drug shop	@LegalDrugShop
http://herbal-highs-shop.com/	Yes		legal drug shop	No
http://www.shayanashop.com/	Yes		legal drug shop	No
http://partyherbals.co.uk/	Yes		legal drug shop	No
http://www.monstersmokeshop.com/	Yes		legal drug shop	No
			legal drug shop	No

Twitter/ FB

@ResearchChemUK	Yes
@EMCDDA	Yes
@HighsInfo	Yes
@Drugscom	Yes
@UK_Highs	Yes
@ProfDavidNutt	No
@whynotfindout	No
@drugsforum	No
@DDNMagazine	No
@legalhighsblog/ https://en-gb.facebook.com/legalhighsblog	No
@Ukresearchchems/ https://www.facebook.com/ukresearchchemicals	No
@BluelightForum	No
@vaultsoferowid @Erowid	No
@UKLegalHighs / https://www.facebook.com/uklegalhighs / g+	No
@ChemsRUs	No
@WEDINOSproject	No
@UKCRofficial	No
@Angelustweets	No
@AliBongoNorwich	No
@cloud9chemicals	No
https://www.facebook.com/LULegalHighs	No
LegalDrugShop	No

Appendix 2.2   List of slang names associated with NPSs

methoxetamine: MXE, M-ket, MEX, Kmax, Special M, MA, legal ketamine, Minx, Jipper, Roflcoptr, Kwasqik, Hypnotic, Panoramix, Magic, Lotus, X.

mephedrone: miaow miaow, meow meow, plant feeder, plant food, bubbles, blow, Subcoca-1, Tornado, Real Euphoria, top cat, Krabba, 4-MMC, MCAT, drone, meph, rush, kitty cat

synthetic cannabis: spice, spice silver, spice gold, spice diamond, Bliss, Black Mamba, Bombay Blue, Blaze, Genie, Spice, Zohai, JWH -018, -073, -250, Yucatan Fire, Skunk, Moon Rocks, K2, Red X Dawn, Fake Weed.

dimethylamylamine: DMAA, Geranamine, Forthane

Appendix 3   List of self-harm/suicide-related social media resources

Website/ Forum/ Blog	Primary search	Secondary search	Keyword search
Self-harm			
http://pro-cutting.webs.com/apps/forums/	Yes		Pro self-harm
http://www.myproana.com/index.php/forum/24-self-injury-self-harm/	Yes		Pro self-harm
http://icut.livejournal.com/profile	Yes		Pro self-harm
http://pro-si.livejournal.com/	Yes		Pro self-harm
http://bstrawberrygashed.runboard.com/	Yes		Pro self-harm
Suicide			
https://groups.google.com/forum/#!forum/alt.suicide.holiday	No	http://ash2.wikkii.com/wiki/Links	
https://groups.google.com/forum/#!forum/alt.suicide.methods	No	http://ash2.wikkii.com/wiki/Links	
http://www.dyingpictures.com/forums/	Yes		pro suicide forum
http://www.reddit.com/r/ASHTheResurrection/	Yes		suicide methods
http://archive.ashspace.org/ash.xanthia.com/ashnazg.html?	Yes (archived material)		pro suicide forum
http://peacefulpillforums.com/index.php?/calendar/	Yes		suicide methods
http://www.dyingpictures.com/forums/viewforum.php?f=10&sid=9bd28508a8ec7e86536ef3271e7159be	Yes		suicide buddies
http://assisted-dying.org/blog/	Yes		suicide buddies