Review Article

Healthc Inform Res. 2015 April;21(2):67-73.
http://dx.doi.org/10.4258/hir.2015.21.2.67
pISSN 2093-3681 • eISSN 2093-369X

HIR
Healthcare Informatics Research

Health and Social Media: Perfect Storm of Information

Luis Fernández-Luque, PhD[1], Teresa Bau, BJ[2]

[1]Northern Research Institute, Tromso, Norway; [2]Mobile Health Global, Barcelona, Spain

Objectives: The use of Internet in the health domain is becoming a major worldwide trend. Millions of citizens are searching online health information and also publishing content about their health. Patients are engaging with other patients in online communities using different types of social media. The boundaries between mobile health, social media, wearable, games, and big data are becoming blurrier due the integration of all those technologies. In this paper we provide an overview of the major research challenges with the area of health social media. **Methods:** We use several study cases to exemplify the current trends and highlight future research challenges. **Results:** Internet is exploding and is being used for health purposes by a great deal of the population. Social networks have a powerful influence in health decisions. Given the lack of knowledge on the use of health social media, there is a need for complex multidisciplinary research to help us understand how to use social networks in favour of public health. A bigger understanding of social media will give health authorities new tools to help decision-making at global, national, local, and corporate level. **Conclusions:** There is an unprecedented amount of data that can be used in public health due the potential combination of data acquired from mobile phones, Electronic Health Records, social media, and other sources. To identify meaningful information from those data sources it is not trial. Moreover, new analytics tools will need to be developed to analyse those sources of data in a way that it can benefit healthcare professionals and authorities.

Keywords: eHealth, Mobile Health, Health Social Media, Social Networks, Patients, Public Health Informatics, Public Health, Health Communication

I. Introduction

Internet and social media are becoming new tools to look for health information. Internet use grows year after year. According to the Measuring the Information Society Report 2014 by the International Telecommunication Union [1], nearly 3,000 million people use the Internet, which is more than 40% of the world's population (7,200 million).

Mobile phone penetration is even more spectacular. There are almost as many mobile-cellular subscriptions (6.9 billion) as people on Earth, more than three quarters of them (5.4 billion) in the developing world, and more than half (3.6 billion) in the Asia-Pacific region. We use the mobile phone so much that it might bring medical consequences. A study

Submitted: March 30, 2015
Accepted: April 21, 2015

Corresponding Author
Luis Fernández Luque, PhD
Northern Research Institute, Tromso Science Park, Sykehusvn 21, Tromso, Norway. Tel: +47-934-21-287, Fax: +47-776-29-401, E-mail: luis.luque@norut.no

This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (http://creativecommons.org/licenses/by-nc/4.0/) which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

ⓒ 2015 The Korean Society of Medical Informatics

published by The Lancet described "WhatsAppitis" [2] as the wrist pain a young women had as a result of sending messages on their phones.

The widespread use of mobile phones has resulted in higher access to the Internet through these devices. In 2014, mobile broadband had a penetration of 32%—four times the penetration rate recorded in 2009. The growth is driven by the availability of cheaper smartphones and the variety of types of plans on offer in the market. In South Korea, Internet penetration is very high; 82.1% of the population goes online according to the Korea Internet & Security Agency [3]. This percentage includes people older than three years old that who have used the Internet at least once in the last month. Also, 94.6% of the population used a mobile phone in 2013.

The rising penetration rate of smartphones all over the world opens new possibilities in healthcare. Accessing information, gathering health data and contacting health professionals are some of the promising opportunities that these devices offer. This is not just a small trend, but mobile health (mHealth) has widened acceptance by the public. It is estimated that there are 100,000 mHealth applications [4], but not all of them have the necessary quality [5,6]. There is currently an intense debate about the need to regulate mHealth applications. There is a call by the sector to establish quality control mechanisms to guarantee patients' safety. However, there have been some warnings about the danger of over-regulation. The European Commission [7] recently published a report that gathers the views and actions suggested by stakeholders of the field following a public consultation.

1. Use of the Internet to Search for Health-Related Information

According to the European citizen's digital health literacy report published in September 2014 [8], 59% of European citizens used the Internet to look for health information in 2014. Fifty-five percent looked for general information, 54% looked for information on a specific condition, 23% looked for specific information on a treatment, and 10% used the net to get a second opinion after visiting their doctor. Between 82% and 87% of people (depending on the type of information searched) who searched for health-related information used searches engines. The second source of information (47%–48%) was specific and dedicated websites (blogs and forums), while between 33% and 38% looked for information from official health websites, such as those of the Ministry of Health or the World Health Organization (WHO). Online newspapers or magazines (20%–26%) and social networks (16%–23%) come next, followed by health mobile apps (13%–17%) and patient organization websites (13%–17%).

2. Social Media: Same Networks Everywhere

Social media use is on the rise. Facebook is the most used social network in the world [9], followed by YouTube. Curiously, the same social networks are used in extremely different countries. For example, the leading social network in South Korea is YouTube, followed by Facebook. In Nigeria (Africa), Facebook, followed by YouTube and Twitter are the most popular.

Healthcare organizations are slowly starting to use social media. More and more hospitals, medical professionals, and health authorities have opened accounts in YouTube, Facebook, and Twitter to reach their potential clients. According to a study published by the Journal of Medical Internet Research [10], nearly 95% of US hospitals are on Facebook, while only 50% have a Twitter account.

In Western Europe, the use of social media by hospitals is also growing but there are significant differences between countries. A study published in the Journal of Medical Internet Research [11] shows how its use remains small, except for the Netherlands and the United Kingdom. Nevertheless, it grew from 2009 to 2011 in networks such as Facebook (from 10% to 67%), LinkedIn (from 20% to 31%), and YouTube (from 2% to 19%).

3. e-Patients, Prime Actors in Health 2.0

How do we define Health 2.0? Many concepts explain the use of Health 2.0 in healthcare: Health 2.0, Medicine 2.0, Health Social Media, eHealth, mHealth. There is not a clear consensus between academics. The study "Definition of Health 2.0 and Medicine 2.0: a systematic review" [12] shows that this is a developing area, and there is not a consensus on its definition. Some of the concepts that include Health 2.0 are Apomediation [13], Participation, Openness, and Collaboration. Apomediation, a term coined by Dr. Gunther Eysenbach, a Health Policy and eHealth professor at the University of Toronto, describes the fact that when a user accesses information on the Internet, he/she cuts out the gatekeepers (like the primary care doctor) and goes directly to the relevant source of information.

In the last years, patients have become the main actors of Health 2.0, leading a true revolution in healthcare management. e-Patients (#ePatients) achieve better health outcomes thanks to being connected and sharing experiences in social networks; previously, their health depended solely on their doctors' capacity. ePatients like Dave deBronkart (@ePatientDave), Jan Geissler (@JanGeissler), and Andrew Schorr (@AndrewSchorr) overcame their cancer because they went

 http://dx.doi.org/10.4258/hir.2015.21.2.67

online and connected with peer patients who told them about new treatments or clinical essays for their conditions.

In addition to patients' activism, Health 2.0 also includes the online activity of medical professionals (peer-to-peer), Electronic Health Records, eLearning, online medical publications (Peer Review 2.0), and Science 2.0.

II. Study Cases in Health 2.0: Diabetes, Anorexia, Vaccination, and Ebola

In this section we will explain how Health 2.0 is shaping the health domain using four study cases. First of all, we will explain the role of Health 2.0 in diabetes management as a prime example of a chronic condition. Then, we will focus on the case of an eating disorder, specifically, pro-anorexia (the promotion of anorexia as a lifestyle). The third case study will focus on the use of social media for vaccination communication. Finally, we will address the role of social media in the Ebola crisis.

1. Diabetes and Social Media

1) Expert e-Patients in diabetes

Online communities of patients are very common in diabetes. In these networks people affected with diabetes share their experiences and also find emotional support from peers. These networks can be extremely large with dozens of thousands members and fairly complex networks. Chomutare et al. [14] studied the dynamics of online communities of diabetes patients, and they found that the most centric members (those with more trust within the communities) tend to have more years of experience with disease. Many of these patients have become experts in their disease and provide a great amount of valuable information for their peers. The study by Chomutare et al. [14] shows that the most experienced patients—those who have been living longer with the disease—tend to be leaders in the community. Similarly, a study published in the BMJ [15] found that patients with cancer could be also effective in controlling the quality of health information, thus highlighting the importance of experienced patients in the control of online health information. By contrast, seals of quality that started to proliferate a few years ago do not guarantee the veracity of the information published, as stated in a study by the American Cancer Society [16] about quality criteria in online information about breast cancer.

Online communities of patients can also collaborate with researchers using social media. In TuAnalyze [17], a joint initiative between TuDiabetes and Boston Children's Hospital, diabetes patients can monitor, evaluate, and share their health data, while they are participating in a research on diabetes and social media (Figure 1). Their data is analysed to determine a correlation between people's participation in

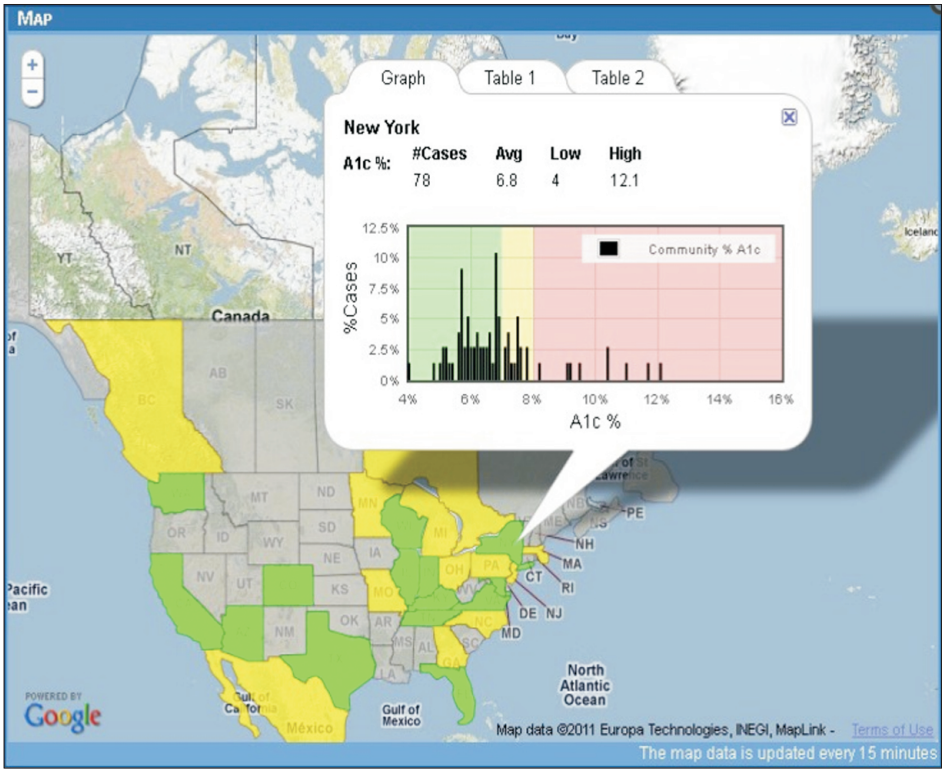

Figure 1. Contextualized map with data of diabetics in the TuAnalyze application [18].

health social networking and level of diabetes management.

2) The boom of mobile applications for diabetes

There is a wide range of mobile applications to help diabetes patients (347 million people [19]) manage their condition. These tools allow them to monitor their glucose level, weight, and other data; share them; and get motivated to lead a healthy life.

Although there is not enough clinical evidence about their efficacy, mobile health tools will probably become essential in diabetes and the management of other diseases. Many interesting initiatives have been created to help patients control their condition through their mobile phones, such as Diabetes Diary [20] and Big Blue Test [21].

According to a study by Research2Guidance [22], there are more than 1,100 apps (iOs and Android) to manage diabetes. Despite the vast number of applications, their quality has been put into question in many studies (e.g., see Chomutare et al. [6]). Researchers have pointed out that most applications do not offer enough educational features and lack social media tools. There have been studies on cancer apps too, and the results show that they also need significant improvement [5].

Physical activity is very important for diabetes self-management. The use of wearable devices that monitor physical activity and gather vital data has also grown in recent years, and they are popular among patients with diabetes. A few studies about the medical applications [23], calibration, and validation of wearable devices [24] have been done. Studies have shown that the development of wearable systems targeting specific clinical applications has potential in healthcare (Figure 2).

This new wide range of tools to store health data raises major questions regarding their integration into the healthcare system, the need for mass storage systems, and the privacy of users' data. The big challenge is to find a way to access this knowledge while respecting people's privacy.

Figure 2. Example of application to manage diabetes [25].

2. Anorexia: the Power of Misinformation

It is striking that such a serious health problem as anorexia has an army of activists that defend this disease as a lifestyle. Pro-anorexia activists (the so-called Pro-Ana) are very visible in social networks, especially YouTube and Flickr, where image is predominant. They have even created mobile applications that defend their 'lifestyle' (Thinspo [26], currently available in Google Play).

On YouTube, one can easily stumble across pro-anorexia videos when looking for health information on eating disorders. The study [27] shows that pro-anorexia videos are better rated and more highly favoured than videos with serious information about eating disorders. Anorexia activists use the same tags as reliable health videos, and their websites sometimes rank higher in YouTube or Google. This happens because of the way searching engine algorithms are designed, according to researchers.

A study [28] shows the high level of interaction between pro-anorexia and pro-recovery communities in social networks (Figure 3). Findings suggest that clinicians need to be aware of pro-anorexia contents online and focus on new intervention methods, possibly tailored to individual characteristics.

3. Anti-vaccination, a Dangerous Movement on the Net

Over decades, vaccines have saved millions of lives and have helped to eradicate numerous diseases. Nevertheless, there is still a strong anti-vaccination movement (it has existed since vaccines were invented more than 200 years ago), which in recent years, has moved its campaign to social networks. Their activists are very good at manipulating information and spreading rumours that question vaccine efficacy and safety.

"With ever increasing access to internet-based information, an unsubstantiated rumour about vaccines can rapidly circle the globe and undermine immunization services, sparking outbreaks of disease and untold deaths" stated WHO, UNICEF, and World Bank in 2010.

Various studies have analysed the influence of the anti-vaccination movement in social networks and in vaccination decisions [29] or on the public trust in vaccines [30]. Some anti-vaccination websites, such as the National Vaccine Information Center [31], look absolutely credible and can easily trick users into questioning vaccines safety.

Research has shown that anti-vaccination contents are more popular in social networks than validated vaccination

 http://dx.doi.org/10.4258/hir.2015.21.2.67

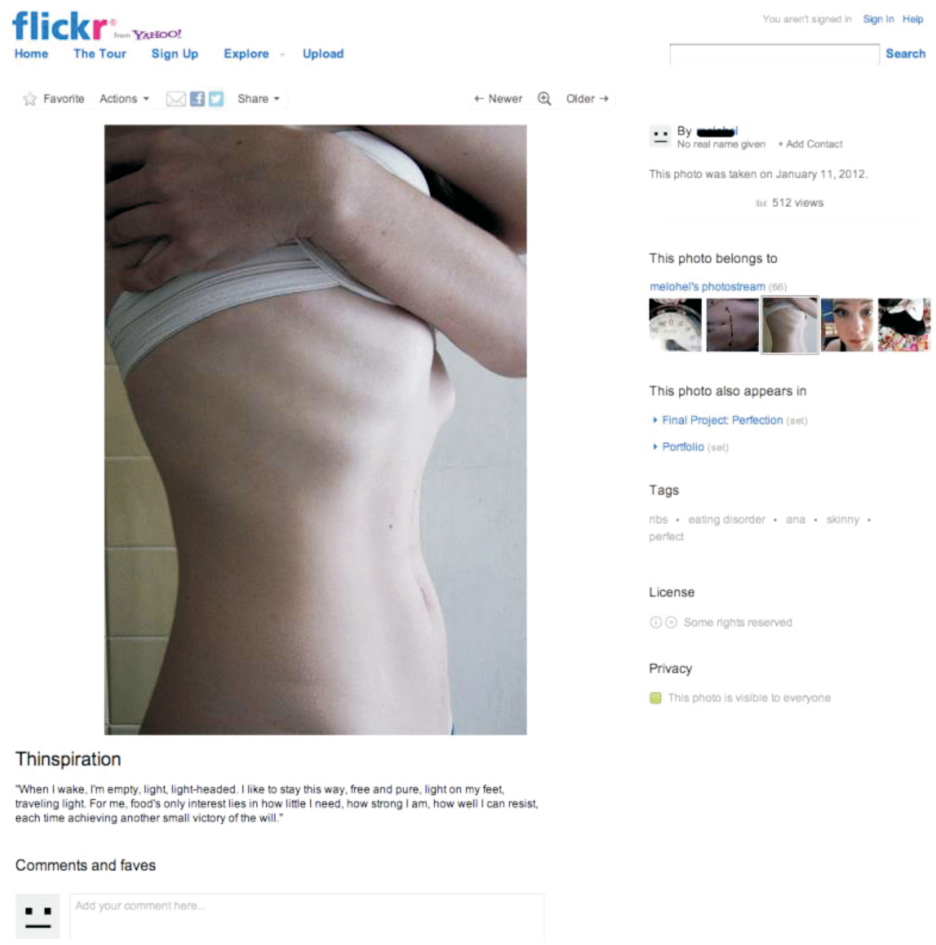

Figure 3. Example of a pro-anorexia image on Flickr [28].

contents. The study [32] analysed 172 YouTube videos about the HPV vaccine. Most videos (news clips or consumer generated content) were negative in tone, disapproving of the vaccine. Also, negative videos were liked more by viewers than positive ones.

Another study [33] analysed vaccination search and concluded that previous attitudes towards vaccination will influence the results of a search; trusted health websites often use different vocabulary than those with concerns about vaccination; search behaviour needs to be considered in online public health interventions.

On the other hand, the study [34] showed that there is a correlation between the sentiments expressed in social networks towards a new vaccine and the vaccination rates in a region.

Recently, the Vaccine Confidence Project [35] was created to monitor people's trust in vaccination through social networks, given the importance that these tools have in vaccination decisions. The London School of Hygiene and Tropical Medicine leads the project with the support of prestigious health organizations [36], such as the Bill & Melinda Gates Foundation and the World Health Organization.

4. Ebola: How Panic Spreads through Social Media

The recent Ebola outbreak in Western Africa is another good example of the power of social networks in influencing people's behaviour. The news of the epidemic created a climate of global nervousness with rumours and misinformation quickly spreading through social networks. The outbreak was first detected by HealthMap [37], a website that delivers real-time data on infectious diseases for health institutions and governments.

The role that social networks have played in the spread of rumours about Ebola has been analysed in several studies. The British Medical Journal published an article [38] that evaluated tweets regarding the outbreak emitted from African countries. The researchers concluded that most of the messages had false information and that 'bad' tweets were more retweeted than the ones with truthful information.

Social networks also helped spread rumours about fake treatments; some of them even making the general news. Similarly, fake news stories were also spread by SMS and WhatsApp messages.

At the same time, mobile technologies can be a useful tool to control and contain epidemics, as some experts pointed

out during the Ebola crisis. SMS is an instantaneous, interactive, and cheap tool that can reach a great number of people. Through mobile phones, the population can get informative messages on prevention, control, and treatment. A few initiatives of this type have already been deployed in the Ebola outbreak [39].

III. Conclusion

As we have seen, the Internet is rapidly expanding and is being used for health purposes by a great number of people. Social networks have a powerful influence in health decisions. Sometimes they help spread rumours and fake information and can undermine public health policies.

Given the lack of knowledge on the use of health social media, there is a need for complex multidisciplinary research (mathematical, computer science, sociology, health, communication, etc.) to help us understand how to use social networks to support public health. A better understanding of social media will give health authorities new tools to help decision-making at global, national, local, and corporate levels.

Data analytics will become a major aspect of future research. For example, epidemiology is gradually becoming a discipline in which digital sources of information are becoming more important, and this has led to the creation of the sub-discipline of digital epidemiology [40]. There is an unprecedented amount of data that can be used in public health due the potential combination of data acquired from mobile phones, electronic health records, social media and other sources. However, to identify meaningful information from those data sources it is not trivial. Moreover, new analytics tools need to be developed to analyse those sources of data in a way that can benefit healthcare professionals and authorities.

Conflict of Interest

No potential conflict of interest relevant to this article was reported.

Acknowledgments

Special thanks to José M. Sánchez Parrado for his collaboration reviewing this article.

References

1. International Telecommunication Union. Measuring the Information Society Report 2014. Geneva: International Telecommunication Union; 2014.
2. Fernandez-Guerrero IM. "WhatsAppitis". Lancet 2014; 383(9922):1040.
3. Korea Internet & Security Agency. 2013 Survey on the Internet usage [Internet]. Seoul: Korea Internet & Security Agency; c2015 [cited at 2015 Apr 15]. Available from: http://isis.kisa.or.kr.
4. Research2Guidance. Mobile health economics [Internet]. Berlin: Research2Guidance; c2014 [cited at 2015 Apr 15]. Available from: http://mhealtheconomics.com.
5. Bender JL, Yue RY, To MJ, Deacken L, Jadad AR. A lot of action, but not in the right direction: systematic review and content analysis of smartphone applications for the prevention, detection, and management of cancer. J Med Internet Res 2013;15(12):e287.
6. Chomutare T, Fernandez-Luque L, Arsand E, Hartvigsen G. Features of mobile diabetes applications: review of the literature and analysis of current applications compared against evidence-based guidelines. J Med Internet Res 2011;13(3):e65.
7. European Commission. Summary report on the public consultation on the green paper on mobile health. Brussels: European Commission; 2015.
8. European Commission. European citizen's digital health literacy. Brussels: European Commission; 2014.
9. Alexa. The top 500 sites on the web [Internet]. San Francisco (CA): Alexa; c2015 [cited at 2015 Apr 15]. Available from: http://www.alexa.com/topsites.
10. Griffis HM, Kilaru AS, Werner RM, Asch DA, Hershey JC, Hill S, et al. Use of social media across US hospitals: descriptive analysis of adoption and utilization. J Med Internet Res 2014;16(11):e264.
11. Van de Belt TH, Berben SA, Samsom M, Engelen LJ, Schoonhoven L. Use of social media by Western European hospitals: longitudinal study. J Med Internet Res 2012;14(3):e61.
12. Van De Belt TH, Engelen LJ, Berben SA, Schoonhoven L. Definition of Health 2.0 and Medicine 2.0: a systematic review. J Med Internet Res 2010;12(2):e18.
13. P2P Foundation. Definition of Apomediation [Internet]. [place unknown]: P2P Foundation; 2010 [cited at 2015 Apr 15]. Available from: http://p2pfoundation.net/Apomediation.
14. Chomutare T, Arsand E, Fernandez-Luque L, Lauritzen J, Hartvigsen G. Inferring community structure in healthcare forums: an empirical study. Methods Inf Med 2013; 52(2):160-7.
15. Esquivel A, Meric-Bernstam F, Bernstam EV. Accuracy and self correction of information received from an

 http://dx.doi.org/10.4258/hir.2015.21.2.67

internet breast cancer list: content analysis. BMJ 2006; 332(7547):939-42.
16. Bernstam EV, Walji MF, Sagaram S, Sagaram D, Johnson CW, Meric-Bernstam F. Commonly cited website quality criteria are not effective at identifying inaccurate online information about breast cancer. Cancer 2008; 112(6):1206-13.
17. TuDiabetes.org. Information about TuAnalyze [Internet]. [place unknown]: TuDiabetes.org; 2010 [cited at 2010 May 30]. Available from: http://www.tudiabetes.org/forum/topics/tuanalyze-is-here.
18. Weitzman ER, Kelemen S, Mandl KD. Surveillance of an online social network to assess population-level diabetes health status and healthcare quality. Online J Public Health Inform 2011;3(3):1-12.
19. World Health Organization. WHO fact file [Internet]. Geneva: World Health Organization; c2015 [cited at 2015 Apr 15]. Available from: http://www.who.int/features/factfiles/diabetes/facts/en/.
20. Norwegian Centre for Integrated Care and Telemedicine. Diabetes and self-management [Internet]. Tromso: Norwegian Centre for Integrated Care and Telemedicine; c2015 [cited at 2015 Apr 15]. Available from: http://www.telemed.no/diabetes-and-self-management.4982935-162159.html.
21. Glu. Big blue test [Internet]. [place unknown]: Glu; c2015 [cited at 2015 Apr 15]. Available from: https://myglu.org/articles/big-blue-test-results.
22. Research2Guidance. Diabetes app market report 2014. Berlin: Research2Guidance; 2014.
23. Bonato P. Advances in wearable technology and its medical applications. Conf Proc IEEE Eng Med Biol Soc 2010;2010:2021-4.
24. Bassett DR Jr, Rowlands A, Trost SG. Calibration and validation of wearable monitors. Med Sci Sports Exerc 2012;44(1 Suppl 1):S32-8.
25. Cafazzo JA, Casselman M, Hamming N, Katzman DK, Palmert MR. Design of an mHealth app for the self-management of adolescent type 1 diabetes: a pilot study. J Med Internet Res 2012;14(3):e70.
26. Google Play. Thinspo application [Internet]. Mountain View (CA): Google; c2015 [cited at 2015 Apr 15]. Available from: https://play.google.com/store/apps/details?id=com.github.browep.thinspo.
27. Syed-Abdul S, Fernandez-Luque L, Jian WS, Li YC, Crain S, Hsu MH, et al. Misleading health-related information promoted through video-based social media: anorexia on YouTube. J Med Internet Res 2013;15(2):e30.
28. Yom-Tov E, Fernandez-Luque L, Weber I, Crain SP. Pro-anorexia and pro-recovery photo sharing: a tale of two warring tribes. J Med Internet Res 2012;14(6):e151.
29. BetschC, Sachse K. Special issue: the role of internet use in vaccination decisions. Vaccine 2012;30(25):3723-818.
30. European Centre for Disease Prevention and Control. Communication on immunisation: building trust. Stockholm: European Centre for Disease Prevention and Control; 2012.
31. National Vaccine Information Center [Internet]. Sterling (VA): National Vaccine Information Center; c2015 [cited at 2015 Apr 15]. Available from: http://www.nvic.org/.
32. Briones R, Nan X, Madden K, Waks L. When vaccines go viral: an analysis of HPV vaccine coverage on YouTube. Health Commun 2012;27(5):478-85.
33. Yom-Tov E, Fernandez-Luque L. Information is in the eye of the beholder: seeking information on the MMR vaccine through an Internet search engine [Internet]. Bethesda (MD): American Medical Informatics Association; 2014 [cited at 2015 Apr 15]. Available from: http://knowledge.amia.org/56638-amia-1.1540970/t-004-1.1544972/f-004-1.1544973/a-227-1.1544992/an-227-1.1544993?qr=1.
34. Salathe M, Khandelwal S. Assessing vaccination sentiments with online social media: implications for infectious disease dynamics and control. PLoS Comput Biol 2011;7(10):e1002199.
35. The Vaccine Confidence Project [Internet]. [place unknown]: The Vaccine Confidence Project; c2015 [cited at 2015 Apr 15]. Available from: http://www.vaccineconfidence.org/.
36. The Vaccine Confidence Project. Partners and collaborators [Internet]. [place unknown]: The Vaccine Confidence Project; c2015 [cited at 2015 Apr 15]. Available from: http://www.vaccineconfidence.org/about/#partners.
37. HealthMap [Internet]. [place unknown]: HealthMap; 2015 [cited at 2015 Apr 15]. Available from: http://www.healthmap.org/.
38. Oyeyemi SO, Gabarron E, Wynn R. Ebola, Twitter, and misinformation: a dangerous combination? BMJ 2014; 349:g6178.
39. Kelion L. Ebola text-message system set to expand [Internet]. London: BBC News; 2014 [cited at 2015 Apr 15]. Available from: http://www.bbc.com/news/technology-29610865.
40. Salathe M, Bengtsson L, Bodnar TJ, Brewer DD, Brownstein JS, Buckee C, et al. Digital epidemiology. PLoS Comput Biol 2012;8(7):e1002616.