Using social media for improving health literacy

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Introduction

In 2011, about 30.2% (2.1 billion) of the world's population had access to the Internet (78.3% of North America and 58.3% of Europe's populations), and searching for health information online became increasingly common; for example, about two-thirds of US adults look online for health information according to recent figures released by the Pew Internet & American Life Project (Fox and Jones, 2009; Fox, 2010).

A digital divide

Almost half of all Europeans show limited health literacy, according to the European Health Literacy Survey results published in 2011. Internet users therefore certainly include among them people with limited health literacy skills, although a US '2007 Health Information National Trends Survey' found that Internet users tended to be more educated, with higher income, and preferred numbers rather than words to describe chance (Koch-Weser et al., 2010).

Neter and Brainin (2012) report similar observations among a sample of Israeli adult population (people in the high literacy group were significantly younger, had significantly higher socioeconomic status (as measured by education) and had significantly more access to computers and used the Internet more frequently compared with the low literacy group in the studied sample). But perhaps the most interesting finding in Neter and Brainin's (2012) study is that respondents who reported they were chronically ill (and hence, ironically, the ones most in need of, and who would benefit the most from, online health information and support) had a significantly lower literacy scores than respondents with no reported chronic illnesses. In a parallel vein, Fox and Purcell (2010) found people fighting chronic illnesses to be less likely than others to have Internet access, but once online they are more likely to blog or participate in online discussions about health problems.

eHealth literacy skills

Skills needed for health literacy on the Internet include all the conventional health literacy skills, in addition to computer and Internet literacy skills, and skills for locating and appraising online health information. But having access to the Internet and mastering the essential computer and Web browsing skills does not automatically guarantee that a person will be able to properly evaluate and understand online health information and make sound decisions based on it (Knapp et al., 2011; Stellefson et al., 2011).

Norman and Skinner's (2006a) concept of 'eHealth Literacy' is a renaming of an old concept, 'health literacy in the Internet age'; see, for example, Kamel Boulos (2005). Their 'Lily Model' is a nice graphical way to depict the well-known hierarchy of skills and 'literacy types' that are involved in the

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process, namely traditional literacy, information literacy, media literacy, health literacy, computer literacy and scientific literacy. Chan and Kaufman (2011) apply a framework of increasing levels of cognitive complexity (based on Bloom's taxonomy) to these literacy types, covering the abilities to remember, understand, apply, analyse and evaluate online health information. Norman and Skinner's (2006b) proposed companion eHealth Literacy Scale (eHEALS) was translated to other languages including Dutch, but one study found it not able to properly distinguish between people with high and low health-related Internet skills (van der Vaart et al., 2011).

Role of social media

Social media penetration in society

Social media and social networking¹ now reach four out of five (i.e., 80% of) active Internet users in the USA, according to a Q3 2011 report by Nielsen.⁵ According to figures from the same report, Americans now spend more time on Facebook (53.5 billion minutes a month) than on Yahoo!, Google, YouTube, Blogger, Tumblr and Twitter combined. Most of the latter Web sites used in that comparison with Facebook also belong to the Social Web. Similar findings have been reported in Europe, with 73% of European Internet users said to be using social network sites, according to an InSites Consulting survey published in September 2011.⁶

Unlike the commonly held belief that social networking is mainly used by teenagers and young adults, a recent Pew survey reported (in August 2011) that use of Facebook and other social networking sites is on the rise among those aged 50-64 (51% of Internet users in this age group use social networking sites), with 33% of Internet users in the 65+ age group also using such sites (Madden and Zickuhr, 2011), an observation some have described as the ‘greying of social networking sites’. Introductory courses are now available that teach how to use Facebook and Twitter for those aged 60 and older, another testimony of the growing popularity of social networking tools among older generations.⁷

What can social media bring to health literacy?

There are many definitions of ‘health literacy’ (Sørensen et al., 2012), but for the purpose of discussing the role of social media in health literacy, we will refer to the following working definition of health literacy from the US Department of Health and Human Services’ report ‘Healthy People 2010’: “The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (US Department of Health and Human Services, 2000).

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¹ The term ‘social media’ refers to Social Web applications and networks such as Facebook, Twitter and Wikipedia, where people can meet, share and co-edit content with other users. The term is commonly used in the research literature (PubMed: http://tinyurl.com/PubMed-Social-Media) and does not include conventional print media or other forms of mass media such as conventional (non-Internet-based) radio, TV and cinema. Facebook, Twitter and YouTube are the three main/most popular social media tools in use today by number of users (e.g., Facebook alone had 845 million active monthly users as of December 2011—see Cheredar T. VentureBeat, 1 February 2012: http://tinyurl.com/facebook-ipo-usage-data) and by amount of content generated/consumed, making them most suited for social and viral marketing campaigns.


Using the above definition of health literacy (focusing on the verbs in it), social media can potentially improve users’ capacity to (1) obtain, and (2) process and understand health information and services needed to make appropriate health decisions. But it is particularly the first of these two capacities, the capacity to obtain/access health information, which can be immediately improved by social media. The second capacity to filter/evaluate, process and understand health information depends on factors that vary widely across the Web, namely the content quality and presentation of online health information and the degree they match the needs and health literacy levels of target audiences.

Viral social marketing (reaching out to many more people, more quickly and with minimal costs, compared to other forms of marketing/advertising) is among the strongest aspects of social media and can play an important role in health education, promotion and outreach programmes (Gosselin and Poltrás, 2008). For example, viral marketing and other social media techniques have been successfully used to promote condom use in Turkey (Purdy, 2011).

Online social networks and participatory communication methods can also provide excellent opportunities for peer-to-peer support (patients and members of the general public supporting each other) (Fox, 2011), and thus contribute to reducing the burden on conventional healthcare systems. PatientsLikeMe, a social networking site for patients with various medical conditions, is now a classic example of online patient-to-patient support and those using it often report a number of perceived benefits and improved disease self-management and outcomes (Frost and Massagli, 2008; Wicks et al., 2012).

Wongvipat Kalev et al. (2011) describe T2X (Teen2Xtreme), an online site that harnesses the power of social media to improve adolescents’ health literacy. Run jointly by UCLA School of Public Health and Health Net, Inc. in the United States, T2X offers a Facebook-linked, teen-only community of users, with teen and professionally produced content, competitions, games, quizzes, polls, blogs, (YouTube) video clips and other interactive and participatory communication methods. T2X covers lifestyle issues for teens, such as nutrition, fitness, stress management, substance abuse and sexual behaviour (Figure 1).

**mHealth (mobile health)**

A Morgan Stanley presentation published in 2010 is predicting that mobile Web access via smartphones and other small-form-factor Internet devices, such as the Apple iPad and clones of small touch-screen tablets, will overtake conventional desktop Internet use by 2015. UK mobile Internet use is already nearing 50%, according to a 2011 ONS (Office for National Statistics) report. The mobile Social Web is now enabling people to easily share, rate, recommend and find software ‘apps’ (applications) about almost any topic under the sun. Before the advent of smartphones, small-form-factor tablets, and the latest generations of operating systems and Web browsers that support the concept of apps and associated ‘app stores’ or ‘markets’, downloading and installing software was not as easy or popular (among average Internet users) as it is today. For example, a mobile app for trusted and reliable health advice offered by the NHS (National Health Service) in England has been downloaded by over one million persons in its first six months after launch in May 2011.

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9 Teen2Xtreme: [http://www.t2x.me/](http://www.t2x.me/).
Smartphones and their apps are rapidly and radically transforming healthcare, particularly the care of patients with long-term conditions, enabling it to become more mobile at the point of need and more participatory by engaging all involved stakeholders, including patients, non-clinical carers, the general public, clinicians and various organisations (Kamel Boulos et al., 2011a; Leslie et al., 2011). The potential of many of the available and planned specialised mobile apps in reducing healthcare costs and improving clinical outcomes is significant (see, for example, Liang et al., 2011).  

![T2X welcome page](image)

**Figure 1.** Screenshot of T2X welcome page showing how different social media elements have been successfully integrated into the portal. One can see the Facebook login option (blue button - top right corner) and embedded video clip, as well as other social aspects such as the rotating individual community member photo essays ("What does xtreme teen mean to you?"), which may help other teens instantly relate to the service. Also note the 'Club' rubric and the 'Contests' and 'Invite Friends' (social media sharing) links near the centre-bottom of the screenshot. In this way, the portal 'goes where teens already are on the Social Web' and uses the same social media interfaces they are familiar with, all while providing a unique, distinctive "wrapper", with carefully selected teens quotes, colours and style that would appeal to a teens audience, motivate them and foster their engagement with one another and with the service content.

Given the growing popularity and broad range of health-related mobile apps available today, the US Food and Drug Administration is now proposing guidelines that outline the types of mobile apps the agency plans to oversee, namely those medical apps that could present a risk to patients if the apps do not work as intended.  

13 Wodajo F. Apps for management of diabetes could be vehicles for reducing health care expenses in future [mHealth]. iMedicalApps.com, 2 February 2011: [http://tinyurl.com/5snfo9u](http://tinyurl.com/5snfo9u).

14 T2X Club, an online video series in which teens explore friendships, relationships, health topics, and school: [http://www.t2x.me/club.aspx](http://www.t2x.me/club.aspx); also available on YouTube: [http://www.youtube.com/user/t2xTheClub](http://www.youtube.com/user/t2xTheClub).

15 See: [http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm263332.htm](http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm263332.htm) and [http://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/ucm255978.htm](http://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/ucm255978.htm).
One excellent example of a mobile app in the context of health literacy is the 'Plain Language Medical Dictionary' iPhone app from the University of Michigan's Taubman Health Science Library. This free app "converts" medical language jargon into everyday English and could thus prove handy and extremely helpful to people struggling to understand the exact and correct meaning of medical terms they encounter online (Figure 2).

Figure 2. Screenshot of the Plain Language Medical Dictionary iPhone app. The few terms shown in this screenshot of the app, such as 'abdomen', 'ability', 'absorption', and 'accelerate', remind us, clinicians, scholars and policy makers with a professional background, how such terms that we treat as easy, simple, and self-explanatory can be a source of confusion for many other people, even highly literate people, hence the importance of such online dictionary apps and tools. For example, the word 'unsweetened' could cause much confusion to diabetic patients with low reading skills, who may only recognise the 'sweetened' part in 'unsweetened' and skip the 'un' prefix, thus leading to the opposite behaviour (Kamel Boulos, 2005).

The reader is referred to Chris Gibbons et al. (2011), Fordis et al. (2011), Kamel Boulos (2012), Kamel Boulos and Toth-Cohen (2009), Kamel Boulos and Wheeler (2007), and Metzger and Flanagin (2011) for an overview of the different types of social media available today and a more thorough discussion of the potential roles that social media, including three-dimensional virtual worlds such as Second Life®, can play in health literacy, public education and 'crowdreaching'. Kamel Boulos et al. (2011b) discuss the crowdreaching and opinion-shaping opportunities offered by social media for reaching out to people and engaging with them wherever they might be, e.g., by deploying a free tool

17 See also: http://www.pfizerhealthliteracy.com/media/WordsToWatch.aspx.
such as InSTEDD RemindEm\textsuperscript{18} to target the simplest mobile phones using customisable plain text messages. However, a discussion of the use of social media for health literacy purposes remains incomplete without also addressing the potential risks, pitfalls and workarounds that are involved in the process.

Risks of social media and workarounds

**Social media’s viral nature: a double-edged sword**

Social media pose higher risks compared to other conventional media (e.g., TV and print material), due to the much wider (and faster) outreach of the Social Web and its messages, and its partly uncontrollable/non-moderated nature (‘anyone can publish whatever they want’). The risks include spreading misinformation and disinformation, which can propagate very rapidly through viral messages, videos and eWOM (Electronic Word of Mouth) and even through hacked social media accounts of reputable organisations.\textsuperscript{19}

The potential for the dissemination of biased, incomplete (and thus potentially risky) or inaccurate/wrong information over social media has been discussed and documented with examples in the literature. For example, Clauson, Polen, Kamel Boulos and Dzenowagis (2008) reported gaps in the scope, completeness, and accuracy of drug information in Wikipedia. Scanfeld et al. (2010) examined evidence of misunderstanding and misuse in information about antibiotics in Twitter status updates. Steinberg et al. (2010) and Knösel and Jung (2011) analysed prostate cancer and orthodontics videos on YouTube for presence of bias. Briones et al. (2011) examined the content of 172 YouTube videos related to the human papillomavirus (HPV) vaccine and found that the majority of them were negative in tone, disapproving of the HPV vaccine. Moreover, they found that negative videos were liked more by the viewers than positive or ambiguous ones (the number of ‘likes’ or YouTube ‘views’ can serve as a crude proxy for the impact of the liked or watched videos). Liang and Mackey (2011) identified cases of online drug marketing by illicit online drug sellers using eDTCA 2.0 (Direct-to-Consumer Advertising using social media technologies, hence the ‘e’ and ‘2.0’ in the acronym).

The ‘viral nature’ of the Social Web means that (mis)information can travel and get boosted very fast (‘water ripple effect’), especially during times of ‘mass stress’ and panic. Furthermore, on the Social Web, the ‘source’ (an important clue in assessing information credibility) is often omitted or lost (e.g., in ‘retweets’,\textsuperscript{20} where only a limited number of characters, 140, are allowed) and the information is sometimes paraphrased in such a way that distorts the original message or takes it out of its intended context. These issues are discussed in detail in Kamel Boulos et al. (2011b). The concept of self-correction of misinformation over time by the community (‘Darwikinism’) is also covered in Kamel Boulos et al. (2011b), as well as in Kamel Boulos and Wheeler (2007). But a person might read and act/make decisions based on the wrong or incomplete information in a way that causes harm, before that information gets corrected by the community (or without the person also finding/seeing any corrections that followed the original message; the Internet is very vast and can be confusing or hard for some users to navigate and locate/track related pieces of information). Some lawyers may identify

\textsuperscript{18} InSTEDD RemindEm: [http://remindem.instedd.org/](http://remindem.instedd.org/). Ensuring and optimising the readability (‘reading with understanding’ by target audiences) of the content/language of text messages sent using RemindEm is what would matter the most in the context of our discussion of health literacy.


\textsuperscript{20} Retweets: [https://support.twitter.com/articles/77606-what-is-retweet-rt](https://support.twitter.com/articles/77606-what-is-retweet-rt).
a 'liability' issue here that requires careful attention by online health information providers whose sites include Social Web elements.

On the other hand, presenting correct, unbiased information on social media but in a way that is hard to understand by its intended audience or one which makes misunderstanding a likely possibility can also have serious negative consequences.  

**Mitigation tactics**

There is no easy way to remove or stop all the 'bad' information out there, but we can always provide and advertise good information and educate people about, and expose, misleading online material (or representative examples of it). Consumer education and guidance on how to critically appraise online health information and where to find good information online can be effectively done using the same social media tools and streams, while "pushing" plenty of good material can be achieved by creating trustworthy social media channels for this purpose, and socially marketing these channels; see, for example, the official NHS Choices (National Health Service in England) and US CDC (Centers for Disease Control and Prevention) channels and anti-tobacco campaign examples on Facebook.  

(22) (The NHS in England/DH (Department of Health) also spent £2.7m on a Google AdWords campaign in 2009/2010 to promote NHS Choices, but a few groups criticised them for doing so.  

However, with users being able to freely write text and post comments on an organisation's social media presence, e.g., on a Facebook 'wall', maintainers of social media pages should regularly monitor and moderate their content for any forms of spam, abuse, or copyrights or patient privacy violations (turning off all user posting/commenting is not a good option as this will remove the 'social' from social media). Account admins should also protect their presences with strong passwords to avoid their accounts getting hacked by spammers.

Organisations should develop and enforce clear policies and guidelines regarding what their members of staff can post on various social media (Kamel Boulous, 2012) and should also allocate sufficient personnel time and resources to look after their social media presences. This latter task can be a very demanding task, but can be partially helped by identifying, training and appointing online community leaders from among patients ('expert e-patients') and the general public to assist in the task of moderation and facilitation of social media postings.

Other workarounds and strategies include connecting social-media technologies to evidence-informed online resources, matching new applications with the correct user populations, and integrating health communication best practices, including addressing health literacy issues in the relevant social media content and regularly running the latter through readers' panels representing the full range of target audiences (Chris Gibbons et. al., 2011; Kamel Boulous, 2005; Metzger and Flanagin, 2011).
However, even the most readable (social media) posts will remain difficult to fully and properly understand for a sizeable proportion of the population. For this reason, in addition to written text, online health information providers should also consider alternative and complementary social media modalities such as interactive games and live seminars in virtual worlds (Kamel Boulos and Toth-Cohen, 2009) and plain English videos\(^{26}\) (or in other languages as appropriate), so that no one is left behind.

**Guidelines and key resources**

Social media content and choice of medium (e.g., using a blog article vs. a YouTube video vs. using both media vs. a dedicated mobile app, etc.) need to be tailored to suit the profiles and preferences of target audiences and their 'reading with understanding' levels. Involving representatives from the target audiences in planning, implementing, disseminating and evaluating online health information and services is of prime importance (Kamel Boulos, 2005). A strategy based on 'shared-audience information sets' (based on evidence-based material originally compiled for clinicians) (Kamel Boulos et al., 2006) can be adopted to maximise the efficiencies of content authoring and delivery vs. varying degrees of patient literacy, from the 'expert patient' to the completely illiterate layperson (Figure 3).

\(^{26}\) See, for example, the official NHS Choices channel on YouTube: [http://www.youtube.com/user/NHSChoices](http://www.youtube.com/user/NHSChoices) (had more than ten million video ‘views’ as of March 2012).
Key resource 1: free online course and companion booklet (US CDC)

The US CDC uses social media extensively in its own public campaigns and outreach activities and offers a number of excellent health literacy, social media and social marketing training materials, guidelines and toolkits that can prove very helpful to social media content developers and public health practitioners in general. These include a free online course, ‘Health Literacy for Public Health Professionals’ (Figure 4) and a free 43-page online booklet, ‘Simply Put: A guide for creating easy-to-understand materials’ (Third Edition). The advice provided in this booklet can be readily applied to the creation of Social Web materials.

Key resource 2: ‘Gateway to Health Communication & Social Marketing Practice’ and ‘The Health Communicator’s Social Media Toolkit’ (US CDC)

This comprehensive gateway offers many resources to help build successful health communication and social marketing campaigns and programmes, including a monthly ‘Health Communication Science Digest’ and guidance and tips for analysing and segmenting an audience, choosing appropriate channels and tools, and evaluating the success of campaigns and their messages. The US CDC has also recently published a 55-page practical toolkit covering the different Social Web media options that are available today. The toolkit is meant to help public health practitioners and managers make informed choices and formulate a more effective social media communication strategy and evaluation plan for their uses of these media.

Key resource 3: ‘Health Literacy Online: A Guide to Writing and Designing Easy-to-Use Health Web Sites’ and companion online portal (US DHHS/ODPHP)

Authored and published by the US Department of Health and Human Services’ (DHHS) Office of Disease Prevention and Health Promotion (ODPHP), this free 103-page online guide entitled ‘Health Literacy Online: A Guide to Writing and Designing Easy-to-Use Health Web Sites’ is aimed at Web designers, Web content specialists, and other public health communication professionals to help them deliver online health information that is actionable and engaging, create health Web sites that are easy to use, particularly for people with limited literacy skills and limited experience using the Web, and evaluate and improve health Web sites with user-centred design. Although not specific for social media sites (the guide applies to online health information sites in general), this guide remains very useful and directly relevant to social media developers and communicators. The ODPHP has also pulled together key tools, research and reports, and other resources for public health and health communication professionals on the subjects of health communication, health literacy and e-Health, and made them available through a dedicated online portal.

27 See: http://www.cdc.gov/socialmedia/.
30 US CDC Gateway to Health Communication & Social Marketing Practice: http://www.cdc.gov/healthcommunication/.
Figure 4. Screenshots of the US CDC (free) online course entitled 'Health Literacy for Public Health Professionals'.

Improving Health Literacy

Improving health literacy skills requires a comprehensive set of strategies that includes those listed below. Using these strategies will improve the usability of the health information, making your messages more understandable.

- Use plain language.
- Use culturally and linguistically appropriate messages.
- Design messages that are participatory and user-centered.
- Evaluate the effectiveness of communications.
- Engage regularly with the communities who are targeted by the communication.
- Consider the current literacy level of the intended audience, and design messages based on that level.

creating podcasts and videos are one way of improving the delivery of public health messages. The following links provide examples that incorporate user-centered design principles for effective communication.

- Puff City (Web-based program) [link]
- Put Your Hands Together (video clip) [link]
- Seniors: Vaccinate For Your Health's Sake! (podcast) [link]

As you listen to these examples, think about how they demonstrate the principles.
Policy recommendations

**Future eHealth educators should be provided with formal learning experiences in eHealth literacy and social media**

Medical and health professionals need adequate eHealth literacy training for finding, interpreting, and evaluating the usefulness (and appropriateness of presentation) of health and medical-related information on the Social Web, in order to better serve their patients and the general public (Stellefson et al., 2011).

**Bridge the new media inequalities and digital divide and ensure proper inclusion of marginalised and disadvantaged populations**

The new social media tend to reinforce existing social differences. The more comprehensive and sophisticated use of the Social Web and the subsequent increased gains among the high eHealth literate have created new inequalities in the domain of digital health information. There is a need to educate at-risk groups and populations in need such as the chronically-ill and to design social media presences in a way befitting more consumers (Neter and Brainin, 2012). Inclusion (‘e’ for digital) and accessibility should be adequately addressed in such designs, ensuring ‘technology accessibility by all’ and the participation of older people with lower access rates to the Internet and without the necessary skills to use the various Social Web tools, as well as the inclusion of other marginalised or disadvantaged groups of the society (Fox and Purcell, 2010).

**Use the language patients are already using and can understand, and embrace a culturally-competent approach that accounts for cultural variations among different populations**

This recommendation is directly related to the previous ones and should contribute to informing and realising them. Patients (and their non-clinical carers and the general public) are the target audiences of patient-oriented Web sites. In a Social Web environment, patients and the public also contribute to content generation on these sites, as seen, for example, in PatientsLikeMe, the online social networking community for patients. In PatientsLikeMe, patients use their own natural language terms to describe their symptoms to others, resulting in ‘folksonomic’ (loose, user-created vocabularies) tags available for browsing by other users to find ‘patients like me’. In a study by Smith and Wicks (2008) of patients’ folksonomic symptom terms in PatientsLikeMe, only 43% of patients’ terms could be mapped to controlled medical vocabularies in the Unified Medical Language System (UMLS) Metathesaurus of the US National Library of Medicine. Slightly more than half of the symptom terms either did not match the UMLS, or were unclassifiable. This means that patients and clinicians do not speak the ‘same language’. Clinicians and health communicators need to learn and use those vocabularies used by real patients, in order to effectively communicate with laypeople. They also need to consider, for that same purpose, any specific cultural needs and the socioeconomic levels of different ethnic groups in the communities they are serving.  

**Conclusion**

Today, the question is no longer whether or not to use social media (among other tools) for health literacy purposes. Rather, the question is which social media to target (within available budget and resources) and how to best do so. With more than 800 million active Facebook users (half of them log on each day) and 100 million active Twitter users, healthcare and public health communicators and organisations cannot afford to ignore social media as a powerful means for reaching out to their

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34 See the US National Medical Association’s Cultural Competence Primer: [http://www.webcitation.org/66BPe3CTo](http://www.webcitation.org/66BPe3CTo).
stakeholders, including patients, lay carers, and the general public. Health organisations should go where people already are online (on social media), rather than just build their own isolated Web islands of 'read-only' information portals and expect people to come and visit.

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