

Evidence Search and Synthesis NHS Education for Scotland

The use of social networking in the self-management of long-term conditions.

This document summarises current evidence on the use of social networking to aid in the self-management of people with long-term health conditions and indicates where systematic reviews are lacking.

1. Key Messages

- The use of social networking was found to have some impact in improving specific clinical and psychosocial outcomes when used to aid in the self-management of long-term conditions.
- Social networking enables users to feel supported and can aid in establishing and maintaining social connections. It was found to improve self-efficacy and led to a feeling of empowerment when self-managing long-term conditions.
- Adults with long-term conditions were found to use varying types of social networking including: discussion forums; message boards; chatrooms; blogs; Facebook; YouTube; Twitter and Second Life.

2. Systematic review gaps

- More qualitative research is necessary to examine the psycho-social aspects of social networking use for self-management.
- Risks and benefits of social networking for self-management, including safety and any practical or ethical considerations.
- Greater diversity of participants and the engagement/accessibility of social networking for a more diverse audience. This would include varying long-term conditions, co-morbidities, ages, genders and ethnicities.
- Future research should be of a higher quality- involving more randomised controlled trials and an increase in participant numbers.

3 Background

Access to the Internet in the modern day has become almost ubiquitous; in 2014, 38 million adults in the UK (76%) went online on a daily basis (Office for National Statistics, 2014) and a vast quantity of these users are now utilising social networking services. Adults aged 18-49 years make up the largest group of users of social networking services and in 2014, around 74% of adults who went online also used social networking sites such as Facebook or Twitter (PEW Research Centre, 2014). There are three main principles used to define social

networking: they are web based applications; they allow users to create an online profile which can be public or private and they facilitate communication between individuals or groups of users (Toma et al., 2014). Social networking services can be synchronous, providing real-time connections (e.g. chatrooms) or asynchronous, where users do not need to be online at the same time to engage (e.g. message boards).

As more and more people use the Internet, the abundance of available information also grows and it is becoming routine to search for information relating to personal health and wellbeing. It has become a 'first-stop' for many people and this is particularly the case for people living with one or more long-term conditions; an online tool has the potential to be convenient, private and if used correctly, safe and accurate.

This evidence summary was commissioned by Lisa Curtice, Director of People Powered Health and Wellbeing Programme, The ALLIANCE. This programme helps to support people's right to independent living, good health and wellbeing. The summary was requested in order to answer questions for a reference group of people living with long-term conditions. It will be used to investigate best practice and will be reported back to members of the group in order to provide evidence for further use of social networking in self-management.

4. Question(s)

This evidence summary aims to examine the available evidence relating to this topic and highlight gaps for further research. It addressed three specific questions:

- ***What impact does social networking have on the self-management of adults with long term conditions?***
- ***Does the use of social networking enable people with long term conditions to feel empowered when self-managing?***
- ***What types of social networking do adults with long term conditions use and for what purposes?***

5. Scope of this summary

	What the authors of this evidence summary searched for
Population	<i>Adults (18+) with one or more long-term conditions. All genders, nationalities.</i> <i>LTCs defined by the ALLIANCE (2010): "A long term condition is one of prolonged duration, generally lasting longer than a year".</i>
Intervention	<i>Use of online social networking. Defined as "web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those</i>

made by others within the system. The nature and nomenclature of these connections may vary from site to site.” (Toma et al., 2014)

- *Importance of interactive nature of social networking-does not include more general web interventions such as self-monitoring or web based education unless used in conjunction with social networking services.*
- *Can be synchronous or asynchronous.*
- *Any form of interaction between any groups of people e.g. between patients, caregivers, health professionals etc.*

Comparison Any

Outcomes *Effective self-management of long- term condition(s).*

- Setting**
- *Online social networking, this can include mobile applications.*
 - *Exclude any solely using online teleconferencing.*
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Studies were searched for between January and February 2015 within the following electronic databases: Cochrane Database of Systematic Reviews, Epistemonikos and Health Systems Evidence. A specific time period was not defined. For an example of the search strategy see Appendix 1.

6. Results

After searching the relevant databases, 122 documents were found which were de-duplicated and screened by using the inclusion criteria stated above. Seven systematic reviews were selected as relevant and the full texts were examined. Of these, two documents were excluded after close inspection and five systematic reviews were selected for this evidence summary (Alvarez-Jimenez et al., 2014; Highton-Williamson et al., 2015; Koskan et al. , 2014; Stellefson et al., 2013; Toma et al. , 2014). Included reviews were all published in the last two years.

A number of the reviews found did not examine social networking as the sole intervention; it was used in conjunction with other interventions such as psychotherapy or web-based CBT.

Characteristics of included reviews

Alvarez-Jimenez et al. (2014) Online, social media and mobile technologies for psychosis treatment: A systematic review on novel user-led interventions	
Objectives of the review	To examine the usability, acceptability, feasibility, safety or efficacy of user-led internet or mobile-based technologies.
Date of last search	August 2013
Number of studies	12
What were the characteristics of the participants in the studies?	At least 80% of participants were diagnosed with schizophrenia-spectrum disorders.
Type of intervention	Internet interventions and mobile-based interventions. These include: web-based psycho-education; web-

	based psycho-education plus moderated forums for patients and supporters; integrated web-based therapy; social networking and peer and expert moderations; web-based CBT; personalised advice based on clinical monitoring; and text messaging interventions.
What outcomes were measured?	Clinical Psychosocial
Authors' comments on quality of included studies	The authors say that the description of methodology and results was poor in many studies, making it difficult to ascertain methodological quality.
Reliability of conclusions	Conclusions of effectiveness not based on statistical meta-analysis.
Review quality	This review has an AMSTAR score of 9/10. ¹
Key findings	Results showed that 74-86% of patients used the internet-based interventions efficiently, 75-92% perceived them as positive and useful, and 70-86% completed or were engaged with the interventions over the follow-up. Preliminary evidence indicated that internet and mobile-based interventions show promise in improving positive psychotic symptoms, hospital admissions, socialization, social connectedness, depression, and medication adherence.

Highton-Williamson et al. (2015) Online social networking in people with psychosis: a systematic review	
Objectives of the review	To examine the use of online social networking in people with psychosis, in terms of: (a) differences in use between different populations; (b) for what purposes people use online networking.
Date of last search	January 2014
Number of studies	11
What were the characteristics of the participants in the studies?	People with a diagnosis of psychosis (inclusive of bipolar disorder).
Type of intervention	Any type of online social networking, on any type of online social networking site (with the exception of interactions between participants and mental health professionals)
What outcomes were	Psychosocial

¹ AMSTAR, A MeaSurement Tool to Assess Reviews, provides an overall quality rating on a scale of 0 to 11, where 11 represents a review of the highest quality. Categories of quality were determined, as follows: low (score 0 to 3), medium (score 4 to 7), and high (score 8 to 11).

measured?	
Authors' comments on quality of included studies	The authors do not comment on the quality of included studies.
Reliability of conclusions	N/A
Review quality	Unclear, but author report that it was conducted following PRISMA guidelines.
Key findings	People with psychosis seem to spend more time in chat rooms or playing online games than control groups. The use of other online tools, such as Facebook or communication through e-mail, is lower or the same than controls. Online social networking was used by patients with psychosis for establishing new relationships, maintaining relationships/reconnecting with people and online peer support.

Koskan et al. (2014) Use and taxonomy of social media in cancer-related research: a systematic review	
Objectives of the review	To examine the taxonomy and timeline of social media sites used in cancer care; to categorise the designs of studies that assessed the role of social media in the context of cancer care; to examine the extent to which articles in this area discussed the digital divide, health literacy, and the potential impact of social media interventions on cancer disparities.
Date of last search	October 2013
Number of studies	69
What were the characteristics of the participants in the studies?	Any type of participant (inc. patients, caregivers, survivors etc) using social media to find cancer information or support.
Type of intervention	Any social media.
What outcomes were measured?	Psychosocial
Authors' comments on quality of included studies	The authors do not comment on the quality of included studies.
Reliability of conclusions	N/A
Review quality	Unclear, but authors report that they followed PRISMA guidelines.
Key findings	Early research (1996–2007) was predominantly descriptive studies of online forums. Later, researchers began analysing blogs, videos shared on YouTube, and social networking sites.

Stellefson et al. (2013) Web 2.0 chronic disease self-management for older adults: a systematic review	
Objectives of the review	To examine the planning, implementation and overall effectiveness of Web 2.0 self-management interventions.
Date of last search	Unclear (probably end October 2012)
Number of studies	15
What were the characteristics of the participants in the studies?	Older adults (mean age 50+), all genders, one or more chronic conditions.
Type of intervention	Participatory web 2.0 technologies (e.g. social networking, telemedicine, mobile health applications)
What outcomes were measured?	Self-management of any chronic disease(s)
Authors' comments on quality of included studies	The authors used the RE-AIM framework, to organise findings and compute a Study Quality Score for the included studies which ranged from 16 (26%) to 52 (85%). Higher percentages were indicative of higher quality study design. The mean SQS was 38.33 (63%) which was notably low. Only 4 studies scored 80% or higher.
Reliability of conclusions	Conclusions of effectiveness not based on statistical meta-analysis.
Review quality	This review has an AMSTAR score of 5/11.
Key findings	<p>Studies indicated that Web 2.0 participants felt greater self-efficacy for managing their disease(s) and benefitted from communicating with health care providers and/or website moderators to receive feedback and social support. Participants noted asynchronous communication tools (e.g. email, discussion boards) and progress tracking features (e.g. graphical displays of uploaded personal data) as being particularly useful for self-management support.</p> <p>Greater Web 2.0 engagement may be associated with improvements in health behaviours (e.g. physical activity) and health status (e.g. HRQoL). However, few studies indicated statistically significant improvements in medication adherence, biological outcomes, or health care utilisation.</p>

Toma et al. (2014) Online social networking services in the management of patients with diabetes mellitus: systematic review and meta-analysis of randomised controlled trials	
Objectives of the review	To examine the effects of social networking services, compared with standard care.
Date of last search	November 2013
Number of studies	34
What were the characteristics of the participants in the studies?	Patients with Type 1 or Type 2 diabetes.
What interventions /treatments or services were provided to participants in the intervention/experiment or treatment group?	Social networking services (SNS) via mobile and web-based tools.
What outcomes were measured?	Clinical
Authors' comments on quality of included studies	The authors used the Jadad scale (ranging from 1 to 5) to measure quality of studies. They stated that 20 studies were high quality and 14 of low quality. However, no study met all assessment criteria and the highest score given was 4.
Reliability of conclusions	Conclusions of effectiveness based on statistical meta-analysis.
Review quality	This review has an AMSTAR score of 8/11.
Key findings	SNS interventions beneficially reduced HbA1c (glycated haemoglobin) when compared to controls, which was confirmed by sensitivity analysis. SNS interventions also significantly improved systolic and diastolic blood pressure, triglycerides and total cholesterol. Subgroup analysis according to diabetes type demonstrated that Type 2 diabetes patients had a significantly greater reduction in HbA1c than those with Type 1 diabetes.

7. Narrative summary

Five systematic reviews were selected for inclusion in this evidence summary. They all examined the use of social networking by people with long-term conditions but there was considerable variety in each population group's specific condition. Two reviews focused on people with psychosis (Alvarez-Jimenez et al., 2014 and Highton-Williamson et al., 2015). Toma et al. (2014) examined patients with diabetes mellitus; Koskan et al. (2014) reviewed cancer related studies and Stellefson et al. (2013) were concerned with chronic diseases more generally, including diabetes and arthritis. Key themes were extracted from the literature in order to answer the research questions and presented below.

7.1 What impact does social networking have on the self-management of adults with long term conditions?

This question was answered by three systematic reviews (Alvarez-Jimenez et al., 2014; Stellefson et al., 2013; Toma et al., 2014).

Clinical outcomes

Three studies found that social networking services improved participants' clinical outcomes.

For patients with psychosis, online and mobile based interventions showed promise in improving psychotic symptoms, hospital admissions and depression (Alvarez-Jimenez et al., 2014). Social networking interventions were also found to be successful when used by participants with diabetes mellitus; Toma et al. (2014) reported that there was a significant reduction of glycated haemoglobin when using social networking services. They also state that the intervention aided in reducing triglycerides, total cholesterol and both systolic and diastolic blood pressure. Stellefson et al. (2013) also reported improvements in glycated haemoglobin, blood pressure and depression in participants with diabetes. However, overall, Stellefson et al. (2013) found little evidence that web 2.0 interventions had an impact on biological outcomes among older adults.

One study suggested that it may be necessary to use social networking and online interventions in conjunction with other technological interventions to be effective. Mobile only interventions (such as text messaging) were not found to improve health but were more effective when used in conjunction with online services (Toma et al., 2014).

Psychosocial outcomes

Three studies found social networking interventions to be effective in improving psychosocial outcomes, such as stress and social connectedness.

Alvarez-Jimenez et al. (2014) reported that social networking, when used in conjunction with online psychotherapy, was both feasible and acceptable to patients with schizophrenia and their carers but had conflicting results relating to carers' perceived stress and social support. It may improve positive psychotic symptoms when both patient and carer are targeted by the intervention. They also state that integrated online therapy, social networking and expert and peer support moderation showed promise in improving social connectedness in patients with first episode psychosis. Toma et al. (2014) found that social networking has transformed communication in healthcare – patients can interact and connect with healthcare professionals and other patients on a global scale to receive information and peer support (Toma et al., 2014). Stellefson et al. (2013) reported that participants found discussion boards, resource pages and asynchronous electronic

messaging as being particularly useful for self-management support and interactive health communication.

7.2 Does the use of social networking enable people with long term conditions to feel empowered when self-managing?

Two studies found that social networking interventions could enable empowerment when self-managing long-term conditions (Alvarez-Jimenez et al., 2014, Stellefson et al., 2013).

Empowerment is a key feature of self-management; it allows patients to discover and develop their own knowledge and capacity to manage their condition(s) effectively. Stellefson et al. (2013) found that participants using social networking interventions felt greater self-efficacy for managing their disease(s) and that their perception of social support improved which is perceived as crucial for empowerment. They also note that as familiarity with Web 2.0 improves, participants may gain knowledge, skills, and mastery experiences to reinforce recommended self-management strategies and as programme exposure increased among participants, so too did comfort with using computers and the Internet. The review by Alvarez-Jimenez et al. (2014) suggested that social networking can empower people with psychosis; they reviewed one study that provided preliminary support for the benefits of using social networking when discussing psychotherapy and practising therapeutic techniques to manage their condition(s).

7.3 What types of social networking do adults with long term conditions use and for what purposes?

Two systematic reviews identified the types of social networking used by people with long-term conditions (Highton-Williamson et al., 2015; Koskan et al., 2014).

Koskan et al. (2014) found that from 1996 to 2013 the most popular types of social networking for cancer-related information were: online forums, discussion boards, message boards and online support groups. Also used (from 2008 onwards) were: blogs, video sharing sites such as YouTube, recognised social networking sites such as Facebook, and a virtual world – Second Life. Microblogging services, such as Twitter, were reported as being used from 2012 onwards

One review found that the public prefer to search online directly for cancer related information or to seek support on online message boards rather than on social networking sites (Koskan et al. 2014). The authors suggested that this may be due to issues of anonymity and confidentiality. Highton-Williamson et al. (2015) report that online forums are popular amongst people with psychosis and used for discussion relating to the more

social and emotional aspects of the condition. It found several studies that highlighted the “support”, “empathy” and “help (not advice)” made available from discussion forums.

Highton-Williamson et al. (2015) found that social networking services are used by patients with psychosis for establishing new relationships (with or without the possibility of offline interaction), maintaining relationships/reconnecting with people and for online peer support. However, some studies in the review suggested that people with psychosis may find e-mail or Facebook less preferable than other online social networking tools.

Koskan et al. (2014) reported that many of the studies included in their review analysed the content of social media sites and the main purposes for using them. It found they were used as sounding boards to express emotions and raise awareness about cancer; to provide support for cancer survivors and caregivers; to promote information sharing and problem solving; to recommend specific treatments; and (less often) to raise funds for cancer related initiatives.

8. References

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Date this summary was last updated: 21/5/2015

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Appendix 1

Example of search strategy used in Cochrane Database of Systematic Reviews. Similar strategies were adapted for other databases searched.

Cochrane

ID	Search
#1	MeSH descriptor: [Social Media] explode all trees
#2	MeSH descriptor: [Social Networking] explode all trees
#3	"web 2.0"
#4	twitter
#5	youtube
#6	facebook
#7	dailystrength
#8	patientslikeme
#9	instagram
#10	MeSH descriptor: [Blogging] explode all trees
#11	wiki*
#12	"online support group"
#13	"electronic support group"
#14	"message board"
#15	"chatroom"
#16	"discussion forum"
#17	"bulletin board"
#18	{or #1-#17}