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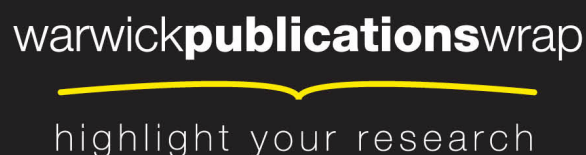
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**Digital social networks and their potential for impact on health and health systems: a scoping review and case studies**

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## **Digital social networks and their potential for impact on health and health systems: a scoping review and case studies**

### **Abstract**

Interaction through digital social networks potentially results in the contestation of prevailing ideas about health and health care and to mass protest where health is put at risk or health care provision is wanting. Through literature review and case studies of social networking sites we establish the extent to which this phenomenon is documented, seek evidence of the prevalence and character of health-related networks, and explore their structure, function, participants and impact, seeking to understand how they came into being and how they sustain themselves. Our case studies are PatientsLikeMe, Mumsnet, Treatment Action Campaign and My Pro Ana. The study is limited to English language and relatively well-established platforms only. Results indicate individuals mostly use social networking to assist with individual health issues and to provide reciprocal support for others. There is some evidence of protest activity that aims to change health systems. Platform owners and managers have considerable power over whether and how activity leads to campaigns for change. Campaigning activity becomes integrated with established social structures. Further research is needed to understand the potential for social networking to influence health policy and provision if the structure, functions and ownership of the platforms were different.

### **Introduction**

The ability to access and disseminate information through digital communication networks (e.g. internet, mobile phones) is changing societal activities including national politics and election campaigns (Gruzd & Roy, 2014), local politics and activism (Biondo, 2013), and accountability (Sagar, 2013). Within the health domain there is potential for interaction through digital social networks to enable individuals to interact with others with similar concerns about health risks or where health care is wanting. This could result in change in health care demand or mass protest that impacts on health policy. This paper considers whether there are indications that this is happening.

We know that digital communication is changing how people access and receive information about health and health care (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004), share health and health care data including personal experience (Ziebland & Wyke, 2012), and collate and interpret this data (Griffiths et al., 2012). There have been examples of social media being used as part of media campaigns for specific treatments to be made available (Pullman, Zarzeczny, & Picard, 2013). People living with chronic illness often become expert at managing their own condition, but not always in the way health professionals expect (Greenhalgh, 2009). Engaging with health related digital social networks is one route for gaining this expertise. Although misinformation about health can spread through such networks (Scarfeld, Scarfled, & Larson, 2010), there is evidence that this is rapidly corrected by network participants (Jessica S. Ancker et al., 2009; Armstrong & Powell, 2009; Esquivel, Meric-Bernstam, & Bernstam, 2006a). Interaction through digital social networks can lead to the identification of problems related to health that the professionals have not yet thought about, and to the contestation of prevailing ideas about health and health care. This interaction also has the potential to enable mass protest where health is put at risk or health care provision is wanting. It is argued that although digitally networked groups, such as mothers of young children and people with rare diseases, are becoming powerful, special-interest, lobby groups, this phenomenon is not replicated across all health issues, population groups and contexts (Griffiths et al., 2012). However, in the future, the impact of protest about health care provision, engendered through digital social networking, could be greater in countries where accountability of health providers is weak and the health system is inefficient and inadequate. We suggest that digital social networking could provide an innovative approach to enhancing community representation, ownership and participation in health service policy formulation, as called for by the World Health Organisation (World Health Organisation (WHO): Regional Office for Africa, 2012).

In this paper we explore the potential impact of digital social networks comprised of people who are not health professionals but who interact about health-related issues. We are interested in how such networks impact health and health systems and seek to understand how their effect varies in different contexts and why. Our research question is:

What is the potential for impact of health-related, lay-controlled networked digital communication on health and health systems?

We are interested in any direct effect on health and health systems at the individual level; for example, where people learn about their health or access health care in a different way as a result of peer interaction on a social network. Policy makers need to take into account such changes in how their populations seek health and health care. However, social networking potentially could have a wider political role. Peer interaction has the potential to lead to political action and influence policy about health and health care. In our case studies we consider the balance between these different activities and impacts on health, health care and health care policy.

Digital social networking activity may vary in pattern, content and evolution, depending on the health condition. Similarly, for different health conditions people engaging with the digital social network may make use of or adapt to the social network in different ways. We focus on health-related social networks that are initiated and controlled by people who are not part of formal health care systems but may be interested in health for themselves or on behalf of other people, including society more generally. Network activity can be relatively transient, for example, an exchange on Twitter in response to changes in health care provision (King et al., 2013), or more sustained, such as patients seeking support on how to cope with a specific health problem such as Parkinson's disease (Attard & Coulson, 2012). The networks may be within a wider network context such as Mumsnet (Mumsnet Limited). Currently, the networks that are most visible are those which have evolved into commercial enterprises, with management teams who may not be health experts but are experts in a managerial sense.

For this study we initially include digital social networks where individuals interact with other individuals directly, such as within a discussion forum or on a blog with responses. The interaction may be visible to a limited group of registered users or to the general public. We also include indirect interaction via other individuals (retweets on Twitter are an example), and interaction between an individual and a large group people (such as occurs on PatientsLikeMe). We identify more sustained and established social networks as transient networks that form and disperse quickly are relatively more difficult to capture and study. An example of a transient network would be a thread on Reddit or a Twitter conversation about a health issue. The interaction is transient because of the nature of the platform on which it takes place and the form of the interaction. Most Twitter conversations are between a small set of people but even when large numbers are involved they are still relatively transient. A platform such as Reddit is divided into communities around themes. Examples related to health are fitness, and diabetes. Hundreds of new threads can be created daily within each theme. Those that are visible on the front page are those receiving user votes. However, even popular threads do not last more than one or two days before being buried. With transient social networks it is possible to analyse the overall content using text analysis (e.g. (Mishori, Singh, Levy, & Newport, 2014)). However, it is difficult to capture sufficient detail of these conversations to understand why they take place, the informational quality, and how and why they may be taken up by other individuals or dropped. Therefore, although we included this type of social network in the initial stages of our scoping study, they were excluded from our case studies.

We explore the impact of sustained health related digital social networks as follows. For the scoping review we establish the extent to which the phenomenon of social networks related to health is documented in publically available literature, and evidence of the prevalence of these networks. In order to select our case studies, we describe the characteristics of documented networks and how they vary. We then select four networks as case studies (Yin, 2009) and explore their structure, function, participants and impact, seeking to understand how they came into being, how they sustain themselves, and what changed as they matured.

## **Methods**

Our research uses peer reviewed academic literature, other literature including news stories, and examination of social network sites.

*Phase 1: Understanding the extent to which social networks related to health are documented and evidence of the prevalence of these networks related to health.*

The following databases were searched: Medline, Web of Science, Embase and the Applied Social Sciences Index and Abstract (ASSIA) using the keywords: Lay, volunteer\*, lobby\*, pressure group\*,

interest group\*, self help group\*, social media, digital media, digital communication, web 2.0, internet, blog\*, twitter, facebook, tweet, forum\*, crowdsourcing, wiki, email, health, healthcare, medicine, medical. This retrieved 3154 references after de-duplication. For this scoping review we rapidly sorted this literature based on title to exclude irrelevant papers and to exclude for example, reports of health professionals using social networking as an intervention, or the use of social networking within closed support groups. This initial sift identified 133 potential papers. These papers were read in full and data extracted on: the identity of the studied social network, the research approach used and a summary of results. News items on social networks were identified through using individual newspaper search systems. We excluded non-English language literature.

### *Phase 2. Describing the characteristics of documented networks and how they vary*

From reading the literature and discussion within the research team we drafted a framework for characterising the social networks identified in phase 1. We then examined and compared each social network to refine this framework (see Box 1). We then re-examined each social network and summarised its characteristics within this framework (see Table 1). Distinct network elements—blogs, discussion forums, multimedia – were easily discernible from the homepage of networks. The dimensions of each network represent the key outcomes from a user’s engagement with a particular network. Websites which included considerable informative material (such as explaining more about certain conditions and giving expert advice) permanently embedded within them were classified as active in disseminating information. Where networks had opportunities for person-to-person interaction, we considered this as potentially facilitating emotional support and providing guidance. Through our discussions, we decided to distinguish between the spread of established information (text or links to outside sources) versus the collection and collation of information derived from the network itself. We also considered how online network activity between users might translate to wider changes in society and developed dimensions capturing campaigning and fundraising activities. Evidence about network formation came from published literature or the website itself. The character of each network, such as whether a visible network was present and the degree of anonymity in the network, was deduced by emulating the process of an interested user: accessing certain elements (e.g. discussion forum), registering a username if required, and exploring the avenues for interaction. Of those we have logged, none had the requirement that users be patients themselves in order to register. In many instances it is possible to register as a researcher. One anorexia network asked all those registering to either be a current or recovering patient with eating disorders. We therefore did not look into it.

### *Phase 3: Choosing and undertaking our case studies*

We reviewed the results of phase 2 to identify four diverse case studies. We excluded network sites run by medical professionals. We did not exclude those run by professional managers as this would have excluded the larger more established sites. We then selected from those remaining, four networking sites with different purposes and origins: Mumsnet, PatientsLikeMe, Treatment Action Campaign (TAC) and My Pro Ana (see Box 2). For each case study we then searched for relevant literature using ABI Inform and Business Source Premier searching using the four case study site names. Ninety-one potential articles were identified. A review of the abstract and full text identified over thirty papers which discussed the history and development of the case studies, examples of their influence in health related issues, and articles reporting interviews with key individuals. We also undertook further investigation of the social networks themselves. This included examining: site structure, site function (purpose; activity volume; content), participants (local/global; condition specific or not; numbers of new and existing members), impact (evidence of impact on health of participants, on health care services, health care policy, wider issues), how the network came into being, how it sustained itself and what changed as it matured. Following Yin (2009), in order to provide a structure for our data extraction from the social network sites, we developed propositions about social networks through team discussions. To develop these propositions we drew on our literature review and the disciplinary knowledge of the research team (internet science, social science, behavioural economics, epidemiology, clinical/health science, health policy). We developed the propositions to focus our data extraction on our interest in the balance promoted by social network sites of individual level activity related to health/health care versus the formation of politically active groups including mass protest. We used these propositions to guide the data extraction and analysis for the four case studies. The propositions were as follows:

- a) The structure and function of the social network site impacts on usage and ultimately on sustainability: (i) quality of user interface; (ii) responsiveness (feedback taken into account);

- (iii) needs fulfilment (extent to which user preferences can be met); (iv) security (Harrison, Barlow, & Williams, 2007)
- b) The explicit purpose of the site influences the content of social network activity but does not completely limit it (e.g. side conversations can erupt)
- c) Volume of traffic (in general or on a specific health issue) of social network sites will determine its impact on health/health care
- d) The nature of the health condition discussed through the social network influences the nature of the social network activity (e.g. sustained use by stable community of members, people coming and going rapidly)
- e) The presence of moderators or established active/expert/respected users influences the impact of social network on individual health but can limit its potential for challenging prevailing norms and knowledge
- f) Social networks influence service provision and health care policy
- g) Condition specific content maintains a focus on individual gains from social network and limits the likelihood of the social network influencing community issues such as service provision
- h) Geographically local networks are more likely to develop campaigns in relation to community issues such as service provision
- i) Lay controlled networks that lack professional managerial expertise are not sustained
- j) As social networks mature they become integrated into the real world network of established social structures (industry, health providers, governments, community, advocacy groups etc.) and take on attributes and activities of those social structures which have similar purpose.

## Results

*Phase 1. Understanding the extent to which social network related to health is documented and evidence of the prevalence of these networks related to health.*

Most of the 133 papers identified reported analysis of content posted on social health networks or reported researcher-created surveys. Studies included exploring user motivations for participating in such networks, the role of networks in empowering patients and the influence on the patient-doctor relationship from the perspective of the user. How the social networks were created and maintained was rarely studied, and there was little distinction in the literature between lay-initiated (or controlled) and professionally-managed networks.

Studies commonly focused on a specific network and/or specific health condition. There are analyses of discussion forums dedicated to various conditions including: miscarriage (Betts, Dahlen, & Smith, 2014), cancer (Barker & Galardi, 2011; Bender, Jimenez-Marroquin, & Jadad, 2011; Broom, 2005; Chen, 2012; Huber et al., 2011; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009), Parkinson's disease (Attard & Coulson, 2012), eating disorders (Flynn & Stana, 2012; Haas, Irr, Jennings, & Wagner, 2011). These studies monitor network activity over a set period of time, compile scenarios of user interaction and analyse content for trends. Results indicate that participants tend to seek out networks for emotional support and to find solace in their condition. For example, a study investigating a miscarriage forum found that users accessed the network to find a 'reason for hope', sharing stories and real life experiences with others to connect for empathic support (Betts et al., 2014). Having experience in common with others in the social network can result in interactions that are less judgemental than in other social arenas. Individuals are willing to openly discuss conditions which are socially very sensitive or embarrassing, for example, on an online men's eating disorder forum (Flynn & Stana, 2012). Where a health issue is very personal in nature, a study of the social networking site EverydayHealth suggests that interaction with lay-people or other patients may be more influential in inspiring healthy behaviour than discussion with medical professionals (Abrahamson & Rubin, 2012).

The quality of information circulating within these networks was studied. We report on studies which focus on the participants' perception of informational quality and exclude studies where authors formally analysed the quality of information shared. Papers detailing how users perceive quality (J. S. Ancker et al., 2009; Armstrong & Powell, 2009; Slaughter, Keselman, Kushniruk, & Patel, 2005; Vennik, Adams, Faber, & Putters, 2014; Williams, Huntington, & Nicholas, 2003) show that many individuals acknowledge that posted information may be from non-expert sources. Individuals enter such networks to establish a broader understanding of a condition, what it is like living with it, and to seek further details to satisfy their own needs, whilst having reservations about the source of the information. When users look at network credibility (whether they can trust the information they

read), they do so – imperfectly – in various ways including: content comprehensiveness, website complexity, personal knowledge of the source (Kravitz & Bell, 2013). An analysis of a breast cancer discussion list found that it was considered in the community interest to correct misinformation, with false claims often being corrected in a short span of time (Esquivel, Meric-Bernstam, & Bernstam, 2006b). While most studies focused on the perspective of the network user, several also detailed the motivations behind those who created or actively moderate networks. A survey across patient moderators in various online support groups revealed that creators felt that no existing provision accommodated people with the particular health condition, that they wanted to help educate those living with difficult diseases or conditions, and ultimately that they wished to ensure patients did not feel isolated (Coulson & Shaw, 2013).

Non-peer reviewed literature provided stories behind a user's experience within a network and their motivations for participation. It also reported the circumstances which prompted founders to establish these networks. An article linked the founding of the health community PatientsLikeMe by brothers Ben and Jamie Heywood to the diagnosis of their brother with ALS (Amyotrophic lateral sclerosis also known as Motor Neurone Disease) (Independent, 2011), and another described how people living with chronic diseases seek online communities to connect with others and relieve the day-to-day stress of their condition (Miller, 2010).

Table 1 lists the social networks identified through this literature review and other well-known sites identified by the research team.

#### *Phase 2. The characteristics of documented networks and how they vary*

The dimensions of the networks identified are summarised in Table 1. It was straight forward to identify most characteristics. When considering formation of connections we were not concerned with type of element used. For example, the connection could be made through replying to a post on a discussion thread or 'commenting' on a Facebook status. When categorising the levels of 'memory' in a network we viewed the network as a whole rather than considering individual posts or components, although memory – the visibility of information or content – is longer in popular or highly active content.

#### *Phase 3: The case studies*

Of the 23 networks identified, only 8 did not have formal medical professional input. From these, four case studies were selected. One network – PatientsLikeMe – focused on the collection, collation and correction of information derived from the network itself. This was an important distinction because almost all other identified networks emphasised the dissemination of existing information. Two had clear campaigning elements attached to them: MumsNet and Treatment Action Campaign (TAC) in South Africa. TAC was identified from local knowledge, as it represents a network which started as a face-to-face network and developed a web presence. The fourth case study, My Pro Ana, claims not to be pro-anorexia but its content includes participants encouraging others to skip meals and fast. We selected this network as its content is not in line with normal health care advice.

Below we describe each case study in terms of its structure, function, participants and impact, how it came into being, how it is sustained and what has changed as it matured. In Table 2 we summarise the evidence to support or not support each proposition. Our description of each case study is based on our examination of the case study network sites, supported by reference to relevant literature.

#### *Case study 1: PatientsLikeMe*

Two brothers founded PatientsLikeMe in 2004 as a result of their experience supporting a close family member suffering from ALS (Motor Neurone Disease). Their belief was that by creating a network or platform for individuals to share their experiences, patients would gain support and researchers could use contributed data to accelerate the development of treatments. PatientsLikeMe was restricted to only those with ALS until it expanded in 2011 to individuals experiencing any condition. Currently, it claims over 250,000 unique users covering over 2,000 different conditions. The user interface is of high quality. To participate within the network, users create personal profiles highlighting their health conditions and any symptoms they have been feeling. Once a profile has been created, the network automatically links users (via a chart that aggregates data) to others who are experiencing similar problems. Site members can observe how similar or different their experience is from others with a similar health condition (see example: <http://en.wikipedia.org/wiki/File:StephenProfile2011.jpg>). The

aggregate data is continuously updated based on symptoms reported by users each day. PatientsLikeMe advocates for open sharing of health data for speeding up the development of treatment development. It suggests it can play a role in emerging 'patient experiments' where patients initiate studies, monitor their disease related symptoms and pool their data (Frost, Okun, Vaughan, Heywood, & Wicks, 2011; Wicks, Vaughan, & Heywood, 2014). It claims that over 50 published research studies have used information generated through the network. PatientsLikeMe finances its operational costs through the selling of data to its partners, which include pharmaceutical companies and medical device makers. The site provides a Crisis section including a hotline for users and advice about contacting their usual doctor. It does not allow advertising.

#### *Case study 2: Mumsnet*

Mumsnet was launched in 2000 by a mother who aimed to create an advice-based website for parents. Although it covers all aspects of parenting, it hosts many health-related discussions. Overall it has a following of over 4.8 million unique monthly visitors to its website. While predominantly UK-centric, in recent years Mumsnet has begun to attract a wider international audience. The components of the network are themselves quite simple: static information and references to material beyond the site, an active discussion forum, blog and user reviews. Users interact within thematic discussion forums. They can search for retail products relating to parenting in order to view reviews generated by other network users. Mumsnet also hosts an active bloggers' network which links the blog posts of over 5,000 Mumsnet users to one common source. Mumsnet has developed a political campaigning role. Posts to Mumsnet forums and blogs demonstrated discontent with miscarriage care and breast feeding facilities. Groups of individuals formed around these issues into campaign groups and achieved impact on health care policy in the UK. Mumsnet also provides links to external national and local campaigning efforts.

#### *Case study 3: Treatment Action Campaign*

Treatment Action Campaign was first launched in late 1998 as an on-the-ground campaign group for improved treatment access for HIV/AIDS in South Africa. The majority of network activity occurs offline. Currently, the TAC website is static, providing information and displaying links and contact details to further become involved within the network. There are no networking facilities. This may reflect the poor penetration of internet access until recently in South Africa. There is no evidence from the website of the role of mobile-based forms of communication such as text messaging which is widely used in South Africa.

#### *Case study 4: My Pro Ana*

My Pro Ana lists itself as an online forum and community to support users afflicted with eating disorders. Formally, the community denies any role in fostering or encouraging those with eating disorders. Little information about the history of My Pro Ana – or networks of a similar nature content-wise – is available on the website itself. The earliest traceable date for this site is 2013. This might reflect the short lifespan of relative niche (and often negative) health communities, either due to dormancy or forced closure, though more formal investigations are still needed in this regard. The site has a standard set of components which encourage users to share information or discuss their experiences. This includes various thematic-grouped discussion forums, a live chat log, and gallery for images of inspiration (or 'thinspiration' as dubbed by users within the anorexia community). In total, My Pro Ana hosts approximately 115,000 members. Although a majority are from the US, participants are drawn from across the world (Alexa Internet). At any given moment the community is quite active, having at most times 1,000 users online. Typically, the community is split into a variety of sections covering emotional support, physical exercise, diets, and pro-anorexia behaviour. It also has a Twitter presence with almost 2000 followers. Our examination of posts on My Pro Ana suggests that considerable activity is about sustaining eating disorders. We traced an online petition asking for My Pro Ana to be shut down (change.org, 2014).

## **Discussion**

This scoping review and case studies aimed to understand the potential for health-related, lay-controlled networked digital communication to have an impact on health and health systems and so act as a driver for policy. In particular we were interested in whether digital social networking had its impact through influencing individuals' health and health care seeking with policy makers needing to



pay attention to this effect. Or, whether social networking generated more general political activity, including mass protest, that lead to influence on policy.

Our case studies suggest interaction through social networking sites related to health has the potential to link people who have a health experience in common and would otherwise not interact because they are geographically isolated from each other (e.g. uncommon conditions), they are limited in their ability to interact socially (e.g. parents of small children and people with disabling conditions) or because interaction about their health condition is stigmatised (e.g. anorexia nervosa) (Rouleau & von Ranson, 2011). Most interaction on the social networking sites involves individuals seeking peer support as they struggle with their health condition or managing their parenting role (Plantin & Daneback, 2009). There is evidence from previous research that individuals may gain in terms of emotional support and learning how to live with their condition. This includes how to access specific treatments. A change in what people expect from health care services and their confidence in demanding treatments and other services is likely to impact on health care policy and provision. Two case study sites (PatientsLikeMe and Mumsnet) claimed to have been established as a response to difficult experiences of the founders and are based on the desire for support in their situation. These have become established sites. My Pro Ana claims to support those with anorexia, although its content – similar across other pro-eating disorder social networks - seems to promote the condition (Haas et al., 2011; Rouleau & von Ranson, 2011). It is relatively new and is a small, condition-specific site.

On three case study sites there is evidence of more general activity that aims to change health systems (TAC, Mumsnet and PatientsLikeMe). The level of control by the digital platform owners over what issues are identified for campaigns and how campaigns are supported varies. PatientsLikeMe keeps complete control as they aim to change health care through selling data for research. There is evidence on Mumsnet of Mumsnet members taking forward campaigns as individuals or groups and reporting back through Mumsnet, and some of the campaigns appear to be based on the concerns expressed in Mumsnet posts (Pedersen & Smithson, 2013). TAC started as an offline social network and has not yet established active online social networking. Research on TAC campaigning suggests that in addition to the direct effect of the campaign, individual behaviours in relation to HIV in the context of such active political campaigns can contribute to change in social attitudes (Levy & Storeng, 2007). This suggests a further potential indirect route of influence for social networks on policy – individuals aware of the campaign gain confidence in demanding health care. All activities of the social networks directly aiming to change health systems have become integrated with established social structures and social systems rather than giving rise to a new form of mass protest. The content of My Pro Ana is arguably anti-established health care but actions taken are by individuals in relation to their own health and not as a social grouping.

### **Limitations of the study**

Using our study approach we were unable to study transient network interactions on health issues. Understanding how transient interactions, such as on Twitter or Reddit, influence health or health systems is likely to require both online data collection and offline methods, for example, the ethnographic approach used to study parents of children with genetic conditions (Schaffer, Kuczynski, & Skinner, 2008). As passive observers of the case study sites, the only evidence available to us on the level of moderation of posts on the site was the published site policy. Our study is limited to English language sites and related literature. However, many non-English speaking areas of the world are at least as engaged in social networking in relation to health. For example, several Vietnamese online newspaper includes a health section with forum for posting or blogs with comments posted (see <http://bacsytructuyen.com/> ; <http://www.webtretho.com/> ;<http://www.lamchame.com/>).

### **Conclusion**

The social networking sites we studied are mostly used by individuals to assist with their own individual health issues and to provide reciprocal support for other individuals. This has potential to impact on policy through changing demand for health care. Where the social networking platforms are active in trying to change the health system, this activity is currently controlled at least to some degree by the platform owners. The activity becomes integrated with established social structures and systems rather than prompting mass protest. However, the active campaign may prompt individuals to change their demand for health care which might impact on policy. The professionals managing the social networking platforms potentially have considerable power in shaping the direction of campaigns to change health care. Our study has been limited to relatively well established platforms.

Further research is needed to understand the potential for social networking to influence health policy and provision if the architecture, functions, ownership and evolution of the platforms were different.

## Components

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Personal profiles	Users are given an individual page which can display personal details, interests, friends, photos, likes, and more. This is customisable and the amount of information available to the public is typically user-defined.
Videos and multimedia	Network has permanently embedded videos or multimedia which serves to inform or provide emotional support.
Ask an expert	Participants are able to directly contact medical professionals with their health-related questions through the network website.
Discussion forum	A list of discussion threads which are user-generated and in which other users can post replies or comments. Often discussion forums are separated into various sub-groups or categories (eg for specific conditions). In some instances forums are moderated by professionals.
Blog (expert)	Network hosts articles or blog posts written by medical professionals. This can be to either provide information or advice/tips to users.
Blog/journal (participant)	Users have the ability to post their own blog (journal) entries which are visible to others. Typically these involve personal reflections, experiences or advice for others who may read the entries.
Posts/comments	To be distinguished from discussion forums. Posts or statuses are similar in nature to threads but are not structured or categorised by the network owner. They are typically added to a 'stream' of other posts made by other users.
Chat/private messaging	Participants within the network have the ability to send private messages (emails) which are only visible to the two interacting parties.

## Dimensions

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Dissemination of information	A central aim of the network is the dissemination of <u>established</u> information or advice to users. This may be through permanent text or multimedia; expert contributions through guest articles or blogs; or references to other sources of information.
Collection, collation and correction of information	To be distinguished from the dissemination of information. This explicitly touches on the emergence ('collection' or 'collation') of information which is derived from network activity and user

contributions *within the network*.

- Emotional support Classifies networks which embed elements that support user exchanges of experiences, personal advice, or any other function which serves to promote emotional wellbeing.
- Campaigning Through the network, users are active in setting political goals or creating social movements around health issues. Critically, these actions are founded through collective action *within* the particular network (initiation can be both by owners and users of the network)
- Fundraising The network clearly integrates options for participants to donate or raise money for health-related causes *which are not concerned with the maintenance and operation of the physical network*. For instance: links or built-in platforms to donate for charity research.

### Network formation

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- Medical professional Network founded by an experienced medical practitioner or 'health expert'.
- Managerial professional Network created by an individual with managerial, technical, commercial or other expertise but *which is not associated with expert health knowledge*.
- Lay Network formed by individuals who do not possess professional skills that would otherwise be associated with the previous categories. Often these individuals are patients or close to other individuals who have gone through or live with a health condition.

### Network character

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- Visible network In networks where users are able to form connections (see below), a visible network means that the social network of each user (for instance they people they follow or friends they have) is *visible* to other users. Applying this to a macro scale, the list of participants of the network is visible to others.
- Sub-network This refers to health networks which are embedded within larger, non-health related social networks. For example: a Facebook group dedicated to raising awareness for cancer.
- Formation of connections Users are able to create 'physical' links or ties to other participants within the network. Typically, the formation of link with another user results in greater sharing of information between the two individuals.
- Anonymity Anonymity captures the extent to which participants can remain anonymous or conceal personal information about themselves. In almost all cases, this is user-defined: there is an element of choice over how much personal information a user wishes to disclose. Within this characteristic, there are three sub-classifications (low, medium,

	high) which are assigned based on the total amount of information which can <i>potentially</i> be displayed about a user (if they choose to do so)
Accessibility	Accessibility is broken down into two sub-parts: (i) the restrictions in place which prevent individuals to <i>view</i> content on the network and (ii) restrictions on whether an individual can <i>participate</i> within the network.
Memory	The memory of a network refers to the length of time content is visible in the network. Transient networks – those with very short memories – rapidly update content, with older content pushed down. Within this characterisation, permanent memory refers to information or content which is controlled by the owner of the network. In various settings, the memory of a particular piece of content can be influence by user activity (more posts on a discussion thread make it more visible and last longer).
Moderation	Moderation refers to the filtration of user-created content in the network. This is often done by network owners or experience users to ensure behavioural guidelines and etiquette are upheld and to prevent the spread of misinformation.
Expert research	This characteristic refers to the use of information derived from activity <i>within the particular network</i> by professionals for research purposes, with the intention of using this information to enhance the experience of users.

**Box 1 Definitions of the characteristics of social networking sites**

Network	Elements								Dimensions				
	Personal profiles	Video / Multimedia	Ask an expert	Discussion forum	Blog (Expert)	Blog/Journal (Participant)	Posts / Comments	Chat / Private messaging	Dissemination of information	Collection, collation + correction of information	Emotional support	Campaigning	Fundraising
Facebook group	x	External Link					x	x	External Link			x	x
Twitter	x	External Link					x	x	x			x	
LinkedIn group	x	External Link					x	x	External Link			x	x
Reddit		External Link		x			x	x	External Link	x	x	x	x
YouTube	x	x					x	x	x		x	x	x
PatientsLikeMe	x			x	x	x		x		x	x		
DailyStrength	x		x	x	x	x		x	x		x		
Mumsnet	x			x	x			x	x		x		
HealthTalk Online		x			x					x			x
HealthBoards	x	x		x		x			x		x		
WebTribes				x	x	x		x	x		x		
beyondblue			x	x				x	x		x		x
HealthCentral		x	x		x	x			x				
HealthfulChat								x			x		
PsychCentral			x	x	x			x	x				
CureTogether (23andme)							x	x		x			
Big White Wall	x						x	x			x		
HealthUnlocked	x						x	x	x		x		
Everyday Health		x			x				x				



HealthUnlocked	x	x		
Everyday Health		x		
BrainTalk Communities	x		x	
DiabeticConnect (Alliance Health)		x		x
TAC		x	Initial	
My Pro Ana			x	

			Registration	Registration	Medium	
					Permanent	
	User-defined (High)	Full	Registration	Medium		x
x	User-defined (Medium)	Full	Registration			
		Full			Permanent	
	User-defined (Medium)	Full	Registration	Medium		x

**Table 1 Characteristics of health related social networks**



<b>Proposition</b>	<b>PatientsLikeMe</b>	<b>Mumsnet</b>	<b>TAC</b>	<b>My Pro Ana</b>
<b>The structure and function of the social network site impacts on usage and ultimately on sustainability.</b>	Yes. 'Virtuous cycle': high quality user experience and relevant personalised feedback – high volume users providing data – commercially viable -	Yes. High quality user experience with relevant information, high user numbers, sustainable as commercial venture.	No. Structure of the website is largely static. The social network is largely sustained by interaction beyond the website.	Yes. Anonymity and ease of interaction (discussion threads) promote activity (Gavin, Rodham, & Poyer, 2008; Rouleau & von Ranson, 2011).
<b>The explicit purpose of the site influences the content of social network activity but does not completely limit it (i.e. side conversations can erupt)</b>	No. Purpose directs and completely constrains activity. No facility for side conversations.	Yes. There is no evidence that conversations not relevant to Mumsnet's aims are removed.	N/A (no direct social network activity)	Yes. The stated purpose – supporting for those experiencing eating disorders – frames the discussion, but a central focus (proliferation of eating disorders as implied by the name Pro-Ana) is not limited by site's explicit purpose
<b>Volume of traffic (in general on a specific health issue) of social network sites will determine its impact on health/health care</b>	Potentially yes. Claim that the high volume data will enable medical innovation to improve health (Frost et al., 2011). No examples of success available except one where an intervention was shown not to work as claimed. Unclear if this proposition could be proven even in the future unless commercial companies buying the data released the evidence.	Yes. Evidence that Mumsnet monitors both volume and content of posts to decide on political campaigns, future content and advertising.	Yes, albeit volume refers to on-the-ground activity. This is because TAC is largely a political / campaigning oriented network which requires high involvement and awareness to be successful.	Yes but only via individual behaviours. The activity on the site seems to encourage individuals in what is arguably behaviours that go against mainstream health care (Boero & Pascoe, 2012). There is no evidence of impact beyond individual behaviours.
<b>The nature of the health condition discussed through social network influences the nature of the social network activity (sustained use by stable community of members, people coming and going rapidly)</b>	Social network activity is constrained by the design of the site – peer to peer sharing is indirect.	Yes. The social network activity on the site and its topic- being a parent both touch on all aspects of life (Pedersen & Smithson, 2013).	TAC initially formed through networked groups of HIV/AIDS activists. Large issues – social stigmatisation and medicine costs – attributed with HIV/AIDS influenced network campaigning activity (Grebe, 2011).	Yes. The topic – eating disorders - with specific emphasis on supporting pro-anorexia – attracts a specific type of user. This type of user is more likely to represent an unorthodox view over the health issue, but one which forms consensus within the network itself

				(Boero & Pascoe, 2012). It is not clear how this impacts on people leaving or joining the network.
<b>The presence of moderators or established active/expert/respected users influences the impact of social network on individual health but can limit its potential for challenging prevailing norms and knowledge</b>	No moderators or established experts except via 'Crisis' section which provides hotline for users.	Yes: several channels for 'experts' to influence individual health/wellbeing.  There are challenges to prevailing norms through the Mumsnet campaigns.	N/A	Unlikely. There is network moderation of discussion threads, but most conversations seem to flow freely. The website claims only to filter out spam or unrelated content. It makes no claim on the role moderation plays in ensuring the medical accuracy or legitimacy of statements made within the network.
<b>Social networks do influence service provision and health care policy</b>	No evidence of any direct influence on service provision and health care policy	Some evidence of successful campaigns related to maternal and child wellbeing	Campaigning influences which services should be prioritised or improved.	The controversial nature of the content on such websites has prompted movements to establish policies aimed at banning such networks or limiting their online presence (Chesley, Alberts, Klein, & Kreipe, 2003).
<b>Condition specific content maintains a focus on individual gains from social network and limits the likelihood of the social network influencing community issues such as service provision</b>	For user the content and structure of site limits gains to individual gains. Influence on service provision is potentially possible but only indirectly via commercial companies buying the data and using it to innovate in health care.	The main focus is on individual gains from the social network. However, the campaigns that are taken up by Mumsnet do seem to be on issues identified in posts to the site but with active monitoring and some intervention from site owners. Mumsnet members also take on campaigns and report on them through Mumsnet.	No. Purpose is improving community provision of treatments.	Yes. Focus is on an individual experience or issue, with the end or outcome being personal emotional relief.
<b>Geographically local networks are more likely to develop campaigns in</b>	No facility on site that would enable development of campaigns.	This is a UK network. Mumsnet campaigns are UK centred (although their	Yes. Targets local issues by bringing together users within a specific locality	No. The network is not local and appears to attract users from a variety

<b>relation to community issues such as service provision</b>		'guest campaigns' may be international – text and links provided for users).	(sub communities in South Africa)	of different countries (Alexa Internet).
<b>Lay controlled networks that lack professional managerial expertise are not sustained</b>	Yes. This site has professional managerial expertise and is sustained.	Yes. This site has professional managerial expertise and is sustained	Yes. TAC has functioned as a large activist organisation, which has enabled it to have a much wider impact and sustain itself as a leading campaigning body in South Africa.	Conflicting evidence exists. Niche conditions lead to such networks forming tight lay communities with network-specific traits which are sustained (Adler & Adler, 2008). However, the frequent disappearance or dormancy of such niche (negative) health networks – such as several case study networks in (Haas et al., 2011) -- showcases that it becomes difficult to sustain overtime.
<b>As social networks mature they become integrated into the real world network of established social structures (industry/health providers/governments/community and advocacy groups etc.) and take on attributes and activities of those social structures which have similar purpose.</b>	<p>Little integration with established social structures for provision of understanding of the experience of illness and treatment except the provision of a crisis hot line.</p> <p>Yes. This site has become integrated with health related industry for the production of innovation in health care. Although providing a novel data collection conduit, the activity of collecting data about what happens as disease progresses and treatments tried is conceptually similar to medical research activities.</p>	Yes. Campaigns, social networking and commercial aspects are all integrated with real world network of established social structures.	To be seen. Almost the reverse direction: TAC has emerged out of established social structures into a social network.	No. Socially-sensitive and stigmatised conditions such as pro-anorexia are unlikely to influence or mature to affect real world networks as participation and involvement is held quite secretive (Gavin et al., 2008).

**Table 2. Summary of case study findings for each proposition**

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