Impact of digital social networks on health and health systems

Authors:
Frances Griffiths, University of Warwick, UK
Tim Doberman, University of Warwick, UK
Margaret Thorogood, University of Warwick, UK
Jane Goudge, University of the Witwatersrand, South Africa
Samantha Johnson, University of Warwick, UK
Kavé Salamatian, University Pierre et Marie Curie, France
Xavier Gómez Olivé, University of the Witwatersrand, South Africa
Jonathan Cave, University of Warwick, UK

The ability to access and disseminate information through digital communication networks (e.g. internet, mobile phones) is changing societal activities including national politics (Harsin) and election campaigns (Gruzd & Roy, 2014), local politics and activism (Biondo, 2013), and accountability (Sagar, 2013). In the health domain, digital communication is changing how people access and receive information about health and health care, share health and health care data, and collate and interpret this data. It is also changing how those seeking health care and those providing health expertise and skills communicate (Griffiths et al., 2012).

Over the past decade there has been recognition for those living with chronic illness that they become expert at managing their own condition, and often not in the way health professionals expect (Greenhalgh, 2009). One route for gaining expertise is through engaging with social networks related to health. Although digital social networks have the potential to spread misinformation about health (Scanfeld, Scanfeld, & Larson, 2010), there is evidence that mis-information is often rapidly corrected by others on social networks related to specific health problems (Jessica S. Ancker et al., 2009; Armstrong & Powell, 2009; Esquivel, Meric-Bernstam, & Bernstam, 2006b).

From the perspective of the public or community, it could be argued that digital social networking has the potential to enable mass protest where health is put at risk or health care provision is perceived to be wanting. Interaction through social networks may also lead to the identification of issues that health care professionals have not yet thought about and to the contestation of prevailing ideas about health and health care. Drawing on published empirical and theoretical evidence we have argued that although 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). The impact of activity on social networks on health care provision may be greater in countries where accountability of health providers and associated governance is weak and the health system is inefficient and inadequate. Innovative approaches to enhancing community representation, ownership and participation in health service policy formulation have been advocated (World Health Organisation (WHO): Regional Office for Africa, 2012).

Networked communication in relation to health has the potential to increase further as access to the internet, including through smart phones, increases worldwide. Through such social networks, information about health issues spreads and people can encounter others with similar health conditions and potentially build on this networking to improve their situation. There is network activity in relation to health that is 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 activity on social networks by people with long term conditions, such as patients seeking support on how to cope with a chronic disease such as Parkinson's disease on specific internet forums (Attard & Coulson, 2012). It is possible that activity on a social network about one health condition may make use of or adapt to the social network in a different way to people active on a social network about another health condition. The

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networks that are currently most visible are those which have evolved into commercial enterprises with management teams who may not be professional health experts but are professional managers of social networking sites.

In this paper we explore the potential for digital networked communication to impact on health and health systems and seek to understand how their effect varies in different contexts and why. In particular we focus on 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. The networks related to health may be within a wider social network context such as Mumsnet (Mumsnet Limited). Networked communication may be relatively sustained such as on discussion forums for specific chronic diseases, or transient such as a discussion on Twitter. For this study we include individuals interacting with other individuals directly such as a discussion forum or blogs with responses, where 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 as can take place on Twitter with retweets and interaction between an individual and large groups of individuals such as occurs on patientslike me.

In this study we will be identifying more sustained and established social networks as transient networks that form and disperse are relatively 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 sometimes they can involve large numbers of people but 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 within a theme each day. Those that are visible on the front page are those voted for by users. Although some threads can become very popular they do not last more than one or two days before being buried. For transient social networks it is possible to analyse the overall content by analysing tweets for certain words (e.g. (Mishori, Singh, Levy, & Newport, 2014)) but what cannot be easily captured is sufficient detail of these conversations in order to understand why they take place, the informational quality, and how and why they may be taken up by other individuals or dropped.

Our exploration of the impact of sustained and established social networks involves three steps. First we establish the extent to which the phenomenon is documented and evidence of the prevalence of these networks related to health. Then we describe the characteristics of documented networks and how they vary. To understand the impact of identified social networks we then use a case study approach 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.

Step 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 networkingl within support groups with no outward facing purpose. 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.

Step 2. Describing the characteristics of documented networks and how they vary
From reading the literature and discussion within the research team we developed a framework of dimensions of interest for characterising the social networks identified in step 1. We developed a definition of each of the dimensions (see box 1). We then examined each social network and summarised its characteristics within this framework (see Table 1). The dimensions of each network were used to classify the key outcomes from a user's engagement with a particular network. This captures user motivation and what participants hope to gain from accessing the network. To develop the matrix we first consulted the literature. There is considerable research indicating the role of such networks as a source of information and emotional support deriving from person-to-person interaction. From 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. We therefore developed dimensions capturing campaigning and fundraising activities.

To characterise the networks we analysed the components of each identified social network using the dimensions in our framework. Distinct network components – blogs, discussion forums, multimedia – were easily discernible from the homepage of networks. Where networks had opportunities for person-to-person interaction, we considered this as potentially facilitating emotional support and provision of guidance. Websites which included considerable informative material (such as explaining more about certain conditions, giving expert advice) permanently embedded within them were classified as active in disseminating information. Characteristics, such as whether a visible network was present or the degree of anonymity in the network, were 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 one is able to identify themselves as researchers or professionals. 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. By observing the tools, level of activity, and content posted within this components, we were able to analyse the characteristics of these networks.

Step 3: Choosing and undertaking our case studies

We used the case study method described by Yin (Yin, 2009). We reviewed the analysis of each of the identified social networks to identify four diverse case studies. We excluded from our potential case studies those that were run by medical professionals. We chose not to exclude those that were run but professional managers as this would have excluded the larger more established sites. We then selected case studies with different purposes and different origins: MumsNet, PatientsLikeMe, Treatment Action Campaign (TAC) and My Pro Ana (MPA). 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. Over one hundred potential articles that discussed the history and development of the case study, examples of their influence in health related issues and articles reporting interviews with key individuals were included in the initial sift. A review of the abstract and full text identified papers of direct relevance. 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) we developed propositions about the social networks based on our earlier literature review and team discussions. These propositions were used to guide the data extraction and analysis for these 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 (i.e. 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 social network influences the nature of the social network activity (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 do 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 and advocacy groups etc.) and take on attributes and activities of those social structures which have similar purpose.

Results

Step 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. The angle of investigation varied, from looking at user motivations behind participating in such networks to the role these networks played in empowering patients and the influence this has on the patient-doctor relationship from the perspective of the user. Little of the existing literature reported on how the social networks were created and maintained and there was little distinction as to whether the networks were lay initiated (or controlled) or if they were managed professionally.

Studies commonly focused on a specific network and/or specific health condition. A popular element of networks analysed were discussion forums dedicated to various conditions: 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), among others. These studies often monitored network activity over a set period of time and compiled scenarios of user interaction. The content was then analysed for key trends which emerged. Results indicated that participants tended to seek out networks for emotional support and to find solace in their condition. A paper investigating a miscarriage Internet 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). This indicates social networking sites are considered a 'safe place to share' personal experiences, attributed to the high degree of user anonymity in most networks. Having experience in common with others in the social network may result in interactions that are less judgemental than in other social arenas. On issues which are very personal in nature, as study of the social networking site EverydayHealth suggests that interaction with lay-people or other patients may be more influential in inspiring healthy behaviour and response than discourse with medical professionals (Abrahamson & Rubin, 2012). This is seen in conditions which are socially very sensitive or embarrassing for patients to openly discuss in person, as found in studies on online men's eating disorder forums (Flynn & Stana, 2012).

The quality of information circulating within these networks was studied. We distinguish between studies which focus on the participants' perception of informational quality and

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, aware that they much have 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 – through various factors: content comprehensiveness, website complexity, personal knowledge of the source (homophily in social networks), among others (Kravitz & Bell, 2013). An analysis of a breast a 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, 2006a). 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.

Step 2. The characteristics of documented networks and how they vary
The dimensions of the networks identified are summarised in Table 1.

Distinctions between or within categories may not always be clear. For instance, the nature of replying to a post on a discussion thread versus replying or 'commenting' on a Facebook status update are the same. Here, we can consider posts as embedded within the discussion forum classification. Categorising the levels of 'memory' in a network are also subject to within variation. Consider a very popular discussion thread, or a highly shared tweet. The memory – the visibility of information or content – is longer in popular or highly active content. Such variations are normal and cannot be avoided; thus, when classifying, we aimed to capture the relative memory of each network, viewing it as a whole rather than individual posts or components.

These variations of memory or the 'shelf-life' of content within a network also pose interesting implications for which types of information are spread throughout a network. It is plausible to suspect that active networks, over time, filter information in a 'self-correcting' manner: a thread which tries spreading misinformation may quickly die out as users discredit it, and not remain visible for long. In short, higher quality content may have a longer memory than poor quality content, based on the actions of network participants.

Step 3: The case studies
Of the 23 networks identified, only 8 did not have medical professional formal input. From these, four case studies were selected. From our case studies, 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, instead of generating its informational content through the activity on the network. Of the four case studies, 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 gradually evolved to become a digital social network. Our last case study, My Pro Ana (mpa), was identified because it contained elements of what is arguable considered a negative health-related activity, discussion and possibly encouragement of anorxia related behaviours (it should be noted that the site states it does not advocate anorexia related behaviours although there is content that suggests some participants do). Anonymous networks which focus on socially-sensitive topics, such as eating disorders, tend to form very tight and active communities, and are hence interesting from an analysis perspective.

Case study 1: PatientsLikeMe

Two brothers founded PatientsLikeMe in 2004 as a result of their experiences in 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 such data to accelerate the development of treatments. First, PatientsLikeMe was restricted to only those with ALS; it expanded in 2011 to be open 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 must 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 symptoms. 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 site provides a Crisis section including a hotline for users and advice about contacting their usual doctor. 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 (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. It does not allow advertising.

Case study 2: Mumsnet
 Text to be added

Case study 3: Treatment Action Campaign (TAC)
Text to be added

Case study 4: My Pro Ana (mpa)
Text to be added

Table 2 summaries the findings of the case studies in relation to each of our propositions.

Discussion

Our two case studies so far 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 interaction about their health condition has or is stigmatised (e.g. HIV, anorexia nervosa). Most of the interaction on the social networking sites is individuals seeking peer support as they struggle with their health condition or managing their parenting role. 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. Two case study sites (Patientslikeme and Mumsnet) claimed to have been established as a response to difficult experiences of the founders and so based on the desire for support in their situation.

There is evidence of activity that aims to change health systems (TAC, Mumsnet and patientslike me). However, the issues were identified and supported by the owners of the platforms. The level of control over this activity varied across platforms. Patientslikeme kept complete control as they aimed to change health care through selling data for research. There was evidence on Mumsnet of Mumsnet members talking forward campaigns as individuals or groups and reporting back through Mumsnet and the campaigns appear to be based on the concerns expressed in Mumsnet posts. The activities aiming to change health systems were integrated with established social structures and social systems. There is evidence that individual behaviours in relation to a health issues such as HIV in the context of active political campaigns can contribute to change in social attitudes (Levy & Storeng, 2007), an issue we are exploring in relation to TAC.

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, influenced health or health systems is likely to require both on and off line data collection 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.

Initial conclusions
In relation to health, social networking sites are mostly used by individuals to assist with their own individual health issue and to provide reciprocal support for other individuals. Where social networking platforms are active in trying to change the health system, this is currently controlled by the platform and integrated with established social structures and systems. The professionals managing these platforms potentially have considerable power in shaping the direction of campaigns to change health care.

Box 1 Dimensions of social networking sites

Components

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 (medical professional)	Network hosts articles or blog posts written my medical professionals. This can be to either provide information or advice/tips to users.
Blog or journal (user)	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 or statuses	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 and private messaging	Participants within the network have the ability to send private messages (emails) which are only visible to the two interacting parties.

Dimensions

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	
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 individual	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.

Characteristics	
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 *potentially* 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 *view* content on the network and (ii) restrictions on whether an individual can *participate* 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 *within the particular network* by professionals for research purposes, with the intention of using this information to enhance the experience of users.

Table 1: Social Networks Matrix

Network	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	x	
HealthTalk Online		x			x					x			x
HealthBoards	x	x		x		x			x		x		
WebTribes				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				
BrainTalk Communities				x					x		x		
DiabeticConnect (Alliance Health)	x		x				x	x	x		x		

Network	Formation			Characteristics								
	Medical professional	Managerial professional	Lay	Visible network	Sub-network	Form connections	Anonymity	Accessibility (Viewing)	Accessibility (Participation)	Memory	Moderation	Expert research
TAC					x				x		x	x
mpa (myproana)	x	x		x		x	x	x			x	
Facebook group	x	x	x	x	x	x	User-defined (Low)	Full	User-defined (Closed/Open)	Short		
Twitter	x	x	x	x		x	User-defined (Low)	Full	Registration	Very Short		
LinkedIn group	x	x		x	x	x	User-defined (Low)	User-defined (Closed/Open)	User-defined (Closed/Open)	Short		
Reddit		x	x		x	x	User-defined (High)	Full	Registration	Medium	x	
YouTube	x	x	x	x		x	User-defined (Low)	Full	Registration	Permanent		
PatientsLikeMe	x	x		x	x	x	User-defined (Medium)	Full	Registration	Permanent		Derived from network
DailyStrength	x	x	x	x	x	x	User-defined (High)	Full	Registration	Medium		
Mumsnet	x	x	Initial	x			User-defined (High)	Full	Registration	Medium		x
HealthTalk Online	x	x		x				Full		Permanent		Derived from network
HealthBoards	x	x	Initial		x		User-defined (High)	Full	Registration	Medium		
WebTribes		x	Initial	x	x	x	User-defined (Medium)	Registration	Registration	Medium		
beyondblue	x		x				User-defined (High)	Full	Registration	Medium	x	
HealthCentral		x		x	x			Full		Permanent		
HealthfulChat		x								Very Short	x	
PsychCentral	x						User-defined (High)	Full	Registration	Permanent	x	x
CureTogether (23andme)	x							Registration	Registration	Permanent		Derived from network
Big White Wall	x							Subscription	Subscription		x	
HealthUnlocked	x	x						Registration	Registration	Medium		
Everyday Health		x								Permanent		
BrainTalk Communities	x		x				User-defined (High)	Full	Registration	Medium	x	

DiabeticConnect (Alliance Health)	x		x	
TAC	x	Initial		
mpa (myproana)		x		

DiabeticConnect (Alliance Health)	x	User-defined (Medium)	Full	Registration
TAC			Full	Permanent
mpa (myproana)	User-defined (Medium)	Full	Registration	Medium	x
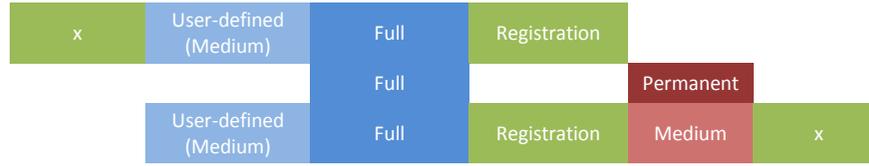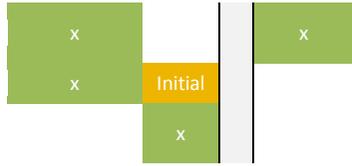
Table 2 summarising case study findings for each proposition (TAC and mpa to be added)

Proposition	Patientslikeme	Mumsnet
The structure and function of the social network site impacts on usage and ultimately on sustainability.	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.
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)	No. Purpose directs and completely constrains activity. No facility for side conversations.	No evidence that conversations not relevant to Mumsnet's aims are removed.
Volume of traffic (in general on a specific health issue) of social network sites will determine its impact on health/health care	Potentially yes. Claim that the high volume data will enable medical innovation to improve health. 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.
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)	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.
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	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.
Social networks do influence service provision and health care policy	No evidence of any direct influence on service provision and health care policy	Some evidence of successful campaigns related to child wellbeing
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	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	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

	to innovate in health care.	intervention from site owners. Mumsnet members also take on campaigns and report on them through Mumsnet.
Geographically local networks are more likely to develop campaigns in relation to community issues such as service provision	No facility on site that would enable development of campaigns.	This is a UK network. Mumsnet campaigns are UK centred (although their 'guest campaigns' may be international – text and links provided for users).
Lay controlled networks that lack professional managerial expertise are not sustained	Yes. This site has professional managerial expertise and is sustained.	Yes. This site has professional managerial expertise and is sustained
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.	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. 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.	Yes. Campaigns, social networking and commercial aspects are all integrated with real world network of established social structures.

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