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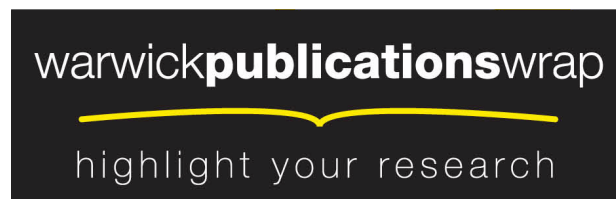
# Accepted Manuscript

Social networks - the future for health care delivery

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**Research Highlights**

- Health care information of value for improving health care is being assembled through digitally enhanced social networks

- Social networking allows patients to control health information accrual without the constraints of traditional health care

- The doctor-patient encounter is more influenced by information from social and professional networks than in the past

- Social networking has the potential to change the pattern of health inequalities and access to health care

- The stability of health care provision and the traditional role of professionals face challenges from social networking

**Abstract**

With the rapid growth of online social networking for health, health care systems are experiencing an inescapable increase in complexity. This is not necessarily a drawback; self-organising, adaptive networks could become central to future health care delivery. This paper considers whether social networks composed of patients and their social circles can compete with, or complement, professional networks in assembling health-related information of value for improving health and health care. Using the framework of analysis of a two-sided network – patients and providers – with multiple platforms for interaction, we argue that the structure and dynamics of such a network has implications for future health care. Patients are using social networking to access and contribute health information. Among those living with chronic illness and disability and engaging with social networks, there is considerable expertise in assessing, combining and exploiting information. Social networking is providing a new landscape for patients to assemble health information, relatively free from the constraints of traditional health care. However, health information from social networks currently complements traditional sources rather than substituting for them. Networking among health care provider organisations is enabling greater exploitation of health information for health care planning. The platforms of interaction are also changing. Patient-doctor encounters are now more permeable to influence from social networks and professional networks. Diffuse and temporary platforms of interaction enable discourse between patients and professionals, and include platforms controlled by patients. We argue that social networking has the potential to change patterns of health inequalities and access to health

care, alter the stability of health care provision and lead to a reformulation of the role of health professionals. Further research is needed to understand how network structure combined with its dynamics will affect the flow of information and potentially the allocation of health care resources.

**Keywords**

health; health care; networks; social networks; complexity; dynamics

**Introduction**

This article considers a potential future in which self-organising, adaptive networks have become, at least for some sections of society, central to the delivery of health care, including assessing health care needs, providing information and guidance, planning the times and places of interventions and evaluating patient care outcomes. This potential future is a consequence of widespread social networking, mediated by information and communication technology (ICT), which is profoundly changing the way that society operates. This article contributes to current debates on the impact of ICT use on health and health care by exploring this potential future, with particular emphasis on the dynamics of ICT networks from the perspective of complexity science. Understanding the potential consequences of communication network dynamics is a current concern given the investment in many countries, including the US and UK, in large-scale health informatics technology for both consumers and health care professionals (Blumenthal, 2010; Blumenthal, 2011; Williams et al., 2012).

From the perspective of health care within the USA and UK we consider the question:

> Can social networks composed of patients and their social circle compete with or complement professional networks in assembling health-related information of value for improving health and health care?

This paper uses the terms 'social network' and 'social networking' to refer to ICT-enhanced social interaction, both on the patient and the professional sides. Other terms are used for non-ICT mediated social interaction, although we recognise the considerable

overlap with ICT mediated interaction. The paper uses the term professional network to indicate health care professional and provider interactions whether ICT based or not. Where we specifically discuss ICT based social networking by professionals we indicate this. The term 'competition' as used in our question is distinct from conflict, which necessarily results in failure for at least one participant. It refers to processes by which competitive forces encourage participants to generate, disseminate and evaluate information and, thus includes elements of cooperation and other mutually-beneficial interaction. The emergent consequences of this form of competition can be improved fitness and performance of each network and the system as a whole, leading to better outcomes for providers and patients alike, or coordination failures, systemic risk and other negative consequences for all concerned. We acknowledge that there may also be conflict between the patient and professional sides, but this may be modulated by the information flows we discuss in this paper. We use the term 'assembling' to mean eliciting, aggregating and disseminating health-related information and making it available for discussion, analysis, testing and application in clinical, scientific and societal settings.

Information from social networks is already used to support diagnosis, self-management and monitoring of treatment for individuals as well as the planning and provision of health care for a community. We provide examples of these activities in this paper. We should hasten to clarify that we would not welcome a future in which clinical procedures (such as performing a physical examination, giving a vaccination, placing a stent in an occluded coronary artery or providing chemotherapy) are undertaken by anyone other

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than an expert in that procedure and its related activities. Even if this would be seen by some participants to reduce costs, improve availability and reduce disparities in access to health care in the short term, it is likely that health care quality and effectiveness might suffer as a result. Rather, in this paper, we refer to social networks supporting the information gathering and decision making related to such medical events, which has the potential to reduce the information asymmetry that exists between clinicians and patients. Of course some interventions that do not demand physical interaction are already delivered online (Griffiths et al., 2006). In this paper, depending on the manner in which the intervention is delivered, we consider these to be either similar to the traditional clinician-patient interaction or to be one among many sources of information available online.

Although traditionally a community seeking or receiving health care would be based in one geographical location, dispersed communities are developing with the use of ICTs. Members of these communities often share a health-related experience such as illness or disability or, with the advent of commercially available genetic tests, a similar genetic susceptibility (Ducournau & Beaudevin, 2011). The development of dispersed health related communities has sociological implications beyond those considered in this paper. For example, Lock and Nguyen (2010) argue that human biology is local, emerging from interaction with social and cultural history and context. In contrast, the formation of ICT-enabled dispersed communities potentially reinforces the biomedical approach of considering all human bodies as universally similar for the purpose of diagnosis and treatment.

There is a longstanding tradition of research on social networks (Scott, 2000). Analysis of network dynamics can contribute to understanding social life as complex adaptive systems (Miller & Page, 2007). In this paper we argue that social networking changes patterns of health and illness in communities and alters access to health interventions. Cognisant of the potential for inequalities in access to communication technologies to exacerbate inequalities in access to health care (Viswanath & Kreuter, 2007; Smythe, 2000), we consider this in relation to the people who are active online, although recognising the varied nature of people's skills and engagement online (Hargittai & Hsieh, 2011; Hargittai, 2010). From the discipline of complexity science we draw particularly on research on adaptive networks (Barabási, 2002; Caldarelli, 2007; Gross & Sayama, 2009), which is beginning to suggest the potential for these changes to occur. The paper is based on a series of discussions involving a team of UK- and US- based researchers drawn from the disciplines of complexity science, economics, health services research, medical sociology, operations management, primary health care, health policy and public health.

We outline the potential of social networks to assemble health-related information, and then suggest a framework for analysis, considering the health care system as a dynamic two-sided network with multiple platforms for interaction. We focus first on the patient side of the health care system, describing the exchange of health information through social networks and how this information is used and to what effect. We next discuss the various platforms of interaction between the patient and provider sides of the health care system, and how changes in these platforms influence the flow of information that

ultimately can affect health care decisions and resource allocation. Throughout the paper, the arguments are illustrated with examples, though they are not intended as an in-depth review of each aspect we consider. Although social networking is providing a new landscape for patients to assemble health information, professionals are limiting its (positive and negative) impacts on health and health care in a number of ways. We conclude by considering the potential implications for health and health care of these evolving informational networks and their interaction with traditional health care.

**The potential of social networking for assembling health-related information**

Social networks enable individuals to exchange information on behalf of themselves or of others on such subjects such as the experience of bodily symptoms, clinical diagnosis and treatment options, adverse treatment effects, sources of medical evidence, experiences with individual providers and opinions about their quality. These experiences are also shared more widely through websites, web forums, blogs and web-based social networks. Examples include the web fora of Diabetes UK and Arthritis Care (Diabetes UK and Arthritis Care) and NHS Choices (NHS Choices). Innovative methods for compiling, searching and analysing information are extending the potential of social networks to provide health-related information of value for both improving health and health care. This section describes some of these innovations and sources of information.

Individuals report on their own health when using online health assessments (such as those for well-being or alcohol intake from NHS Health Tools) or when gaining access to web-based interventions such as cognitive therapy (e.g. MoodGYM). Online self-reporting is also used for monitoring specific conditions such as bipolar disorder (e.g.

Oxtext, where those on treatment send self-completed mood ratings to their health care team by email or text message) (Cain Miller, 2008). Although such self-reported data are usually kept confidential, people are becoming increasingly familiar with placing data about their health on the Internet. Personal health information is openly shared on Internet sites such as PatientsLikeMe, often without concealing personal identities (Aldhous, 2008). Other potential sources of health-related information include accelerometers (incorporated within mobile devices and used to indicate level of physical activity), voice analysis (that can indicate a state of depression), and geographic tracking data (that might indicate proximity to infection or environmental contamination) (Pentland et al., 2009).

There exist many large health-related datasets collected for clinical or administrative purposes or for research and evaluation. Technological and analytical innovation has enhanced the potential for using these data to inform the planning of health care provision (Buchan et al., 2010). Using massive computing power with extensive data sets, it is controversially argued, can replace scientific expertise for extracting new knowledge (Anderson, 2008). In the UK, National Health Service medical records are considered a national asset for research in the life sciences (Department of Health Research & Development Directorate, 2011), whereas the US does not yet have a similar resource (Bollier, 2010). The ability to mine text using powerful computing, such as IBM's 'Watson' – the computer that won the TV quiz show 'Jeopardy!' (New York Times, 2011), is also stimulating excitement about the potential for exploiting text information from publicly-available sources such as Internet sites. With appropriate user interfaces, patients and

professionals can tap into text information assembled by social networks.

When analysed across large populations, anonymised (but geotagged) searches on the web for information about a health issue, such as influenza, have been shown to correlate to some extent with the spread of influenza indicated by traditional health data collected in the same timeframe (Ginsberg et al., 2009). Both searching and physician consultation provide biased estimates of true prevalence, so these data sources could usefully complement each other, especially where public health authorities encourage people who think they might have influenza not to seek appointments with their physicians. Further research is needed to understand the impact of network dynamics on prevalence estimates.

Another innovation contributing health-related information is what has become known as 'crowdsourcing' (Howe, 2008), a term that covers both static sampling (using the Internet to sample large populations) and dynamic sampling (for example, PatientsLikeMe), which allows individuals to observe and react to information provided by others, learning what to report and how to interpret the data (Williams, 2011; Charness et al., 2006). This interaction can lead to faster production of more accurate and relevant information (Polgreen et al., 2007; Graefe & Armstrong, 2011). However, both have drawbacks; static sampling is subject to selection bias and dynamic sampling may misidentify consensus if the crowd has been captured by the resonant re-propagation of a single idea.

'Reality mining' can provide contextualised health-related information. A group of individuals is recruited to provide data on many aspects of their lives by completing frequent surveys about what they think and do, often delivered through mobile phones

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(Eagle & Pentland, 2006). Some data, for example on exercise, can even be collected automatically in this way (Aharony et al., 2011).

In this paper we take a step back from these potentially exciting innovations to explore what is already known about social networking and about interaction between patients and providers of health care. We assess whether innovations of the type described above have the potential to enable social networks to compete with or complement professional networks in assembling health-related information of value for improving health and health care. First, we map out a framework of analysis of health care systems to assist this exploration.

**The health care system as a two-sided network**

Health care systems are typically viewed as two-sided, with patients and providers interacting over common platforms (Figure 1). On one side, traditionally the supply-side, medical technology and pharmaceutical companies, health care providers, managers and professional groups are organised in expert or professional networks which control large amounts of patient data, which can be analysed to inform, and even drive, health care system change. On the other side, traditionally the demand-side, individual patients operate independently, relying upon expert information obtained from professionals and on advice and support from their social circle. Information flows within and between the two sides of the health care system drive resource allocation decisions that determine who receives what care and how much.

[Place Figure 1 approximately here]

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Platforms for interaction include individual patient-doctor consultations, hospitals and community health services, organisations acting as funding conduits (such as Medicare and NHS Trusts) and other mechanisms for interaction between specialist equipment or treatment providers and patients. Internet sites can also be interaction platforms. The platforms can serve various roles such as gatekeeper, broker or conduit of information. The outcome of interaction on one platform, such as the patient-doctor consultation, might determine access to other platforms.

We consider the two-sided health care system as a network with large components linked to each other through multiple platforms. As we will discuss later, ultimately the impact of social networking on health care depends on the changing nature of the interaction platforms as well as social networking activity on either side. Here we provide some examples of the potential impact on health care of interactions and their dynamics that occur in the health care system network. Different types of platform have different dynamics. This has implications for the delivery of health care, including the pricing of services (Weyl, 2010) and the development of trust among patients, doctors and health care organisations (Tarrant et al., 2010). Competition between different interaction platforms can influence activity on both sides of the platform. For example, with online platforms, high network activity on one side of a platform can attract participation on the other side of the platform, and away from competing platforms (Koh et al., 2010). This can affect the quality of healthcare to the extent that it rests on the effective matching of information to audiences, the credibility of different information sources and the propensity to act on the information thus derived. We also suggest that the dynamics of

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competition within and between social networks and professional networks will vary depending on the nature of the information flowing in the networks. As already mentioned, health-related information shared in social networks takes a number of forms, including medical evidence, personal experience and opinion. Social networks and professional networks can both contribute to refining medical evidence (Schaffer et al., 2007). Experiential information from individuals with apparently the same illness will vary – in a social network we argue that one type of experience can come to dominate or the variation can lead to the elicitation of further information. In both scenarios the information may be incorrect (Prior, 2003). Personal opinion about particular doctors or treatments, we suggest, can be challenged in a social network or become widely accepted; this may or may not represent an accurate judgement or lead to improvement. Changes in the way social networks and professional networks interact can affect how the health care system adapts to collective patient pressure.

Membership of the health care network is changing. Much of the health-related information provided by individuals, including that shared through social networks, is currently held by organisations, both public and private, many of which do not belong to traditional health systems. These organisations have widely varying abilities and motives for storing, sharing, combining, assessing and reusing this information. This raises both practical and ethical concerns about its ownership, control and use (Aldhous, 2008), and thus ultimately about the trust that underlies its availability, quality and utility. The benefits from mining large health-related information repositories depend on its consistency and accessibility and thus on the context and the history of sharing and use.

Protocols used to exploit them can vary from the very tight framing of a systematic review of research evidence to an almost complete lack of *a priori* framing where almost any pattern is potentially of interest. In much the same way, Bayesian learning (generally framed in terms of one 'learner' or players of a well-defined game) differs from emergence or evolutionary recognition of patterns (inevitably involving groups) (Sandholm, 2008). Organisations now becoming active within the health care network often approach the use of health related information in very different ways to traditional health care organisations.

The next section considers what is known about health information and social networks, their impact on health-related experiences and how people use health-related information from these networks.

**Social networks and health-related information**

There is evidence that social networking is changing people's health-related experience. The numerous interaction platforms (listservs, forums and social networking sites such as Myspace, Facebook and Twitter) have made faster and more accessible the interaction around health issues such as seeking or sharing information, validation of experience, and validation of information/advice/treatment obtained elsewhere (Fox et al., 2005; Fox, 2011; Scanfield et al., 2010). As Fox et al. (2005) note, consequences include the emergence of online expert patient groups and the discovery of community around particular health conditions and states, such as Alzheimer's disease (White & Dorman, 2000), cancer (Turner et al., 2001), Asperger's syndrome (Mitchell, 2003) and childhood genetic disabilities (Schaffer et al., 2007). For those living with the demands of a chronic

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and/or disabling condition, the Internet may be an assistive technology for communication and networking as participation can be fitted around the day-to-day constraints posed by such conditions (Seymour & Lupton, 2004). Furthermore, social networking in relation to health can result in engagement with a more heterogeneous and geographically dispersed group of people than would otherwise be possible offline (Drentea & Moren-Cross, 2005). For rarer conditions, online social networking can be the only means for geographically scattered populations to interact and share knowledge about their condition.

Social networks are becoming sources of medical opinion in their own right, as online communities develop their own quasi-professional knowledge of their health conditions. Schaffer et al. (2007) studied the mothers of genetically disabled children and explored the strategies they used to develop specialist knowledge. These included working online to produce scientific knowledge and disseminating this knowledge through social networks and professional networks in order to ensure access to the best possible treatment for their children. They also share practical tips and advice online. Recent research suggests that sharing personal health data can benefit individuals living with disabling conditions (Frost & Massagli, 2008; Wicks et al., 2010). Growing numbers of health care providers maintain web-based platforms for their patients to seek information and to share information and experience with other patients. However, one study suggests that patients using these provider platforms gain most benefit from the information they contain, rather than from the opportunity for peer to peer sharing (Nambisan, 2011).

Sillence et al. (2007) have developed a model of trust development to describe the way

lay people interact with each other online, interrogate online health resources and incorporate information from them into health decisions. Factors such as website design and user-friendliness as well as the inclusion of personalised stories were significant factors when appraising the credibility of such information sources. Advice from family, friends and doctors was integrated, cross-referenced and checked with online information sources. However, when choosing what advice to follow, priority was given to advice from doctors. Although social networking sites and online information about health are used extensively in the US, Fox (2011) nevertheless found that when asked about the last time they had a health issue, the vast majority of her survey participants sought information, advice or support off-line. However, it is difficult to rule out social acceptability bias in this study. A UK study suggests social networking and other online sources of information are increasingly used to complement traditional sources and also to challenge them by, for example seeking a second opinion (Powell et al., 2011). However, there is as yet little evidence that they are substituting for traditional sources of information or advice.

Future competition between social networks and professional networks in assembling health-related information will continue to be influenced by traditional health-related interactions, as well as by innovation in online networking, information accrual and analysis. The next section considers various platforms of interaction between social networks and professional networks and how changes within the platforms alter information flows and thus health-related behaviours and decisions about the allocation of health care resources.

**Platforms of interaction between social networks and professional networks**

This section considers formal interaction platforms, in particular the one-to-one patient-doctor encounter and health care provider or funding organisations that collect health information from a community of patients to inform the provision of health care services for that community. We will then consider informal interaction platforms which are more fluid in nature, where interactions and even platforms are temporary, diffuse and/or self-organised.

*The doctor-patient encounter*

The apparent fundamental status of the patient-doctor consultation as a platform of interaction is represented in figure 2. However, social networks and professional/provider networks are becoming more influential in the interaction between patient and doctor.

[Place Figure 2 approximately here]

Interaction between patient and doctor is changing with the promotion of a more patient centred and flexible approach to consultations by the medical profession. Good communication between doctors and patients has been widely recognised by professional bodies in North America (AAMC, 1999) and Europe (GMC, 2009) as essential to the delivery of health care and appears to contribute to healing (Street et al., 2009). Stewart (2001) has argued for a shift away from disease-centred biomedicine to a more holistic patient-centred alternative. This approach encompasses: exploring the patient's reason for consulting; developing an understanding of their context; finding common ground in problem characterisation and management; supporting health promotion; and enabling

the doctor-patient relationship to continue (Stewart et al., 2003). Patient-centred practice reflects (Bensing, 2000) a set of social and political ideas about the nature of the doctor patient relationship (Mead & Bower, 2000), which, it could be argued, forms a complex system (Situngkir, 2004). The resulting ideology promotes consulting enriched with informed flexibility (Epstein et al., 2005), which arguably could or should enable patients to bring to the encounter what they have gathered about their health from social networks and feed information from doctor-patient consultations into their social networks.

The influence of an individual's social circle and social context on their health care seeking behaviour is well documented. For example, even three decades ago an average of 11 lay consultations (advice seeking from family friends or work colleagues) prior to formal professional consultations was recorded (Scambler et al., 1981). The decision to consult a doctor is also influenced by experiences shared in the social setting (Tardy & Hale, 1998) or through the media, (Howe et al., 2002) and advertising (Bonaccorso & Sturchio, 2002; Weissman et al., 2004). Further influences include past experience with their own disease (Parker et al., 2007) and attempts to seek help (Mechanic, 2002; Ashworth et al., 2005). These factors can all form part of the patient's agenda in a health care consultation. Health information from social networks can potentially enter patient-doctor interactions through similar avenues of influence whether or not the individual patients themselves engage with social networks.

Influences on doctor behaviours in health care consultations have been documented. For example, prescribing is influenced by a doctor's past experience of dramatic medical events, other patient encounters and interaction within their professional networks

(Armstrong et al., 1996). Interaction in health care encounters is also influenced by funding available for treatments, guidelines, potential profit, the desire to maintain a profession or specialty (Norris, 2001; Mizrachi et al., 2005) and custom and practice in the local situation (Joyce et al., 1967). There is evidence that the influence of non-patient factors on doctor behaviour may be increasing (Butler et al., 2009). For example, in the past, doctors might have prescribed an antibiotic when the need for it was doubtful in order to maintain their relationship with a patient (Butler et al., 1998). Now doctors have reduced antibiotic prescribing in line with policy initiatives (Kumar et al., 2003). The influence of doctors on each other's medical decisions through their professional networks, for example prescribing new drugs, which - for better or worse - can result in lock-in is typical of behaviour in networked settings (Young, 1993) but there is evidence that this influence is modulated both by prescription volume and opinion leadership (Iyengar et al., 2011). However, while professional networks seem to be exerting greater influence on the doctor-patient interaction than in the past, the existence of direct-to-consumer drug advertising in the U.S. is providing patients with some countervailing influence on the same interaction (Donohue et al., 2007), with the result that professional networks may be transmitting preferences and information originating on the patient side.

*Health care provider/funder organisations*

Organisations with a funding or approval role (e.g. publicly funded health services, insurance companies and health maintenance organisations) provide platforms for interaction between the patient and professional sides of the health care network. Services, pricing and quality are determined and the terms of patient/provider interaction

set on such platforms. Such organisations use access to patient data to inform decisions about health care provision. Through networking among organisations and with professionals, these organisations are learning to analyse health-related data in more sophisticated and computationally demanding ways than has previously been possible. This innovation in analytics enables such organisations to tailor health care services very precisely to the needs of the population they serve. For example, the existing network of public health practitioners in the UK has access to databases of health and social data covering their local population. Until recently, they have not had access to the tools, expertise and computing power needed to develop models that enable them to exploit this precise local evidence. A framework for undertaking this modelling is becoming available (Buchan et al., 2010; Verma et al., 2011) and professional ICT enhanced networking is being encouraged for sharing modelling expertise (e.g. e-health). Precise modelling that matches services to need has the potential to be more cost effective by improving the use of existing capacity and reducing reliance on excessively precautionary measures. However, there is potential for social networking to destabilise such precisely planned health care, as we discuss in the final section of this paper.

*Diffuse and relatively temporary platforms of interaction between patients and professionals*

Although not represented in figure 2, patients and their social circle and professional networks interact, not least because they partially overlap. The availability of medical information on the Internet gives patients access to the same medical information as professionals, although those without professional expertise face considerable challenges

knowing what information to trust and use (Powell et al., 2011). There are other areas of overlap between the networks. Professionals themselves experience health care as patients. Many important health care roles lie on the boundary of professional networks, such as health care assistants and medical receptionists. Lay people seek health information from those with health care experience in their social network (Tardy & Hale, 1998). Many people are employed in the health care sector and as it is nearly as geographically dispersed as the populations it serves, most of the population have a degree of direct contact with people working in health care, or at least know someone with such direct contact. Social networking has the potential to modulate these interactions.

There are other routes for contact between health care providers and patients. As noted above, pharmaceutical and medical equipment companies advertise directly to patients where this is permitted, such as in the US, and major global pharmaceutical companies provide extensive resources for patients on their websites. The UK government has funded 'Expert Patient' – self-management programmes led by appropriately trained lay people. There is some evidence that patients gain from this experience but with no reduction in health care usage (Griffiths et al., 2007).

There are also increasing patient managed interactions between patients and professionals. Advocacy groups for specific diseases such as Arthritis and Spinal Muscular Atrophy hold networking-events that involve both health professionals and patients (Arthritis Care, 2009; Jennifer Trust for Spinal Muscular Atrophy, 2007). Patients newly diagnosed with chronic health problems are encouraged to join condition-

orientated advocacy groups, and to seek information and support from their often extensive websites and online fora (e.g. Diabetes UK and Arthritis Care). Other advocacy groups represent specific population groups such as Age UK. Such groups could be considered a new form of platform for interaction between patient and professional, but one very much in the control of patients.

In the UK, involvement of patients and the wider public in planning health care is established government policy (Department of Health, 2009; Department of Health, 2010). Implementation of this policy has included volunteer patient advisory panels and public representatives on the Boards of health care organisations. Where studied, this policy has produced little change to health services *per se*, but in specific localities it has influenced the location of services and access to them, the degree of dialogue between professional and patient groups (Milewa et al., 2002; Murie & Douglas-Scott, 2004) and patient-patient interaction (Murie & Douglas-Scott, 2004; Fudge et al., 2008). The impacts of this government policy depend on local context, including the response of professionals and their network (Crawford et al., 2002). It remains an open question as to whether the limited nature of these impacts was due to the unwillingness or inability of professional networks to engage with the policy (Mockford et al., 2012), or whether patients felt they were already communicating effectively through social networking and through disease specific patient-professional fora.

Platforms of interaction between patients and professionals/providers are changing and allowing greater influence from both social networks and professional networks. In the concluding section we return to the question we posed for this paper, and consider the

implications of the changing interaction between social networks and professional

networks related to health.

**Social networks and health information - the future**

This paper posed the question:

> Can social networks composed of patients and their social circle compete with or
> complement professional networks in assembling health-related information of
> value for improving health and health care?

Evidence currently available suggests that there is both competition and

complementarity, and that social networks are becoming important sources of health

information. This is particularly true for certain groups in the population with health

experiences in common. However, a patient's social circle and personal doctor remain

influential. Patient groups are controlling new platforms for interaction between patients

and professionals. The patient-doctor encounter is now more permeable to influence from

social networks and professional networks. Although patients voluntarily share increasing

amounts of personal health data and have greater access to medical knowledge and

advice outside the doctor-patient relationship, professional networks have greater access

to health data sets and to the skills needed to analyse them. The impact of competition

between the different sources of information on planning and provision of health care and

the evolution of knowledge and clinical practice is unclear. This final section of the paper

considers the implications of new behaviour emerging from the interaction of more

complex information networks and the health care system (Anderson, 1972).

The development of health-related communities through social networking has the potential to alter which patient or disability groups influence the provision of health care through collective pressure. For example, people living with chronic illness or with specific disabilities are forming powerful pressure groups. The ageing population, with time and access to social networking, could likewise exert greater influence on health care. Networking interactions thus have the potential to change the map of health inequalities and access to health care for different patient groups. However, there are risks. Artificial complexity could develop through fragmentation, for example, if people interact intermittently, cease to interact or stop paying attention to each other (Hargittai & Hsieh, 2011). Further, there is variation in the skills people bring to online engagement and the benefits they obtain, even among those growing up with the Internet (Hargittai, 2010). Condition-centred patient networks may be further fragmented over time as many seek health-related information or support only when experiencing a short-term medical condition or when newly diagnosed. However, those living with chronic conditions tend to use online resources regularly (Powell & Clarke, 2002). Interactions can also vary in duration. The analytical tools for characterizing such time-varying networks are now available (Nicosia et al., 2011; Zhao et al., 2011) and are providing insights into the behaviour of these dynamic systems (Holme & Saramäki, 2011).

We have considered how competition between social networks and professional networks varies according to the nature of the information flowing through the network. The dynamic of social networks themselves can also affect what happens to information. There is considerable evidence, at least in economic networks, that bad information can

drive out good (Cotter, 2006) and that most people access their information from a small subset of potential sources (Galeotti and Goyal, 2010). Research is needed on how these dynamics affect the nature of health information flowing through social networks and the ability of the health care system as a whole to learn from experience. Propagation of misinformation can occur very rapidly with social networking technology. For example, Scanfield et al. (2010) found that within 345 status updates on Twitter, misinformation about flu requiring antibiotics reached a total of 172,571 followers. Twitter is particularly interesting for analysis because the length limit on posts forces people to cross-reference with identifiable re-tweets (Boyd et al., 2010). Propagation though this network is thus amenable to quantitative network analysis (Tucker, 2010).

Misinformation can get trapped in one local community despite being rapidly expunged from other communities (Kaski, 2010). Social networking also has the potential to lead to herding. For example, a particular doctor or clinic could become the target of a wave of adulation or complaint or there might be a wave of people interpreting a pattern of bodily sensations as a sign of serious illness. Where these waves are relatively local rather than geographically dispersed, they have the potential to destabilise a local health care system. Such destabilisation at more local levels may not easily be accommodated.

Through social networks, patients are assembling health-related information that has the potential to compete with and to extend the reach of professionally assembled information. The Internet and other networks are providing a new context for this to happen, free from the constraints of traditional health care (Rocha, 2010), although professional networks are in some ways influencing the nature, extent and power of this

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information and its impacts on doctor-patient trust and communication. The new context is not without structure, though more evolved than designed. The structure may be less apparent and less stable than traditional health care, but as the case of Twitter has shown, it is still be amenable to quantitative analysis of its structure and dynamics. Such analysis of networks has the potential to explain unexpected network behaviour, for example the cascade of failures in networks leading to an electrical blackout in Italy in 2008 (Buldyrev et al., 2010) and the finding that driver nodes of a network – that is, the nodes that guide the dynamics of the whole network - tend not to be the highly linked nodes (Liu et al., 2011).

For health-related information assembled through social networking to be of value for improving health and health care, longitudinal consistency of information will be needed, such as follow-up of volunteered personal data, yet privacy also needs to be respected. This paper has not considered information and computer science ontologies and their use in data mining, let alone how usage of words (expert or lay) in social networks will influence how people both perceive and talk about their health, a topic for future research.

Unlike social networks, professional networks tend to operate within established frameworks of training and governance. The rise of social networking has the potential to change the quality of health-related information and decision making. An increasingly interactive discourse between patients and professionals, coupled with an understanding of social network dynamics, could lead to a reformulation of the role of professionals, including their training and governance. Future research is needed to understand how to

enhance expert information and maintain the benefits of information sharing through

social networks whilst avoiding inappropriate dilution or distortion. Research is also

needed to understand how network structure combined with its dynamics might affect the

flow of information and potentially the allocation of health care resources.

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**Figure Captions:**

**Figure 1: Health care as a two-sided network with providers and patients connected across interaction platforms.**

**Figure 2. Diagrammatic representation of the centrality of the patient-doctor encounter between social and professional/provider networks**

Public and Private Funders

Medical Technology Companies

Healthcare Institutions

Pharmaceutical Companies

Clinicians

Platforms of Interaction

Patients and their Social Circle

Communities

**Patient - Doctor Consultation**
Trust relationship
Patient activation & engagement

**Patient Feedback Loop**
Experience with diseases, treatments, and individual providers

**Social Network of Patients and their Social Circle.**

**Patient Groups**

**PATIENT**

**DOCTOR**

**Professional Network of Providers.**

**Commercial and Market Networks**

**Social Networks**

• Mostly unmanaged network
• Mostly non-systematic data on individual & group health experiences
•Information from the Internet and media sources
•Data stored by Internet/Web providers

**Doctor Feedback Loop**
Experience with treating "the patient" and other patients

**Provider Networks**

• Mostly managed networks
• Systematic data collection (e.g., medical records, financial data, practice guidelines, research data)
• Data stored by health industry groups & public entities