

UK policy on social networking sites and online health: From informed patient to informed consumer?

Daniel Hunt¹, Nelya Koteyko¹ and Barrie Gunter²

Abstract

Background: Social networking sites offer new opportunities for communication between and amongst health care professionals, patients and members of the public. In doing so, they have the potential to facilitate public access to health care information, peer-support networks, health policy fora and online consultations. Government policies and guidance from professional organisations have begun to address the potential of these technologies in the domain of health care and the responsibilities they entail for their users.

Objective: Adapting a discourse analytic framework for the analysis of policy documents, this review paper critically examines discussions of social networking sites in recent government and professional policy documents. It focuses particularly on who these organisations claim should use social media, for what purposes, and what the anticipated outcomes of use will be for patients and the organisations themselves.

Conclusion: Recent policy documents have configured social media as a new means with which to harvest patient feedback on health care encounters and communicate health care service information with which patients and the general public can be 'empowered' to make responsible decisions. In orienting to social media as a vehicle for enabling consumer choice, these policies encourage the marketization of health information through a greater role for non-profit and commercial organisations in the eHealth domain. At the same time, current policy largely overlooks the role of social media in mediating ongoing support and self-management for patients with long-term conditions.

Keywords

Social media, social networking sites, eHealth, health policy, discourse analysis

Submission date: 19 February 2015; Acceptance date: 28 May 2015

Background

The use of electronic communication networks to support the public's health behaviours can be traced back to long before the era of the Internet. Their procurement and application by the United Kingdom (UK) government has formed part of a wider utilisation of information and communications technologies (ICTs) to enhance public participation in health care and economise the costs of public services in general. There was a belief on the part of government administrators that the use of ICTs could result in better, more accountable public services and empower citizens to become engaged with these services as stakeholders.¹ Information technologies were also seen as one vehicle

for delivering the set of consumer-oriented policies that began to underpin the UK government's thinking about health care during the 1980s and 1990s and which embraced the idea of ensuring patients were made better informed. A major priority for these policies was to find ways of delivering greater and higher

¹School of Languages, Linguistics and Film, Queen Mary University of London, UK

²Department of Media and Communication, University of Leicester, UK

Corresponding author:

Daniel Hunt, School of Languages, Linguistics and Film, Bancroft Building, Queen Mary University of London, Mile End Road, London, E1 4NS, UK.
Email: d.hunt@qmul.ac.uk



quality health information to people and to invite the public and patients to become more proactive in taking charge of their personal well-being.²

Under such auspices, government health authorities and private health agencies in the UK have trialled telephone services such as National Health Service (NHS) Direct and launched closed-community electronic networks operating via kiosk interfaces in local doctors' surgeries, health centres, hospitals and other outlets. The objective of such initiatives was not just to make everyone better informed but also to provide actionable information that could empower patients with a wide range of health issues.³ The assumption behind such interventions was that if the public took better care of themselves, they would stay healthier for longer, seek treatment of health problems sooner and give better quality information about symptoms to health professionals, thereby speeding up and enhancing the quality of relevant diagnosis and treatment. The government's promotion of such services have also had an economic agenda aimed at managing the costs of health service provision for a growing and ageing population.⁴⁻⁷

However, the expectation that remote, expert support services would be widely used and would, in turn, remove the strain of patient demand on regular health services did not become a reality. For example, NHS Direct had little significant impact on levels of face-to-face consultations and demands for treatment. Those who used it liked it, but many did not choose to use it and a technological divide persisted especially in the form of the non-using poor, ethnic minority groups and elderly, who are typically most in need of help.⁸ Hence, the idea that by utilising modern communications technology people would inevitably become empowered, involved and better equipped to take care of themselves has proven optimistic. To a great extent such optimism was founded upon a crude technological determinism, the notion that if people are offered technological tools then they will use them and personal benefits will directly follow.

Health, the Internet and social media

This optimism continued to characterise beliefs about newer forms of mediated health communication afforded by the emergence and growth of the Internet during the 1990s.^{5,6} Internet-based communication was envisaged to provide cost-effective solutions for reaching out with diverse health support services to many different types of people and particularly to those whose needs were greatest, such as the elderly.^{7,9} The Wanless Report, for example, encouraged investment in information technology to support the emergence of the 'engaged' and empowered patient who could

take greater responsibility for his or her own care, and thereby relieve pressure on state services.¹⁰

In contrast to this promissory rhetoric, however, the sizeable body of social science research into patients' use of the Internet has revealed more ambivalent health effects. For example, using websites to learn about others' experiences of the NHS services might lead to patients navigating the health care system more efficiently and with a clearer understanding of their care pathways. However, this information may also generate unrealistic expectations for consultations, undermine faith in individual clinicians and fuel demand for more expensive forms of treatment. Similarly contingent outcomes hold for exposure to information on individual conditions and self-management, which may engender both feelings of greater control over one's illness or disempowerment in the face an overwhelming volume of online content.¹¹ Much of this research testifies to the significant volume of online health communication that takes place away from government health websites, particularly in peer-to-peer communities dedicated to the sharing of experiences and mutual support.¹² The uncertain outcomes of patients consuming online health information and the volume of communication taking place away from state-authored websites suggest that the health care implications of public Internet use are unlikely to align straightforwardly with the aspirations of policy from the start of the century.

One of the most significant technological developments of the past 15 years has been the growth of social media, and particularly social network sites (SNSs) such as Facebook and Twitter. A central feature of SNSs is the opportunity to create a personal profile and articulate connections to other users, typically in the form of 'friends', 'followers' or 'connections'. In addition, SNSs enable people to publish personal content, maintain established social contacts, extend their social network and seek information directly from other people or organisations. This means that users can make inquiries or tender requests for advice, help and support from a huge audience of individual and organisational advisers that is specifically tailored to their personal needs. Social media thus contrast with more static websites that might be used for health reasons. The vast majority of content on NHS Choices (www.nhs.uk), for instance, is centrally authored and user contributions in the form of comments remain relatively peripheral. SNSs multiply opportunities for patients to establish peer-led support networks and offer new communicative platforms for supporting public involvement in health care both as informal consumers and as citizens with a more prominent voice over the shape of changes to the design, delivery and evaluation of health care. These same

channels provide government, third-sector and commercial health organisations with additional means with which to influence the public's health behaviours by increasing the volume and accessibility of health care information. SNSs also allow increased interaction between health care organisations and between individual professionals, facilitating the growth of online networks between institutions and clinicians. The various relationships which SNSs can mediate can be summarised as:

- Professionals to patients/public,
- Patients/public to professionals,
- Professionals to professionals and
- Patients/public to patients/public.

Given this communicative potential, the growth in public social media use has energised clinical interest in the implications of SNSs for health care.¹³ By creating opportunities for increasing multi-way communication between health care services, individual professionals and members of the general and clinical populations, social media could contribute in valuable ways to health care provision, including improving care quality through facilitating patient feedback, disseminating public health messages, strengthening professional networks and supporting ongoing disease management.¹⁴ Realising these potentials within state health care systems, however, will depend upon government and professional policy both supporting the use of social media and keeping pace with public practices around SNSs. In light of this, this review paper examines discussions of SNSs in recent government and professional policy documents and seeks to identify how social media have been configured as technologies for use in health care.

eHealth policy analysis: Sample and analytical framework

In order to illuminate contemporary policy understandings and expectations around SNSs, we examined discussions of social media platforms in 40 policy papers, guidance documents and reports dating from 2005, a year that marked a significant increase in the public uptake of SNSs. To capture a broad range of policy perspectives on social media (and particularly its potential for health care), documents were purposively sampled to include policy discussions arising from a range of UK government and professional contexts. These included print and Web-based publications from central government departments, the NHS, health care-related third-sector and professional organisations such as Royal Colleges and the General Medical Council (GMC). Using the search terms

'social media' and 'social networking', documents were initially identified using the National Institute for Health and Care Excellence (NICE) Evidence Search and the UK government (<https://www.gov.uk/government/publications>) and NHS England publication stores (<http://www.england.nhs.uk/publications/>) Additional searches using the same terms were undertaken on the websites of the UK Royal Colleges, NHS Confederation, NHS Employers, and associations representing medical specialties. Documents were included if they involved substantive discussion of the roles of social media in relation to health and health care. Several additional documents were identified through the references in our initial collection of papers, allowing the inclusion of earlier documents that have shaped more recent discussions of social media, such as early Cabinet Office guidance that has been built upon in recent Department of Health recommendations. A list of the documents collated for analysis is included as an Appendix.

Analysis of these documents drew specifically on a discourse analytic framework for the examination of policy developments.¹⁵ A central premise of this method is the role of language in constructing coherent accounts of the world, creating meaning and defining relationships between individuals, institutions and their actions. Hence, in adopting a discourse analytic framework, we aimed to illustrate the particular elements that make up the complex political and professional narratives in which social media and SNSs feature. Discourse analysis is particularly well suited to examining public discussions around complex issues, in which language choices function rhetorically to realise particular representations of a topic and to shape the discursive ground on which future argument and action takes place.¹⁶ Metaphors, for example, have been shown to play an important role in the domain of health communication as they often underlie attempts to define how an issue should be understood and how problems in that domain can be resolved.¹³ Hence, from our discourse analytic perspective, the policy and guidance texts we analyse below function simultaneously as both descriptions of the role of SNSs in health care and as 'sensitive barometers of social processes and change' that illustrate wider social and political debates around health care.¹⁷ Discourse analysis is therefore an appropriate approach for examining documents relating to contemporary health care, in which the complexity of a changing health care system create opportunities for redefining the roles of health care organisations, professionals and service users as well as their relationships to SNS use. The particular discourse analytic model we employ focuses on three elements that form the basis for policy discussions and professional guidance on social media.

Agents and motives

The organisations and social actors identified as active stakeholders in SNSs along with the actions and motivations with which they are associated. This category is realised typically through naming strategies and descriptions of social actors, as well as the actions they perform. The choice between different possible naming strategies – such as ‘patients’, ‘the public’ and ‘consumers’ – can itself be revealing of the positions adopted within the texts we analyse, with contrasting ways of referring to individuals or groups encoding expectations about their behaviours and motives.

Rights and responsibilities

A primary function of policy and professional guidance is setting out and enacting change to social and organisational structures. This includes apportioning responsibilities to groups, organisations and individuals for bringing about change, as well as their corresponding entitlements in light of social and institutional changes. In this case, rights and responsibilities are focused around who is entitled to use SNSs, for what reasons, and what obligations SNS use entails for different individuals and groups.

Assumptions about natural relationships

What are the associations and connections between the individuals and groups who are discussed? What personal and political outcomes are assumed to follow from their use of SNSs and how do these warrant particular courses of action? Here attention is paid to predication (attribution of quality or property to a person or object), particularly through the use of metaphors.

The following sections address each of these elements in turn to demonstrate salient features of how SNSs are represented in recent policy and professional health care discourse.

Social media stakeholders and their motives

A key distinction throughout the collated documents is between the use of SNSs by political and health care professionals and the organisations they represent on the one hand, and lay members of the public on the other. As these groups were consistently described as having contrasting roles and motivations in relation to social media we discuss them separately here, while their different rights and responsibilities are considered in the following section.

Organisational users, promotion and transparency

The collated documents nominate a range of organisations and professionals as users of SNSs and ascribe motivations to them that reflect the agendas of their authoring organisations. For example, papers from across central government departments have expressed optimism about the potential of social media to facilitate more efficient policy development and ‘help Government to communicate with citizens in the places they already are’.^{18–20} The government’s motivations here are explicitly democratic – the ‘Government wants to be a part of the conversation’²⁰ – with policy consultations mediated by SNSs purportedly allowing engagement with diverse sections of the population and increasing public accountability. Similarly, the Department of Health’s (DH’s) public consultation reports include suggestions for greater use of social media platforms to seek patient feedback on healthcare services and to engage the public in future health policy formation.^{21–23} In reiterating these suggestions in subsequent policies (for example, NHS England’s *Transforming participation in health and care*),²⁴ the government suggests a consensus between the public and their reforms to the health care system, as well as implying a clear link between public feedback and future policy. For example, the Department’s central policy theme ‘no decision about me, without me’, set out in the white paper ‘Equity and Excellence: Liberating the NHS’,²⁵ reappears as the title of a consultation document and a goal in subsequent NHS England publications.^{22,24} In this way, policy statements have been repeated across various documents to signify alignment between proposed health care reforms and a general principles of personalisation and patient involvement in which SNSs are believed to play a role. This link between social media, public opinion and policy development is also articulated explicitly in the Department of Health’s ‘Power of Information’, which states that the ‘social networking generation demands and expects a more interactive, personalised relationship with health and care services’.²⁶ Hence the DH positions itself as responding to the shaping influence of technology on public expectations of public services.

As well as government and NHS organisations as a whole, documents from professional bodies argue that social media can be used effectively by individual health care professionals. For example, NHS ‘executives’ are also identified as valid users of SNSs who should be motivated by the value of public accountability to open up ‘the black box of NHS management’ to the media and public through social media.²⁷ Similarly, guidelines from various Royal Colleges encourage

their members to use SNSs to contribute to public debates on health care policy and practice, to network with their colleagues and to facilitate public access to accurate health information.^{28–30} These guidelines represent healthcare staff not solely as medical professionals, but also as social and political actors who can influence public conversations on health by growing their online networks and providing an expert perspective to those seeking information. However, discussion of these uses is frequently juxtaposed against concerns about patients' confidentiality rights when health care professionals communicate about specific cases.^{28,31} Accordingly, these documents carry an over-arching scepticism on the part of these organisations regarding the potential for SNSs to be used a medium for individual consultations that involve direct communication with individual patients.³²

Individual patients as self-motivated consumers

In keeping with an explicit focus on the users of health care services, documents produced by the DH and NHS also nominate patients and members of the lay public as central actors in the social media field. These discussions are anchored around a view of the public as members of the 'social networking generation', a term which elides the age-related, socio-economic and individual differences in how SNSs are used.³³ The social networking generation are predicated with 'wanting' and 'demanding' a 'more interactive, personalised relationship with health and care services'.²⁶ As such, the public is said to uniformly demand greater information on their health and health care options, increased choice over services and a greater role in deciding which treatments they receive.^{25,34} Rather than patients per se, therefore, a consistent emphasis on 'choice' reflects a discourse of health consumerism that frames the public as self-motivated health consumers, voluntarily seeking out ways to improve their own health because they 'want to do their own research, reflect on what their clinicians have told them and discuss issues from an informed position'.³⁴ This discourse is rendered more explicitly through nominative choices that re-define patients as 'clients' who build 'consumer knowledge'²⁶ rather than coping strategies and who are represented by a 'consumer champion', HealthWatch England.²¹

As well as furthering trends towards patient consumerism apparent in earlier health care policy,³⁵ this construction of healthcare users also rhetorically warrants the DH and NHS England's claims that their role is to provide information through social media in order to facilitate consumer choices. That is, the public are presented as consumers motivated to use information in order to have a greater role over their health care decisions in

the same policies which outline the DH and NHS England's commitments to provide such information.

With this focus on using social media platforms to satisfy the demands of consumer choice, the peer support potential of SNSs remain largely peripheral in mainstream policy and professional documents. Nevertheless, some organisations outside of the DH, NHS England and Royal Colleges acknowledge the potential for SNSs to mediate patients' self-management practices through peer communication and advice sharing.^{36–38} For example, the NHS Confederation outlines several online platforms with social networking components which are overseen by professionals and used to deliver preventive and on-going psychological support for patients.³⁹ In contrast to the prevailing discussion of social media as a medium for corporate communication, these papers recognise the therapeutic opportunities of using SNSs as a venue in which lay knowledge and peer support can be shared and expert interventions can be delivered. This is particularly the case, they argue, for stigmatising conditions where individuals may be reluctant to engage in face-to-face care. For example, the NHS Confederation's 'Joining the Conversation' describes Big White Wall (www.bigwhitewall.com), a mental health SNS that facilitates peer-peer and peer-professional interactions as well as integrating self-administered tests and individual and group therapies. In marked distinction to the majority of the collated documents, therefore, this perspective recognises that lay patients have specific social and emotional needs related to their diagnoses that can be addressed by on-going communication with other patients and professionals via SNSs. In doing so, these documents acknowledge the possibility that, as well as providing data for improving service planning and delivery, peer networks on social media can produce therapeutically beneficial outcomes for their members in terms of improved self-management practices and personal well-being. Nevertheless, these discussions remain marginal relative to the DH's substantive configuration of social media as a platform for increasing service transparency and patient choice, and guidance from Royal Colleges, which is concerned with regulating professional conduct online.

Rights and responsibilities of SNS use

Guidelines from expert bodies consistently argue that the use of SNSs in relation to health care takes place against a background of professional responsibilities. Ensuring that individual clinicians fulfil these responsibilities when using SNSs is intended to curtail online activities that might otherwise risk their privacy, reputation and patients' health. Across the current

guidelines, health care providers are repeatedly exhorted to act with the same professionalism online as they would offline. This is conveyed both through overt attempts to define how they ‘should’ behave and more implicitly through reference to professional standards against which clinicians are judged:

[C]onduct online and conduct in the real world should be judged in the same way, and should be at a similar high standard.⁴⁰

The standards expected of doctors do not change because they are communicating through social media rather than face to face or through other traditional media. [...]Using social media also creates risks, particularly where social and professional boundaries become unclear.⁴¹

As these quotes illustrate, social media environments are presented as an extension of offline professional contexts that involve new opportunities for behaviours that could jeopardise the integrity of the individual and their profession. In seeking to manage these risks, the British Medical Association’s social media guidance argues that the responsibility of clinicians to act professionally outweighs their right to contribute freely to social media discussions:

The freedom that individuals have to voice their opinions on forums and blogs however is not absolute and can be restricted by the need to prevent harm to the rights and reputations of others.⁴²

Accordingly, these guidelines highlight the serious sanctions faced by clinicians who share confidential information, harass others or act unprofessionally online.^{41,43}

The responsibility of clinical commissioning groups to seek and account for the preferences of their communities is a clear theme in documents from the DH and the NHS Commissioning Board. In these papers, commissioning groups’ use of social media constitutes one aspect of the broader public engagement activities with which they should respond to community needs and ‘place patients and the public at the heart of everything that [they] do’.⁴⁴ Commissioners’ obligation to provide information for health service users is also reflected in the DH’s claims regarding its own duty to provide transparent information for the public and in the NHS’s undertaking to ‘empower [patients] to make informed choices’.³⁴ In this regard, a responsibility to collect, analyse and publish health care data – particularly that which captures patients’ experiences – has been conferred upon the different levels of the health care service from the DH down to individual health care professionals.

However, despite alluding to the current ‘social networking generation’ and their demands for interactive, personalised health care, the DH and NHS England do not represent their role in these reforms as to directly establish content for patient support through SNSs. Rather, they define their responsibilities in terms of providing information on services for patient-consumers and clinical commissioning groups and establishing the conditions in which independent organisations are given the ‘space to innovate’ online services for patients.²⁶ In doing so, the DH also presents its ambition to shape a competitive health market of online care services:

[T]he health and care system of the future will direct us, as patients and the public, towards accredited health apps to help us keep ourselves healthy and, as appropriate, manage our conditions. [...]The default position [of the DH] for stimulating the market will be through encouraging internet traffic to third party sites via linking through the single portal or from the endorsement which comes from association with the NHS, rather than directly commissioning or providing the services.²⁶

Despite its commitment to information provision, therefore, this passage indicates the DH’s retreat from state-provided patient support services on SNSs and a concomitant promotion of an increased role for ‘third-party’ charitable organisations and private enterprise in the social media and health domain. This statement can also be seen to distance the NHS from the possibility of patient consultations through social media, which carry risks for patient confidentiality and inappropriate advice provided in conditions where professionals have only digital representations through which to understand a patient’s condition.⁴⁵

In parallel with the state’s obligation to provide health service information, a clear theme of patient and public responsibility features throughout the policy documents, again conveyed through explicit descriptions of how the public ‘should’ act in relation to health:

We are also clear that increasing patient choice is not a one-way street. In return for greater choice and control, patients should accept responsibility for the choices they make, concordance with treatment programmes and the implications for their lifestyle.²⁵

As this passage articulates, the agenda of personalisation through which contemporary health care policy is refracted also confers increased obligations upon individual patients to be involved in their health care and accountable for their decisions in return for greater

choice.^{22,35} Juxtaposed against the previous extract from the DH's 'The Power of Information',²⁶ this passage also reveals an irony around the motif of 'greater choice and control' in relation to social media; it apporions increased choice and accountability to patients whilst patient choice is simultaneously restricted to private and third-sector services over which they have little control.

Assumptions about natural relationships: From information to empowerment

Recent government and NHS documents consistently associate levels of health information with improved health service performance and aspects of patient 'empowerment', which is defined as the capacity to make informed choices around health care. Accurate health care information is defined as an 'essential service' that 'allow[s] us to understand our own health, adopt healthier lifestyles and choose treatment and care that is right for us'.²⁶ Such claims reiterate the correlation of information and patient empowerment apparent in health policy documents that addressed earlier forms of Internet technologies at the turn of the 21st century.^{36,46} In the present data, this assumed relationship underscores the DH's central policy of increasing the two-way flow of healthcare information through online platforms, including social networking sites. The supposedly enabling, empowering potential of information has been encoded in successive DH publications through metaphorical constructions that construe information as a commodity and a 'tool' with which the public can be 'equipped' to seek appropriate care and make informed, responsible choices.^{19,21,22,26} While assuming an active role for the public in utilising online information, these metaphors have been criticised for obscuring questions of who accesses information online, how it is interpreted within each patient's individual circumstances and whether they have the capacity to act upon it in a meaningful way.^{13,47} The framing of information as a potentiating commodity also supports the policy documents' expectations of patient responsibility. Specifically, by assuming a one-to-one relationship between health care information and patients' capacity for making accountable decisions, these documents warrant greater expectations of involvement from patients in return for the centralised provision of health information. References to information as a 'tool' reflects a broader set of mechanical terminology through which SNSs themselves are construed; SNSs are 'tools' to be 'exploited' to deliver services and described as one of several 'mechanisms' that can be 'harnessed' to source public feedback.^{20,21,24} These metaphors anticipate a controlled and skilful deployment of government services on social media

that simultaneously elides their uptake and interaction amongst the public.¹³

There is also a sense in which the empowering effects of information derived from social media may be conferred as much on the managers of health organisations as on patients themselves. As well as delivering information to patients, social media are cited as a means to generate service 'insight' both by soliciting patient feedback directly and by capturing naturally occurring interactions on SNSs to inform changes to services. In facilitating the transmission of feedback from the public to health organisations, SNSs are thus also configured as a complement to existing professional instruments for assessing service performance.^{26,44,48,49} The purported 'empowerment' of social media may therefore be realised as much by furnishing those responsible for auditing health care services with a more pervasive means of scrutinising services and their individual staff members as it is by increasing public involvement in health care.⁴⁴

Finally, an additional outcome of social media use is briefly outlined by the Department of Health's 'Liberating the NHS: An information revolution', which suggests that a greater range of information providers – including SNS venues – could result in variable content quality and patient confusion.²¹ This claim goes some way to acknowledging the complexity of users' responses to online health information and the imbrication of risk and empowerment in public social media use. According to the DH, this risk should be addressed centrally through the provision of a government 'kite mark' system to indicate the quality of online information, a policy congruent with the managerial approach to the online health domain advocated in subsequent DH documents.

Discussion

Recent policy and professional publications have clearly recognised the increased use of social media platforms by government actors and health care professionals for collegiate networking and communication involving health care service users. There has been recognition of the potential of these online platforms to facilitate the flow of government health policy to professionals, patients and public and to stimulate patient feedback to government on policy and professionals on practice. Policy papers from the DH and NHS indicate that government policy for social media use is embedded within an over-arching information strategy focused on using the Internet to publicise data on NHS services, increase patient choice and gather business-relevant 'insight'. The explicit motivation for this policy is to improve patient involvement in all levels of health care by supplying patients with information,

which the ‘social networking generation’ is assumed to uniformly want. In this respect, there is a clear continuity between publications that discussed earlier information and communications technologies and recent policy and professional documents on SNSs. Indeed, just as social media is configured as an emerging vehicle for delivering information, recent health care policies which address social media constitute a vehicle for reiterating long-standing discourses of public involvement participation in healthcare, health consumerism, and the uncritical association of information access with patient empowerment.^{46,50} For the DH, construing the promotion of consumer health care models as a response to the demands of the ‘social networking generation’ also provides an effective way of depoliticising the changes to the health care system enacted by their recent policies.

In orienting to models of consumer health care, such policies have not only public interest objectives but also economic ones; if patients can be ‘equipped’ with personalised government health information they will purportedly take greater responsibility for their own health and seek professional care in a more informed fashion.⁴⁷ From this perspective, recent health policy might be reinterpreted as carrying less emphasis on information for supporting patient choice and more on information for patient compliance, with social media conceived as a means of disseminating information to discipline the public’s health-related behaviours.^{46,51}

The current policy emphasis on patient choice also extends to an expanding online healthcare economy, with government retreating from certain online activities to ‘stimulate’ a digital patient marketplace involving charities and private businesses.⁵² Social media, therefore, constitute another domain in which the government has sought to model the provision of health care services on market principles. While it may be too early to assess the impacts of this policy, we believe there are several reasons to be cautious regarding state marketisation of the social media and health sphere. An active market will mean an increased range of information and support providers. While this may be appealing in enabling the public to find personally suited content, multiple competing sources of information that do not carry the recognised authority of the NHS could also lead to greater uncertainty of the veracity of information, rendering patients inactive rather than empowered.⁵³ Secondly, by promoting third-sector and commercial social media organisations as eHealth providers, government policy is encouraging the public to participate in a digital health economy in which the emotional labour of users’ online contributions and help-seeking is routinely commodified and exploited for commercial ends in ways that are

obscured from users themselves. This can include refining consumer-driven advertising and generating research data but may also involve the sale of user-generated information to other organisations.⁵² Thirdly, the collection of user-generated data by multiple online providers may also stifle opportunities for furthering research and health care provision in cases where organisations are reticent to share data with competitors, even when this could lead to improved service provision and patient care.

Expansion of patient choice also means the sharing of risk among these health care suppliers and, in turn, the reduction of risk potentialities for government as it hands over the provision of individual patient support and advice services to non-government organisations, whether these are third sector, private sector or patient-operated. This allows government to restrict its own predominant use of dynamic online technologies to the comparatively less risky functions of mass information dissemination and sourcing patient feedback. Comparable risk-avoidance strategies can be seen to underlie professional guidance that warns against consultations with patients through social media while encouraging professional participation online interactions that involve fewer risks to patients.

Our introduction outlined four broad types of communication enabled by SNSs in health care: professionals to patients/public, patients/public to professionals, professionals to professionals and patients to patients. Instances of the first three of these are well accounted for in the documents we analysed. However, the fourth has received less recognition, with few publications from government or professional organisations acknowledging the potential of SNSs to mediate patients’ self-management of illness through peer communication. Recent government and NHS policy, in particular, largely side-steps a commitment to using social media to support the self-care of patients’ chronic conditions, a function for which health researchers and many lay individuals already use SNSs. For example, despite being increasingly well documented in research literature, these policy papers make no mention of the care potential of patient networks present on prominent SNSs such as Facebook, YouTube and Twitter.^{54,55} For example, weekly ‘Tweetchats’ using the hashtag ‘#UKDOC’ (UK Diabetes Online Community) address specific aspects of self-management for type 1 diabetes, involving hundreds of participants and ad hoc input from clinicians. Similarly, Mazanderani and colleagues describe networks of multiple sclerosis sufferers using YouTube videos to generate experiential evidence on the efficacy of controversial procedures and thereby advocate for their wider uptake.⁵⁶ In addition, research conducted on the use of the health-specific SNS

PatientsLikeMe by individuals with epilepsy reports that participants had improved understanding of seizures, symptoms and treatment as well as a greater sense of control over their condition.^{57,58} In contrast, current policy focuses on marshalling patient expertise in the form of service feedback. As such, it falls short of fully recognising or planning for a state role in the full range of activities which the current generation of online applications already provides for patients. This is surprising given the burgeoning clinical literature on SNS-mediated care and the fact that the DH has previously acknowledged the importance of offline social networks in the self-management of chronic illness.⁵⁹

Conclusion

Our analysis indicates that recent digital health policy caters effectively to the preferences of self-sufficient patients in need of information and feedback on services but less so for those who need more direct day-to-day support for chronic health problems. While a more informed, health-literate public is a laudable ambition of these policies, optimism surrounding the role of SNSs in health care is premised on the renewed assumption of a direct correlation between expert information on the one hand and patient empowerment and responsibility on the other. This assumption overlooks the fact that individuals may lack the material and social capital to utilise health care information within the context of their own lives and may even be using SNSs to seek alternative modes of healing.^{53,60,61}

The DH's ostensible retreat from providing direct support services through SNSs for patients with long-term conditions may encourage patient-driven SNSs networks to flourish online. Equally, the dearth of NHS services to support specific conditions via SNSs may mean that patient support is increasingly filtered through commercial organisations that dominate SNSs traffic and whose motivations include both patient welfare and profit margins.⁶² In each case, the content of these SNS interactions will lie outside of state influence and their implications may therefore also fall far beyond the expectations of current policy. This policy is also somewhat surprising given that the current NHS Choices website continues to receive 30 million unique visitors each month (a figure far in excess of comparable sites) suggesting a sustained desire for state-authored health content online. Similarly, the NHS Choices Facebook and Twitter accounts, which publish general and seasonal health and lifestyle information, maintain 75,000 and 165,000 subscribers, respectively. In addition to underscoring public interest in content published by the NHS on social media, the activity of these pages indicates that the NHS continues to publish some content on SNSs, despite a limited policy commitment in this area.

While this paper has attempted to shed light on recent policy developments and professional guidance related to social media and health care, it is limited by the relatively short time span in which the sampled papers have been published. This time frame makes it difficult to ascertain long-term shifts in policy discussions around social media. This is particularly the case for the guidance documents from professional bodies that we examined which, with one exception,³² were all published between 2012 and 2013. As such, it will remain important to consider the uptake and outcomes of the recent policy and professional guidance documents considered here, as well as to track changes in how the potentials of social media are discussed. Specific questions that could be fruitfully pursued in future research therefore include: Are public views contributed by social media factored into large-scale and local health service changes, and what are the long-term implications of the increased role of commercial and third-sector organisations in providing direct support for patients through social media? In the context of health policies that increasingly emphasise patient responsibility for health in return for health care information, it will also be important to examine whether there are demonstrable health benefits from the transmission of health service information through social media, and to whom these benefits do and do not accrue.

Funding: This work was funded by the UK Economic and Social Research Council (Grant number: ES/K005103/1). The funders had no role in this publication.

Conflicting interest: None declared.

Ethical Approval: Not applicable.

Guarantor: DH

Contributorship: The authors jointly conceived the study. DH was responsible for the data analysis and all authors drafted, reviewed and edited the manuscript.

Peer Review: This manuscript was reviewed by James Munro, Patient Opinion and one other reviewer who wishes to remain anonymous.

Acknowledgments

We are grateful to the paper's reviewers for their insightful and helpful comments on a previous draft of this manuscript.

The University of Leicester Research Ethics Review board approved the project to which this paper contributes (Project Reference: nk158-f4cc9).

This manuscript was reviewed by James Munro, Patient Opinion, and one other reviewer who wishes to remain anonymous.

References

1. Bellamy C and Taylor JA. *Governing in the information age*. Buckingham: Open University Press, 1998.
2. Department of Health. *Choosing health: Making healthy choices easier*. London, UK: Stationery Office, 2004.
3. Gunter B. *Digital health: Meeting patient and professional needs online*. Mahwah, NJ: Lawrence Erlbaum Associates, 2005.

4. Department of Health. *The new NHS: Modern, dependable*. London, UK: Department of Health, 1997.
5. Department of Health. *Raising standards for patients: New partnerships in out-of-hours care*. London, UK: Department of Health, 2000.
6. Department of Health. *The NHS plan*. London, UK: Department of Health, 2000.
7. Morrell RW, Mayhorn CB and Bennett J. Older adults online in the Internet century. In: Morrell RW (ed.) *Older adults, health information and the World Wide Web*. Mahwah, NJ: Lawrence Erlbaum Associates, 2002.
8. George S. NHS direct audited: Customer satisfaction, but at what price? *BMJ* 2002; 324: 558–559.
9. Department of Health. *Information strategy for older people in England*. London, UK: Stationery Office, 2002.
10. Wanless D. *Securing our future health: Taking a long-term view – the Wanless Report*. London: HM Treasury, 2002.
11. Ziebland S and Wyke S. Health and illness in a connected world: How might sharing experiences on the Internet affect people's health? *Milbank Q* 2012; 90: 219–249.
12. Pitts V. Illness and Internet empowerment: Writing and reading breast cancer in cyberspace. *Health* 2004; 8: 33–59.
13. Koteyko N, Hunt D and Gunter B. Expectations in the field of the Internet and health: An analysis of claims about social networking sites in clinical literature. *Sociol Health Ill* 2015; 37: 468–484.
14. Coiera E. Social networks, social media, and social diseases. *BMJ* 2013; 346: f3007.
15. Dryzek JS. *The politics of the earth: Environmental discourses*. Oxford: Oxford University Press, 2005.
16. Cheek J. At the margins? Discourse analysis and qualitative research. *Qual Health Res* 2004; 14: 1140–1150.
17. Lupton D. *Medicine as culture*, 2nd ed. London: Sage, 2003.
18. Cabinet Office. *Government digital strategy*. <https://www.gov.uk/government/publications/government-digital-strategy> (2012, accessed January 2015).
19. Department of Health. *Digital strategy: Leading the culture change in health and care*. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213222/final-report1.pdf (2012, accessed January 2015).
20. Home Office. *Social media guidance for civil servants*. London, UK: Home Office, 2012.
21. Department of Health. *Liberating the NHS: An information revolution. A summary of consultation responses*. London, UK: Department of Health, 2011.
22. Department of Health. *Liberating the NHS: No decision about me, without me. Government response*. London, UK: Department of Health, 2012.
23. Department of Health. *Liberating the NHS: Greater choice and control*. London, UK: Department of Health, 2012.
24. NHS England. *Transforming participation in health and care*. London, UK: NHS England, 2013.
25. Department of Health. *Equity and excellence: Liberating the NHS (Cm 7881)*. London, UK: Stationery Office, 2010.
26. Department of Health. *The power of information: Putting all of us in control of the health and care information we need*. London, UK: Department of Health, 2012.
27. NHS Employers. *Social media for chief executives: The essential guide*. London, UK: NHS Confederation, 2013.
28. British Medical Association. *Using social media*. London, UK: British Medical Association, 2012.
29. NHS Employers. *HR and social media in the NHS*. London, UK: NHS Confederation, 2013.
30. Royal College of General Practitioners. *Social media highway code*. London, UK: RCGP, 2013.
31. Health and Care Professions Council. *Focus on standards: Social networking sites*. London, UK: HCPC, 2012.
32. Royal College of Anaesthetists. *Guidelines for fellows and members on the use of social media*. London, UK: RCOA, 2014.
33. Adams SA. Revisiting the online health information reliability debate in the wake of 'web 2.0': An inter-disciplinary literature and website review. *Int J Med Inform* 2010; 79: 391–400.
34. Department of Health. *High quality care for all: NHS next stage review final report (Cm 7432)*. London, UK: Stationery Office, 2008.
35. Veitch K. The government of health care and the politics of patient empowerment: New Labour and the NHS reform agenda in England. *Law Policy* 2010; 32: 313–331.
36. Hagell A. *Association for Young People's Health Research Summary: Health implications of new technology*. London, UK: AYPH and Child and Maternal Health (ChiMat), 2012.
37. King's Fund. *Digital technologies*. <http://www.kingsfund.org.uk/time-to-think-differently/trends/information-technologies/new-ways-using-digital-technologies> (2012, accessed January 2015).
38. Royal College of Nursing. *Positioning nursing in a digital world*. London: RCN, 2013.
39. NHS Confederation. *Joining in the conversation – social media and mental health services*. London, UK: NHS Confederation, 2011.
40. Nursing and Midwifery Council. *Social networking sites*, <http://www.nmc-uk.org/Nurses-and-midwives/Advice-by-topic/A/Advice/Social-networking-sites/> (2012, accessed January 2015)
41. General Medical Council. *Doctors' use of social media*. London, UK: GMC, 2013.
42. British Medical Association. *Using social media: Practical and ethical guidance for doctors and medical students*. London, UK: BMA, 2011.
43. British Dietetic Association. *Making sense of social media*. London, UK: British Dietetic Association, 2013.
44. NHS Commissioning Board. *Patient and public voice (board paper NHSCB28022)*. London, UK: NHS Commissioning Board, 2013.
45. Mort M, May CR and Williams T. Remote doctors and absent patients: Acting at a distance in telemedicine? *Sci Technol Hum Val* 2003; 28: 274–295.
46. Henwood F, Wyatt S, Hart A, et al. 'Ignorance is bliss sometimes': Constraints on the emergence of the 'informed patient' in the changing landscapes of health information. *Sociol Health Ill* 2003; 25: 589–607.

47. Morden A, Jinks C and Ong BN. Rethinking ‘risk’ and self-management for chronic illness. *Soc Theory Health* 2012; 10: 78–99.
48. NHS Confederation. *Alive and clicking: Information that benefits all*. London, UK: NHS Confederation, 2012.
49. Francis R. *Report of the Mid Staffordshire NHS Foundation Trust public inquiry*. London, UK: Stationery Office, 2013.
50. Pulvirenti M, McMillan and Lawn S. Empowerment, patient centred care and self-management. *Health Expect* 2014; 17: 303–310.
51. Dixon-Woods M. Writing wrongs? An analysis of published discourses about the use of patient information leaflets. *Soc Sci Med* 2001; 52: 1417–1432.
52. Lupton D. The commodification of patient opinion: The digital patient experience economy in the age of big data. *Sociol Health Ill* 2014; 36: 856–869.
53. Powell JA and Boden S. Greater choice and control? Health policy in England and the online health consumer. *Policy Internet* 2012; 4: 1–23.
54. Merolli M, Gray K, Martin-Sanchez F, et al. Patient-reported outcomes and therapeutic affordances of social media: Findings from a global online survey of people with chronic pain. *J Med Internet Res* 2015; 17: e20.
55. Moorhead SA, Hazlett DE, Harrison L, et al. A new dimension of health care: Systematic review of the uses, benefits, and limitations of social media for health communication. *J Med Internet Res* 2013; 15: e85.
56. Mazanderani F, O’Neill B and Powell J. “People power” or “pester power”? YouTube as a forum for the generation of evidence and patient advocacy. *Patient Educ Couns* 2013; 93: 420–425.
57. Frost JH and Massagli MP. Social uses of personal health information within PatientsLikeMe, an online patient community: What can happen when patients have access to one another’s data. *J Med Internet Res* 2008; 10: e15.
58. Wicks P, Keininger DL, Massagli MP, et al. Perceived benefits of sharing health data between people with epilepsy on an online platform. *Epilepsy Behav* 2012; 23: 16–23.
59. Department of Health. *Research evidence on the effectiveness of self care support*. London: Department of Health, 2007.
60. Gajaria A, Yeung E, Goodale T, et al. Beliefs about attention-deficit/hyperactivity disorder and response to stereotypes: Youth postings in Facebook groups. *J Adolesc Health* 2011; 49: 15–20.
61. Segal JZ. Internet health and the 21st-century patient: A rhetorical view. *Writ Commun* 2009; 26: 351–369.
62. Hunt D and Koteyko N. ‘What was your blood sugar reading this morning?’ Representing diabetes self-management on Facebook. *Discourse Soc*. Epub ahead of print 23 April 2015. DOI: 10.1177/0957926515576631.

Appendix

Department of Health

Department of Health Informatics Directorate. NHS Information Governance: Guidance: Blogging and social networking. Department of Health, 2009.

Department of Health Informatics Directorate. NHS Information Governance: Guidance: Social Interaction – Good Practice. Department of Health, 2012.

Department of Health. Digital Health: Online conversations and your responsibilities as a civil servant, <http://webarchive.nationalarchives.gov.uk/20140522191340/http://digitalhealth.dh.gov.uk/your-responsibilities-as-a-civil-servant/> (accessed January 2015)

Department of Health. Digital Strategy: Leading the culture change in health and care. Department of Health, 2012.

Department of Health. Equity and Excellence: Liberating the NHS (Cm 7881). Stationery Office, 2010.

Department of Health. High quality care for all: NHS Next Stage Review Final Report (Cm 7432). Stationery Office, 2008.

Department of Health. Liberating the NHS: An Information Revolution. A summary of consultation responses. Department of Health, 2011.

Department of Health. Liberating the NHS: Greater choice and control. Department of Health, 2012.

Department of Health. Liberating the NHS: No decision about me, without me. Government response. Department of Health, 2012.

Department of Health. The Power of Information: Putting all of us in control of the health and care information we need. Department of Health, 2012.

Department of Health. Digital Health: Case Study: Social media monitoring, <http://webarchive.nationalarchives.gov.uk/20140522191340/http://digitalhealth.dh.gov.uk/digital-strategy/case-studies/social-media-monitoring/> (accessed January 2015)

Wooton, S. Department of Health Digital Health Blog: How to use social media to engage with stakeholders, <https://digitalhealth.blog.gov.uk/2013/06/11/how-to-use-social-media-to-engage-with-stakeholders/> (2013, accessed January 2015)

Wooton, S. Department of Health Digital Health Blog: Social media advice for DH staff, <https://digitalhealth.blog.gov.uk/2013/06/11/social-media-guidelines-for-dh-staff/> (2013, accessed January 2015)

Wooton, S. Department of Health Digital Health Blog: Why you don’t need a social media strategy, <https://digitalhealth.blog.gov.uk/2013/06/11/why-you-dont-need-a-social-media-strategy/> (2013, accessed January 2015)

NHS organisations

NHS Commissioning Board. Patient and Public Voice (Board Paper NHSCB28022). NHS Commissioning Board, 2013.

NHS Confederation. *Alive and clicking: Information that benefits all*. NHS Confederation, 2012.

NHS Confederation. *Joining the conversation – social media and mental health services*. NHS Confederation, 2011.

NHS Employers. *HR and social media in the NHS: The essential guide for HR directors and managers*. NHS Confederation, 2013.

NHS Employers. *Social media for chief executives: The essential guide*. NHS Confederation, 2013.

NHS England. *Transforming Participation in Health and Care*. NHS England, 2013.

White C. *Smart guides to engagement: Using social media to engage, listen and learn*. NHS Networks, 2012.

Other government departments and agencies

Cabinet Office. *Government Digital Strategy*. Cabinet Office, 2012.

Cabinet Office. *Template Twitter strategy for Government Departments*. Cabinet Office, 2009.

National Information Board. *Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens*. National Information Board and Department of Health, 2014.

NICE. *NICE local government briefings: Community engagement to improve health*. National Institute for Health and Care Excellence, 2014.

The Government Digital Service. *Social media guidance for civil servants*. Home Office, 2012.

Guidance from professional organisations

British Dietetic Association. *Making sense of social media*. British Dietetic Association, 2013.

British Medical Association. *Using social media: Practical and ethical guidance for doctors and medical students*. BMA, 2011.

British Thoracic Society. *Technology and Respiratory Health Working Party Report*. British Thoracic Society, 2012.

General Medical Council. *Doctors' use of social media*. GMC, 2013.

Hagell A. *Association for Young People's Health Research Summary: Health implications of new technology*. AYPH and ChiMat, 2012.

Health and Care Professions Council. *Focus on standards: Social networking sites*. HCPC, 2012.

Nursing and Midwifery Council. *Social Networking Sites*, <http://www.nmc-uk.org/Nurses-and-midwives/Advice-by-topic/A/Advice/Social-networking-sites/> (2012, accessed January 2015)

RCPSYCH Social Media Group. *RCPsych Social Media Strategy and Guidelines*. Royal College of Psychiatrists, 2013.

Royal College of Anaesthetists. *Guidelines for Fellows and Members on the use of Social Media*. RCOA, 2014.

Royal College of Anaesthetists. *What to expect from the RCoA on social media*. RCOA, 2014.

Royal College of General Practitioners. *Social media highway code*. RCGP, 2013.

Royal College of Nursing. *Positioning nursing in a digital world*. London: RCN, 2013.

Third-sector organisations

Right Here. *How to... provide youth-friendly mental health and wellbeing services*. Mental Health Foundation and Paul Hamlyn Foundation, 2015.

The King's Fund. *Future Trends: Digital Technologies*, <http://www.kingsfund.org.uk/time-to-think-differently/trends/information-technologies/new-ways-using-digital-technologies> (2012, accessed January 2015).