

## **Social media, health policy and knowledge translation**

Dr. Damian Roland

Consultant and Honorary Associate Professor in Paediatric Emergency Medicine

Emergency Department Secretaries, Emergency Department, Leicester Royal Infirmary, Leicester, LE1 5WW

1. SAPPHIRE group, Health Sciences, Leicester University, Leicester, UK
2. Paediatric Emergency Medicine Leicester Academic (PEMLA) group, Children's Emergency Department, Leicester Royal Infirmary, Leicester, UK

e-mail: [dr98@le.ac.uk](mailto:dr98@le.ac.uk) phone: 07727158213

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Take Home Points:

1. Social Media is associated with the generation of communities of practice which promote the transfer of information at scale.
2. How Social Media definitively impacts on health policy is not clear and evidence is scant.
3. It will be necessary to generate scholarship and academic interest, specifically in relation to the role of social media in health policy
4. There are 12 potential limitations that policy makers may wish to consider based on literature regarding social media and health communication.

Summary Statement

Effective dissemination strategies, particularly for health coverage, should include a social media strategy informed by the patient perspective. Evidence based guidance on how to effectively do this needs to be derived.

## **Abstract**

Social Media has been cited as a methodology of reducing the knowledge translation gap, creating communities of practice and reducing traditional hierarchical divisions. Social Movements have also embraced Social Media as a means of spreading their aims and reaching wide audiences. However, its impact on Health Policy is seldom considered. This article examines the complexity of clinician use of social media to influence policy and how policy and government groups may utilise social media to help their own objectives.

## **Introduction**

*It is claimed in 2012, as a result Supreme court's website crashing, the decision on whether the Affordable Care Act's mandate was valid was announced via social media; with even the then President Obama dependant on media outlets for the result [1].*

Social Media is a concept that is universally understood but not easily defined. Social Media **are** the various platforms, generally Internet based, which enable communication between users using a unique frame of reference including but not limited to Twitter (140 characters micro-blogs) and You-Tube (video uploads etc.) Social Media **is** also a process by which you can share information and knowledge rapidly. This heterogeneity of definition and use has made it difficult to examine its impact on medicine using traditional academic and research methods. This may explain why despite its widespread and huge usage it's specific role in Health Policy has been relatively poorly explored.

There is clear validity to utilising mechanisms which allow for greater dissemination and reach of information. The ability of social media to close the knowledge translation gap has been postulated [2] but not yet been definitively proven. However the concept of digital communities of practice, collections of individuals linked via social media platforms, engaging in activities which generate new ideas and collaborations is increasingly recognised [3]. This provides a plausible mechanism for the distribution of potentially complex health policy ideas which will challenge and ultimately refine them.

The use of media to change behaviour is not new. For example there have been effective campaigns to reduce drunk-driving, smoking rates and health care utilization [4,5,6]. The ability to build, at minimal cost, impactful multimedia presentations on social media platforms and distribute them effectively, (potentially) further improves the ability to deliver health policy

via this medium. A recent integrative review methodology of a large range of study designs examined planned media interventions, including broadcast, print and social, media in any country, state or community. Studies were excluded if they did not directly assess the association between the media exposures and policy making (i.e. surrogate outcomes such as public preference for certain policies). Outcomes of interest were the impact of the intervention on agenda-setting, policy formulation, adoption, implementation, and evaluation and process benefits were found in all these areas. [7].

Intriguingly for a study submitted in 2016 no evaluations of studies directly relating to social media were found (13764 citations searched). The authors highlighted three reasons for research gaps and deficiencies:

- The bias in conducting research,
- The indirectness of the evidence,
- The insufficiency of information

It may well be that the research methodology to assess social media's role in health policy has yet to be defined. Social Media is almost certainly being utilised in health policy but to demonstrate its impact validated mechanisms to assess its benefit need to be more widely shared and accepted.

The authors did identify, outside of their relatively strict inclusion criteria, social media interventions related to public health. It was identified that mass media campaigns can have a positive impact [4,8], social media may be beneficial for patients with chronic disease [9,10] and that social media has been utilised effectively in child health [11].

The problem goes beyond having the right research tools however. Even if the research is performed, it is well noted that there is a translation gap between the production of evidence and its implementation in clinical practice. This has been described for Beta Blockers [12] and Antenatal steroids [13] for example, in which there were up to 20 year delays between discovery and broad implementation.

In parallel with this is a delay from when the evidence reaches policy makers and when it is formally adopted into public policy. It is probably beholden on both academic researchers and government/organisational policy makers to reduce these time spans without biasing or rushing adequate evaluation and academic rigor. Social Media has already been identified as a mechanism for doing this [2]. However currently some health policy researchers have

described “*social media as being incompatible with research, of high risk professionally, of uncertain efficacy, and an unfamiliar technology that they did not know how to use*” [14]

In a study of researchers’ perceptions, not unexpectedly, junior faculty were more optimistic than senior faculty about the perceived efficacy of social media [14]. It appeared though, despite relatively wide availability of resources in relation to how to use social media to disseminate information, in particular twitter and facebook, many researchers felt poorly informed and equipped to do this. It is fair to say that there is a paucity of well-evidenced material on how to use social media in a health policy context effectively. So, in the current state, what can researchers, academic and health policy makers do with social media? In a systematic review of the uses, benefits and limitations of Social Media for Health communication 12 limitations were identified [15]. All were derived from a review of 98 original research studies which “*..included the uses, benefits, and/or limitations of social media for health communication among the general public, patients, and health professionals*”.

Table 1 lists these limitations, which policy makers may wish to consider when using social media to develop policy or communicate it broadly.

<b>Limitation</b>	<b>Relevant to Public (PU), Patients (PA) or Health Professionals (HP)</b>	<b>Learning/Further Research</b>
Lack of reliability	PU, PA, HP	This relates to the perception of the quality assurance information of the information received. This may be improved by better education and also for content producers to be more clear, or link, to sources of evidence for their material.
Quality concerns	PU, PA, HP	A review of the quality of health policy relevant information delivered via social media should be undertaken and a quality assurance process agreed (inter)-nationally could be

		undertaken to accredit high quality information.
Lack of confidentiality & privacy	PU, PA, HP	There are some theoretical concerns that open debate may inhibit communication from some users. A social media strategy should not be based solely on gaining views from the public space.
Often unaware of the risks of disclosing personal information online	PU, PA	This should be less of a concern for health policy material, as the purpose of policy documents or consultation is that it is designed to be shared. However it is important to recognise that health policy information may cause debate, and diverse views, which must be managed appropriately, but sensitively, on open fora.
Risks associated with communicating harmful or incorrect advice using social media	PU, PA	These risks should be mitigated by improved quality control and assurance of primary content. However it is relevant to note that some sites, containing vexatious or incorrect material, may have large followings and impact. It is important policy makers are aware of this and mechanisms to reduce the harm caused by these sites should be explored and utilised.
Information overload	PU, PA	It is likely there is wide variation in the public and patient capacity to digest

		materials via social media, especially in health policy context and this should be explored.
Not sure how to correctly apply information found online to their personal health situation	PU, PA	There is a large gap in the evidence, specifically in relation to health policy shared via social media in how this is interpreted and acted on (as opposed to very specific health advice which has a greater evidence base)
Certain social media technologies may be more effective in behavior change than others	PU	This needs further academic examination
Adverse health consequences	PU	It is not clear if there has been major harm caused by a social media derived health policy initiative but it is possible this may have occurred
Negative health behaviors	PU	There may be a small, but defined, patient or public group who may deliberately or unintentionally reframe their behaviours in response to personal networks on social media
Social media may act as a deterrent for patients from visiting health professionals	PA, HP	
Currently may not often use social media to communicate to	HP	There needs to be an organizational or regulator debate on social media and digital health

patients		competencies for health care professionals.
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Clearly controlling for all potential limitations simultaneously will be challenging. Engaging with all relevant stake-holders will be key to ensuring progress in this field though. Websites such as [www.patientslikeme.com](http://www.patientslikeme.com) have demonstrated how public, and patients, alike will contribute individual information for the perceived greater good of society. The outcomes of such enterprises are not clear but the debate they generate is beneficial for policy makers. For example the use of Social Media to potentially 'unblind' yourself during a clinical trial may have a significant policy impact on the design of studies [16]. It is important that 'harms' from social media are recognised where they exist. This should not dampen enthusiasm for its use but will enable case studies to be described leading to research on how this risks can be mitigated.

## **Conclusion:**

Social media represents a rapidly maturing channel of communication that can be used to disseminate health policy decisions and evidence that supports those decisions. Effective dissemination strategies particularly for health coverage should include a social media strategy informed by the patient perspective. Evidence based guidance on how to effectively do this needs to be derived.

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