

The use of social media by health service providers and consumers as a tool for health service design and quality improvement: A scoping review protocol

Louisa Walsh¹, Dr Nerida Hyett², Associate Professor Sophie Hill¹

¹Centre for Health Communication and Participation, La Trobe University, Bundoora, Australia

²La Trobe Rural Health School, La Trobe University, Bendigo, Australia

Contact Author: Louisa Walsh: louisa.walsh@latrobe.edu.au

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Background

Social media

Social media is defined as “a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content”(1, p61). As opposed to traditional ‘broadcast’ (one-way, information giving) communication models from organisations to individuals, the ability for individuals and organisations to generate content allows for a full range of communication models between organisations and their consumers – one and two-way; synchronous and asynchronous(2). Additionally, individuals can use social media to be the initiators of communication with the organisations they’re interested in, rather than just the receivers of, or responders to, messages(1). Social media also has benefits of potential increased immediacy and reach compared to traditional communication methods, which provides new opportunities for organisations to interact with, and meet the needs of, their consumers(2).

Social media use is extremely widespread. It is estimated that 2.77 billion people worldwide use social media, equating to 71% of all internet users accessing social media sites(3). The majority

of people in the United States of America (USA) use social media, with 68% of all US adults using Facebook, and 94% using YouTube(4). In Australia, 79% of internet users access social media(5). Data from the Pew Research Centre in the USA indicates that an estimated 80% of American internet users have searched for online health information, including information from social media sites(6), and 57% of Americans with chronic disease have used social media to find information and support for their condition(7). Some identified benefits of health-related social media use are increased support(8, 9), improved self-management(8, 9), greater access to information(10), more equal relationships between health professionals and patients(8), and improved health service data collection(10).

Consumer engagement in health service design and quality improvement

In the context of this review, healthcare consumers are defined as ‘patients and potential patients, carers, and people who use health care services’(11). Around the world, national health systems increasingly require that services involve healthcare consumers and community members in planning, design, delivery, measurement and evaluation(12-14). In response to this requirement, health services are involving their consumers in a wide range of roles including executive boards, advisory committees, quality review processes and development of clinical guidelines and health information(15). Consumer engagement in the design and quality improvement activities of health services has been shown to improve patient outcomes(16-18), improve access to services(18, 19), and make services more patient-centred(20). However, there are barriers associated with consumer engagement in health service design and quality improvement. These include insufficient time, financial and staff resources (18-20), a lack of consumer and service provider experience and training in working together (19), a lack of consumers from socially disadvantaged groups taking part in engagement activities(15, 21, 22), and concerns about how effectively small numbers of consumers are able to represent the views of the wider community being served by a health service (18).

Social media and consumer engagement

Social media has been identified as one way for health services to engage with communities of healthcare consumers(10, 23), building on more traditional engagement methods such as consultations or consumer involvement in face-to-face committees. While social media is still primarily used by health services as a broadcast medium (24-27), there is growing support for the use of social media as a way to address some of the limitations or barriers of traditional consumer engagement methods in health service design and quality improvement(21, 23, 24, 28-30).

Scoping review objective and research questions

The objective of this scoping review is to examine and map the research evidence around how social media is being used by health services and consumers to influence changes to health service design or conduct quality improvement activities. The question that will be answered through this review will be: “How is social media used as a tool for health service design and quality improvement activities?” Under this overarching review question, the following sub-questions will be addressed:

- a. What are the common features of social media platforms used in health service design and quality improvement activities?
- b. What communication models are used in health service design or quality improvement activities, or to influence changes in health service design?
- c. Which populations of people are using social media in health service design or quality improvement activities, or to influence changes in health service design?
- d. What types of health service design or quality improvement activities are being undertaken/influenced through social media communications?
- e. What are the benefits of social media use in design and quality improvement activities within health services?
- f. What are the risks and limitations of social media use in design and quality improvement activities within health services?
- g. What are the barriers to the use of social media in design and quality improvement activities within health services?
- h. What are the enablers for the use of social media in design and quality improvement activities within health services?

Through answering these questions, the scoping review will a) present a summary of current research findings in this area, and b) identify research gaps. This scoping review is being undertaken as the literature review component of a PhD project. Outcomes of this scoping review will be used to inform primary research studies undertaken during the PhD research project.

Stakeholder involvement in co-production of this scoping review

The PhD project is being conducted using a co-production method(31), underpinned by a cooperative inquiry methodological framework(32, 33). This approach sees consumers, service providers and health researchers working together from the inception of the project to solve real-world issues through cycles of reflection and action(32). An advisory committee of consumers, clinicians and policy makers were involved in shaping the proposed program of research during the grant application phase of this project, and included helping to define the topic of this review.

During the scoping review, advisory committee members will be involved in key decision making throughout the review processes, including:

- assisting with decisions around inclusion/exclusion of studies when consensus can't be reached by the author team;
- reviewing and commenting on the analysis of included studies; and
- reviewing and commenting on drafts of the scoping review manuscript.

Involvement of an advisory committee of stakeholders which includes practitioners and consumers is aligned with the methodological framework for scoping reviews from Arksey and O'Malley(34) who proposed an optional 'consultation exercise' stage of the framework to add value to the review by ensuring the results are useful and relevant to the stakeholders who are most impacted by the intervention. It should be noted that in our proposed review stakeholders are not just involved in a separate 'consultation exercise' stage, but they are instead embedded throughout the review – with stakeholder involvement during Arksey and O'Malley(34) framework stages one (identifying the research question), three (study selection) and five (collating, summarising and reporting the results).

The advisory committee will use the information gathered through the scoping review to inform iterative reflective processes(32, 33) that will guide specific research questions and methods during future phases of the PhD project.

Inclusion/exclusion criteria (using Population-Concept-Context model)(35)

The development of this review protocol was guided by the methodology for scoping reviews from the Joanna Briggs Institute(35). A tool to assist screening decisions has been created for this scoping review, and is included in this protocol as appendix 1.

Population

Inclusion criteria:

- a. Users or potential users of a health service (i.e., patients, consumer representatives, consumers with an acute or chronic condition, carers, family members, consumer organization member, community members, public)
- b. Health service providers (health professionals, health service manager/administrator, health policy makers)
- c. Any age

- d. Any gender

Exclusion criteria:

- a. Users or providers in non-health service settings (e.g., universities, education, research)

Concept

‘Social media’ refers to any online platform that allows users and audiences to create content and interact(1). Social media allows for broadcast (one-way) or communicative (two-way) styles of communication, and also allows for communication to happen in synchronous or asynchronous ways(2). This review will encompass all communication models and any platform which is considered ‘social media’ by the definition above, with communication initiated or led by either providers or service users. This includes studies examining public platforms, purpose-built platforms, private groups within public platforms, and review/rating sites (both health-specific and generic sites).

‘Quality improvement’ is defined as “the combined efforts of the workforce and others – including consumers, patients and their families, researchers, planners and educators – to make changes that will lead to better patient outcomes (health), better system performance (care) and better professional development.”(12, p75). This review will encompass activities which are considered ‘quality improvement’ by this definition, as well as activities or actions that attempt to influence change to health services or systems that are initiated from outside the workforce (e.g., advocacy).

Inclusion criteria:

- a. Studies where social media is used as a tool within health service design or quality improvement activities carried out from 2004 (defined start of Web 2.0(1)) to 2019.
- b. Studies where social media is used as a tool to influence or advocate for changes to health service design or delivery carried out from 2004 to 2019.

Exclusion criteria:

- a. Social media for disease surveillance only without intention to change health service design/delivery.
- b. Social media for health information dissemination only.
- c. Social media for patient treatment/care/peer support without intention to influence health service change or quality improvement.
- d. Social media use in health provider education.

- e. Consumer/service provider engagement in research only without changes to health service design or delivery.
- f. Social media use for research recruitment.

Context

Inclusion criteria:

- a. Original primary research or evaluation articles (any methods) and secondary research review articles including: systematic reviews, meta-analyses, meta-syntheses, narrative reviews, mixed-methods reviews, qualitative reviews and rapid reviews, published in either peer reviewed academic publications or grey literature. In the context of this study. In the context of this scoping review, “research” is defined as “activities designed to develop or contribute to generalizable knowledge, i.e., theories, principles, relationships, or the information on which these are based, that can be confirmed or refuted by recognized methods of observation, experiment, and inference”(36) and publications must state the method by which the research was conducted, and include some analysis of the data generated through the research method.
- b. English-language articles.
- c. Studies published between January 2004 to the date the searches are run.
- d. Studies from any geographic location, regardless of country’s income status, will be included.
- e. Studies in healthcare (hospitals, health services, aged care, community health, primary health) or health policy (government health departments) settings will included.

Exclusion criteria:

- a. Opinion pieces, commentaries and editorials without original research will be excluded.
- b. Articles or resources which promote or encourage advocacy activities without accompanying research examining the outcomes or experiences of the advocacy activity being promoted.
- c. Articles which provide an overview of some research literature but do not outline a review method.
- d. Studies in non-healthcare settings (e.g., universities, education, research)

Search strategy

We will search the following electronic databases: Medline OVID, Embase OVID, PsycINFO OVID, CINAHL EBSCO, Health Systems Evidence and PDQ-Evidence. The search strategy will include only terms relating to or describing the intervention. We will conduct hand searching of the reference list of any relevant review studies identified in the search to find additional relevant studies with primary data.

We will also search grey literature to identify non-indexed literature relevant to this study. Grey literature searches will be conducted by using key terms and the search function on websites of key national organisations involved in consumer engagement or health service quality improvement in English-speaking countries (e.g., NICE UK, Australian Commission on Quality and Safety in Health Care, Consumers Health Forum of Australia, The Kings Fund, Health Canada, National Health Institute, Agency for Healthcare Research and Quality, World Health Organization, National Health Service, Health Issues Centre).

Studies will be retrieved using the search strategy outlined above. As this scoping review forms the literature review component of a PhD project, the titles and abstracts of retrieved studies will be screened by one review author (LW), with the other authors providing additional input where the screening decision is unclear. The full text of these potentially eligible studies will be retrieved and assessed for inclusion by one author, with the other authors providing additional input where an inclusion decision is unclear. Where no agreement, we will consult with members of the Advisory Committee.

Example strategy

The example search strategy used in Medline OVID is: (Consumer OR patient OR carer OR public OR service user) OR (Service provider OR health professional OR doctor OR nurs* OR physiotherap* OR physical therap* OR allied health OR dietitian OR speech patholog* OR medical OR pharmac* OR specialist OR occupational therap* OR psycholog*) AND (social media OR facebook OR twitter OR linkedin OR instagram OR snapchat OR blog OR tumblr OR myspace) AND (engag* OR participat* OR involv* OR partner* OR codesign* OR coprod* OR quality improvement) AND (hospital OR health service OR medical service OR policy)

Extraction of the results

This scoping review will likely focus on qualitative data. As such, the following a priori themes based on the overarching review question and sub-questions have been identified:

- a. Common features (e.g., platforms, communication categorisation – one-way/two-way; synchronous/asynchronous) of health provider-led social media use for health service design and quality improvement
- b. Common features (e.g., platforms, communication styles) of service user-led social media use for health service design and quality improvement
- c. Type of health service design or quality improvement activity being undertaken/influenced through social media communications.
- d. The populations of people are using social media in health service design or quality improvement activities, or to influence changes in health service design?
- e. Benefits of social media use in design and quality improvement activities within health services
- f. Risks and limitations of social media use in design and quality improvement activities within health services
- g. Barriers to the use of social media in design and quality improvement activities within health services
- h. Enablers for the use of social media in design and quality improvement activities within health services

There may be additional themes or categories that emerge through the data collection that are not captured above but are of interest to the review. These will be captured through an additional 'emergent themes' field in the data extraction template.

Data extraction

A pre-determined data extraction form will be used to extract data from the included studies. Extracted information will include: article title; year of publication; authors; type of publication (e.g., journal article, book chapter, grey literature); study aims/objectives; methodology; methods; population (using PROGRESS-plus categorisations (37, 38); setting; description of social media intervention; description of intended health service change; categorisation of communication model (one-way, two-way, synchronous, asynchronous); a priori themes (as above); additional emergent themes.

Strategy for data synthesis

The purpose of this scoping review is to a) present a summary of current research findings in this area, and to b) identify research gaps. This is in line with the potential purposes of scoping reviews as outlined by the Joanna Briggs Institute methodology for scoping reviews(35), Arksey and O'Malley(34) and Levac et al(39) which will be used to guide the methodology used in this review. As such, the data will be synthesised and analysed in the following ways:

- a. A numerical overview of the amount, type and distribution of included studies, with a focus on: populations of users, communication models (consumer-led/provider-led; broadcast/communicative), platform features, intended health service change, settings and a priori themes as per the approach for descriptive numerical summary analysis for scoping reviews recommend by Levac(39).
- b. A thematic analysis of the findings relating to the a priori and emergent themes to answer the research question presented in this protocol. This analysis will use the deductive thematic content analysis method based on the content analysis method for qualitative systematic reviews from Finfgeld-Connett(40) and will be informed by a critical interpretive methodology as described by Barnett-Page and Thomas(41).
- c. An advisory committee of key stakeholders working within a participatory research model(42) will be invited to read and comment on the draft data analysis.

Dissemination plan

This review will be published as open access in a journal in the health information, internet medical research or quality improvement fields. Once published, the article will be shared throughout the online, social media and professional networks of the Centre for Health Communication and Participation, La Trobe University. Findings will be summarised and presented at a relevant conference in 2020, and shared with policy makers at Safer Care Victoria, part of the Department of Health and Human Services in Victoria, Australia. This review will also go on to inform a program of research as part of a PhD project, and will be included as a chapter in the PhD thesis.

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Conflicts of interest

The authors declare that they have no known conflicts of interest.

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Appendix 1 – Screening decision tool

Phenomenon of interest: Social media use to influence health service change or conduct quality improvement activities

****To be INCLUDED a study must be rated yes (Y) for EACH criteria in EACH category:**

CATEGORY	Criteria	Y	N	Unclear/Notes
POPULATION	<p>1. Does this study include participants who are health services users and/or health service providers?</p> <p>Rate as Y if the study includes participants who are:</p> <ul style="list-style-type: none"> a. Users or potential users of the health service (i.e., patients, consumer representatives, consumers with an acute or chronic condition, carers, family members, consumer organization member, community members, public) <p>AND/OR</p> <ul style="list-style-type: none"> b. Health service providers (i.e, health professionals, health service manager/administrator, health policy makers) <p>Rate as “N” if the study includes none of the above participants (e.g., academics, educators, researchers only)</p>			
CONCEPT	<p>2. Can the online platforms in the study be considered ‘social media’</p> <p>Rate as “Y” if the online platforms in the study allow all users (not just platform owners/operators) to create content which can be seen by other users of the platform. This may include public open platforms or private platforms requiring registration.</p> <ul style="list-style-type: none"> • Common public platforms are: Facebook, Twitter, MySpace, YouTube (providing comments aren’t disabled), Snapchat, Instagram, Google+, Patient Opinion, Yelp. 			

	<ul style="list-style-type: none"> • Common words/phrases in a platform description that may indicate a platform is social media include (but are not limited to): chat function, discussion board/thread, rate, review, comments, blog, moderator, community manager. <p>Rate as “N” if:</p> <ul style="list-style-type: none"> • the platform is a website only with no indication that two-way communication is occurring • email is the only form of online communication (i.e., communication is not visible to all users) • there is no use of social media (e.g., face to face, teleconference or videoconference meetings). 			
	<ul style="list-style-type: none"> • Are the participants: <ul style="list-style-type: none"> ○ Involved in a quality improvement project or activity? AND/OR ○ Trying to influence a change in health service or system design or the services being delivered? <p>Quality improvement is defined as “the combined efforts of the workforce and others – including consumers, patients and their families, researchers, planners and educators – to make changes that will lead to better patient outcomes (health), better system performance (care) and better professional development.”</p> <p>Rate as “Y” if:</p> <ul style="list-style-type: none"> • The study describes an intention to change how health services or systems are designed or delivered through the involvement of the participants in quality improvement activities and/or other actions aimed at influencing change; OR • The study describes a change/attempt at change that has occurred to health services or systems based on the actions or activities of the participants. 			

	<p>Note: Studies can still be included if the change or quality improvement activity has not been successful or is ongoing/incomplete.</p> <p>Rate as “N” if:</p> <ul style="list-style-type: none"> • Social media is used for disease surveillance only without stated intended or actual change to current health service or system design/delivery (recommendations for change alone not sufficient). • Social media is for health information dissemination only. • Social media is for patient treatment/care/peer support within existing model of care and without intention to influence changes to health service or quality improvement activities. • Social media is used in health provider education or consumer education which doesn’t have impacts on a how a health service designs or delivers existing services (for e.g., social media use in undergraduate health care provider education). • Consumer/service provider engagement in research only without changes to the design/delivery of an existing health service or system. • Social media use for research recruitment. 		
	<p>3. Are the participants using social media as a communication tool for their quality improvement activity/attempt to influence health service/system change?</p> <p>Rate as “Y” if:</p> <ul style="list-style-type: none"> • Some or all of the communication about the quality improvement activities and/or health service/systems change happens via social media. <p>Rate as “N” if the group:</p> <ul style="list-style-type: none"> • Communication about the quality improvement activities and/or health service/systems change happens via other mediums (face to face, telephone, videoconference, email) <u>even if</u> the new/changed service is delivered via social media. 		

<p>CONTEXT</p>	<ul style="list-style-type: none"> • Is this study primary research, review research and/or eligible grey literature? <p>Rate as “Y” if the study is:</p> <ul style="list-style-type: none"> • Original primary research or evaluation article (any methods) or secondary review research article (including systematic reviews, meta-analyses, meta-syntheses, narrative reviews, mixed-methods reviews, qualitative reviews and rapid reviews) • Published as either peer reviewed academic literature or within the grey literature. <p>Rate as “N” if:</p> <ul style="list-style-type: none"> • The article is an opinion piece, commentary or editorial without original research. • The article is an overview of research literature but doesn’t describe review methods. • The article promotes or encourages advocacy activities without accompanying research examining the outcomes or experiences of the advocacy activity being promoted. • The article has no stated research method or analysis of the data collected through the research. 			
	<p>4. Is this study in a healthcare or health policy setting?</p> <p>Rate as ‘Y’ if:</p> <ul style="list-style-type: none"> • The study is set in a hospital, health service, aged care, community health, primary health or government health department; OR • The participants are attempting to influence changes to existing health services designed/delivered in a hospital, health service, aged care, community health, primary health or government (local, federal, state) health department. <p>Rate as ‘N’ if:</p> <ul style="list-style-type: none"> • The study is set in a university, educational, research or other non-healthcare setting and there is no 			

	attempt to influence changes to existing health services or policies.			
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There are three different scenarios after you finish your assessment:

1. IF THE ARTICLE SCORED **Y** ON EACH OF THE ABOVE CRITERIA -> CLASSIFY AS **INCLUDE**
2. IF THE ARTICLE SCORED **N** TO ANY OF THE ABOVE CRITERIA -> CLASSIFY AS **EXCLUDE**
3. If IT IS UNCLEAR WHETHER AN ARTICLE MEETS A PARTICULAR CRITERIA, BUT THE ARTICLE WOULD **OTHERWISE BE INCLUDED**, classify as **INCLUDE** but put a note in the 'notes' section: MORE INFORMATION REQUIRED ABOUT [INSERT RELEVANT CRITERIA]
4. IF IT IS UNCLEAR WHETHER AN ARTICLE MEETS A PARTICULAR CRITERIA, BUT THE ARTICLE WOULD **OTHERWISE BE EXCLUDED**, classify as **EXCLUDE**