The use of social media as a tool for stakeholder engagement in health service design and quality improvement: A scoping review

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Abstract

Background: Health-related social media use is common but few health organisations have embraced its potential for engaging stakeholders in service design and quality improvement (QI). Social media may provide new ways to engage more diverse stakeholders and conduct health design and QI activities.

Objective: To map how social media is used by health services, providers and consumers to contribute to service design or QI activities.

Methods: The scoping review was undertaken using the Joanna Briggs Institute methodology. An advisory committee of stakeholders provided guidance throughout the review. Inclusion criteria were studies of any health service stakeholders, in any health setting, where social media was used as a tool for communications which influenced or advocated for changes to health service design or delivery. A descriptive numerical summary of the communication models, user populations and QI activities was created from the included studies, and the findings were further synthesised using deductive qualitative content analysis.

Results: 40 studies were included. User populations included organisations, clinical and non-clinical providers, young people, people with chronic illness/disability and First Nations people. Twitter was the most common platform for design and QI activities. Most activities were conducted using two-way communication models. A typology of social media use is presented, identifying nine major models of use.

Conclusion: This review identifies the ways in which social media is being used as a tool to engage stakeholders in health service design and QI, with different models of use appropriate for different activities, user populations and stages of the QI cycle.

Keywords

Social media, Facebook, Twitter, digital health, public health, health communications, internet, online

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Introduction

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] (p.61). Any online platform that allows users and audiences to create content and interact with each other can be considered social media.[1] This definition includes

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platforms such as Facebook, Twitter, Instagram and YouTube, and privately developed platforms with functions that allow user interaction (such as forums and chat rooms). Social media allows for broadcast (one-way) or communicative (two-way) styles of communication[2] and allows for communication to happen in synchronous or asynchronous ways.[2]

The use of social media is extremely widespread and growing. It is estimated that 2.77 billion people worldwide use social media sites (equating to 71% of total internet users) with this number predicted to rise to over 3 billion by 2021.[3] The majority of people in the United States of America (USA) use social media, with 68% of all USA adults using Facebook, and 94% using YouTube.[4] In Australia, 88% of internet users have at least one social media profile.[5]

Health-related use of social media is very common. An estimated 80% of American internet users have searched for online health information, including information from social media sites,[6] and Fifty-seven percent of Americans with chronic disease have used social media to find information and support for their condition.[7] Health services around the world are also incorporating social media in communication strategies. A study of general and medical hospitals in the USA showed over 99% had a Facebook, Foursquare and/or Yelp account.[8] A similar study of tertiary hospitals in China showed that 76.2% of hospitals were using the Chinese social media sites Sina Weibo or WeChat.[9] Health-related social media use can increase both consumer to consumer and provider to consumer support,[10,11] improve self-management of conditions,[10,11] increase consumer access to information,[12] create more equal relationships between health professionals and patients,[10] and improve health service data collection.[12]

Stakeholder engagement in health service design or quality improvement (QI) is an established practice in many health systems. 'Stakeholders' are the individuals and groups who can influence an organisation's success or affect its ability to meet its purpose.[13] Stakeholders in health services come from across all levels of health – from the individual to the systems level – and can include providers, consumers, policy makers, health administrators and the general public.[14,15] Stakeholder engagement activities in health are traditionally conducted face-to-face (e.g., involvement in meetings, deliberative processes, interviews, focus groups) or via surveys.[16–18]

An emerging area of practice and research is the use of social media to facilitate stakeholder engagement in service design and QI. Authors argue for the potential of social media for engaging with a broader range of health stakeholders,[19–22] leveraging existing online consumer communities for involvement in co-design of services,[22–24] and using social listening (i.e., the monitoring of online conversations to gather data[25,26]) as a way to gather patient sentiment and experience data.[27–30] However, this literature is largely theoretical or opinion-based,[19–24,27–30] and it is unclear whether these potential uses of social media are being realised in real-world stakeholder engagement activities.

Prior to undertaking the scoping review a preliminary search for previous scoping reviews, systematic reviews and qualitative evidence synthesis reviews which aligned with the same topic was conducted. The databases searched were: Campbell Library, JBI Evidence Synthesis, Cochrane Database of Systematic Reviews, PDQ Evidence, and Health Systems Evidence. No previously published reviews were discovered which aligned with the scope of this review.

Objective

The objective of this scoping review is to map the research on the use of social media by health services, providers and consumers to contribute to service design or QI activities. Research gaps will also be identified. The overarching research question is 'how is social media being used as a tool for health service design and QI activities?' Four research sub-questions (RSQ) are being explored to answer this question:

RSQ1: What are the common features of social media platforms used in health service design and QI activities?

RSQ2: What communication models are used in health service design or QI activities, or to influence changes in health service design?

RSQ3: Which populations of people are using social media in health service design or QI activities, or to influence changes in health service design?

RSQ4: What types of health service design or QI activities are being undertaken/influenced through social media communications?

Methods

This scoping review was conducted using Joanna Briggs Institute (JBI) methodology[31] and has been reported in line with the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).[32] The objectives, inclusion criteria and methods of analysis for this review were specified in advance in a protocol,[33] and this paper addresses questions concerning features,

models, populations and uses of social media. A separate paper will address the additional questions of risks, limitations, barriers and enablers outlined in the protocol.[33] Minor variations in method from the published protocol have been described in Appendix 1 and the the PRISMA-ScR checklist is included in Appendix 2.

Stakeholder involvement in the co-production of this scoping review

This review has been guided by the involvement of an advisory committee of stakeholders, which includes three healthcare consumers and three healthcare providers in clinical and non-clinical roles. Arksey and O'Malley advocate for the use of a consultation exercise with practitioners and consumers within their scoping review framework.[34] In the current review, consultation was expanded to a method of co-production guided by the INVOLVE Principles.[35] Advisory committee members contributed to the review in the following ways:

- Determining the overarching research question for this review.
- Submitting potentially relevant articles for screening.
- Reviewing and commenting on the draft data analysis.
- Providing feedback on the manuscript.
- Answering specific questions about which findings of the analysis were particularly relevant to their experience of the health system, and these responses were used to shape the content of the discussion section.
- Three members of the advisory committee who commented on the draft data analysis, provided feedback on the manuscript, and answered the questions which informed the discussion section are included as co-authors on the review (NJ, CL, SR).

Eligibility criteria

The eligibility criteria outlined below and the subsequent search strategy and methods for the extraction of the results were guided by the Population-Concept-Context structure recommended in the JBI scoping review methodology.[31]

Population. For inclusion in this review, participants in the included studies were:

- 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); and/or
- Health service providers (health professionals, health service manager/administrator, health policy makers).

There were no restrictions on the age or gender of study participants considered for inclusion.

Studies only involving participants from non-health service settings (e.g., educational institutions, social care services) were excluded from the review.

Concept. The core concept to be examined in this review is how social media is used as a tool for health service design and QI activities. This includes uses of social media by health services to facilitate user or provider participation in organisational QI or service design activities, and the use of social media by individuals or groups to influence (or attempt to influence) health service or system changes. To capture the full range of potential uses of social media in QI and service design, two broad study types were included. These were:

- Studies where social media was used as a tool within workforce-based health service design or QI activities, and
- Studies where social media was used as a tool for communications which influenced or advocated for changes to health service design or delivery.

A date range limitation of '2004 – current' was placed on the search. This limitation was chosen because 2004 is defined as the beginning of Web 2.0, when the internet transitioned from being used primarily as a broadcasting medium to supporting and encouraging user-generated content.[1] This shift paved the way for the rise and dominance of social media platforms and tools.[1]

The following types of studies were excluded from the review:

- Social media for disease surveillance only without intention to change health service design/delivery.
- Social media for health information dissemination only with no QI-relevant objectives.
- Social media for patient treatment/care/peer support without intention to influence health service change or quality improvement.
- Social media use in health provider education.
- Consumer/service provider engagement in research only without changes to health service design or delivery.
- Social media use for research recruitment.

Context. To be eligible for inclusion, studies needed to be conducted in healthcare or health service settings

(hospitals, health services, aged care, community health, primary health, health-specific non-government organisations) or health policy settings (government health departments) and published in English. Studies from any geographic location, regardless of income status, were included.

Studies conducted in non-healthcare settings (e.g., educational institutions, social care services) were excluded from the review.

Study design. Original primary research or evaluation articles (any methods) and secondary research review articles, published in either peer reviewed academic publications or grey literature, were eligible for inclusion in the review. In determining eligibility for inclusion in this scoping review, 'research' was 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] To be included in this review, a study had to state the method by which the research was conducted and include some analysis of the data generated through the research method.

Conference abstracts were considered eligible for inclusion if they met the other eligibility criteria. Where it was unclear whether a conference abstract should be included, the author was contacted to determine eligibility.

Sources without original research (e.g., opinion pieces, editorials, commentaries) were excluded from the review.

Search strategy

On 1 February 2019 the following electronic databases were searched: Medline OVID, Embase OVID, PsycINFO OVID, CINAHL EBSCO, Health Systems Evidence and PDQ-Evidence. Restrictions applied across all searches were the date range of Jan 2004 – current (1 February 2019) and studies published in English only. Search strategies for Medline OVID, Embase OVID and PsycINFO OVID are provided in Appendix 3.

Grey literature was also searched to identify non-indexed researched literature relevant to this study. Grey literature searches were conducted using key search terms (e.g., 'social media', 'consumer engagement') and the search function on the websites of key organisations involved in consumer engagement or health service QI in English-speaking countries. All sections of websites that were likely to house relevant publications (e.g., 'Resources', 'Publications', 'Research' or 'Reports' pages) were also located and

searched. The full list of organisational websites and their web addresses searched during the grey literature search is provided in Appendix 4.

In addition to the searches above, the reference lists of included review studies were screened for potentially eligible studies. The members of the research advisory committee were also asked to submit any studies that they thought could be relevant to the authors for assessment for inclusion.

Screening of studies

Studies were retrieved using the search strategy outlined above. The titles and abstracts of retrieved studies were screened by one review author (LW). The full text of these potentially eligible studies was retrieved and assessed for inclusion by LW, and two other authors (NH, SH) provided additional input where an inclusion decision was unclear.

At the full text screening stage, a forward search was conducted on all conference abstracts to identify whether a journal publication had resulted from the conference presentation. Where a journal publication was associated with the conference presentation, the journal publication was included in the review in place of the conference abstract. Additionally, the authors of all potentially included conference abstracts were contacted to provide additional information to either assist with inclusion/exclusion decisions, or to add further information about the study which could be included in the extraction of results.

Extraction of the results

Data extraction was performed by one author (LW). A pre-determined data extraction form was used to extract data from the included studies. Extracted information included: article title; year of publication; authors; type of publication (e.g., journal article, conference abstract, 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 or actual health service change; categorisation of communication model (one-way,[39] two-way,[39] or social listening[40,41]) a priori themes (based on research sub-questions as outlined in the review protocol[33]) additional emergent themes.

Synthesis of results

The data were analysed and synthesised in the following ways:

a. An overview of the amount, type and distribution of included studies was constructed in relation features

of platforms (RSQ1), communication models (RSQ2), populations of users (RSQ3), and intended health service change (RSQ4) informed by the descriptive numerical summary analysis method recommend by Levac.[42] The numerical overview was constructed by LW, with input from SH and NH.

b. A deductive, qualitative content analysis method[43] was used to create a new typology (Table 3) describing social media communication methods through integrating, interpreting and synthesising the content of extracted data and the findings of the numerical overview.

Results

Search results

A total of 2088 titles and abstracts, and 214 full text articles were screened for eligibility. Forty articles from 39 study settings were included in the scoping review. A presentation of the search results using the 'preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow diagram'[44] can be seen in Figure 1.

Characteristics of included studies

All studies were published since 2010 and the majority (82.5%) of studies were conducted in high income countries (as classified by The World Bank[45]) There are 28 primary academic research articles, nine conference abstracts, two systematic reviews (one published in an academic journal, one published as a report) and one dissertation included in this review. The key characteristics of all included studies can be seen in Table 1.

Descriptive numerical summary analysis of included studies

RSQ1: What are the common features of social media platforms used in health service design and QI activities?

The majority of included studies ($n = 33$, 82.5%) used publicly available platforms (such as Facebook, Twitter, Instagram, etc) to conduct their activities, with Twitter being the most common platform, being used in 20 included studies.[48,50–55,59,60,67,69,70,72,74,75,77,79,80,84,85] Seven studies[57,58,63,69,73,80,83] included the use of purpose-built sites for their activities. Fifteen studies[46,49,56,57,65,69,72,74–78,80,84,85] included the use of more than one social media platform.
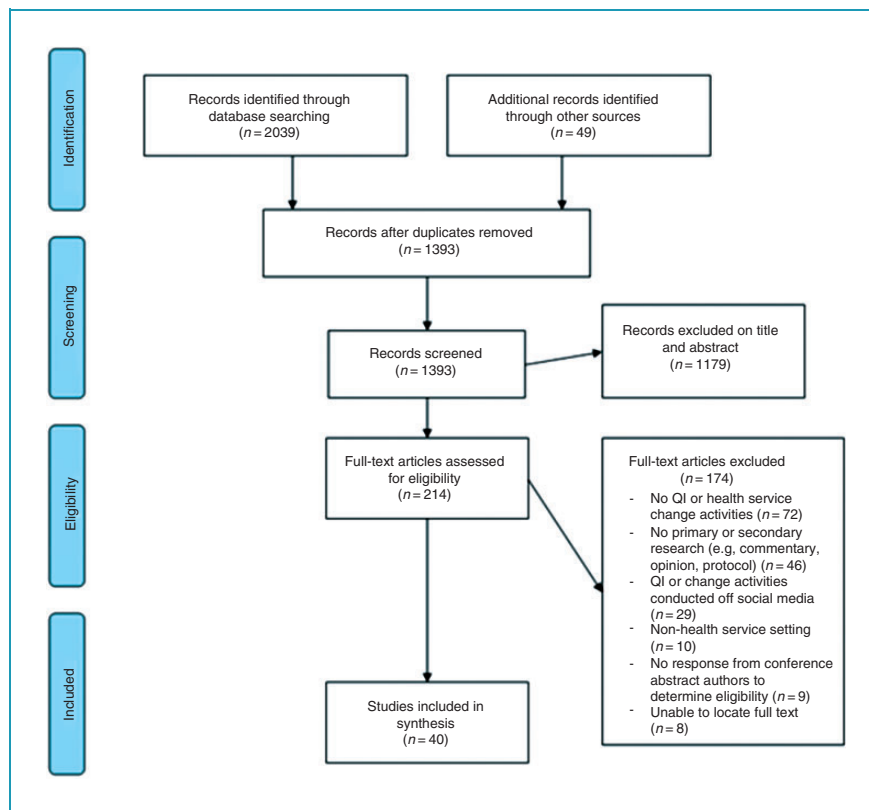

Figure 1. PRISMA flow diagram.

Table 1. Characteristics of included studies.

First author (Year)	Study aim	Study design	Publication type	Region or country	Social media platform and features	Social media user population	Description of health service design and/or QI activity
Amann (2017)[46]	To explore community managers' views on and experiences with knowledge co-creation in online communities for people with disabilities	Qualitative – semi-structured interviews ($n = 9$)	Journal article	Unspecified	Forums – mix of registration required to post only (open to view) and registration required to view and post Chat – registration required (two communities); no registration required (two communities) Moderators Open and restricted access	People with disability, service providers	Consumer involvement in the co-creation of knowledge with other stakeholders to influence health service planning/design, development of products and health research
Booth (2017)[47]	To explore the facilitators and barriers toward the use of social media in Ontario public health, and the evidence required to support the use of social media in Ontario public health	Qualitative – group deliberation activities and nominal group technique activity ($n = 50$)	Journal article	Canada	Unspecified – 'social media'	Public health service providers – health professionals and non-clinical roles	Social media use by public health units for a range of purposes including: communication mechanism for various elements of health promotion, behaviour change, health equity and other related system/policy implications, quality improvement, end-user training
Brightwell (2015)[48]	To use social media to improve the collection of patient feedback, and promote patient and carer engagement, in a district general hospital allergy clinic	Qualitative – analysis of written feedback submissions Number of participants not stated	Conference abstract	UK	Twitter – features undescribed	Children and parents/carers in a hospital paediatric allergy service	Use of Twitter to gather information for improving outpatient clinic services
De Sousa (2018)[49]	To evaluate a QI project of creating and disseminating social media posts about best practices in	Quantitative – social media analytics and knowledge survey Pre-intervention ($n = 101$) Post-intervention	Journal article	Canada	Facebook – Public organisational page Instagram – Public organisational page Open access	Hospital and the nurses working within it.	Dissemination of educational resources to increase knowledge about hypoglycaemia management guidelines

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Table 1. Continued.

First author (Year)	Study aim	Study design	Publication type	Region or country	Social media platform and features	Social media user population	Description of health service design and/or QI activity
	hypoglycemia management for nurses	(n = 60)					
Greaves (2014)[50]	To examine whether tweets sent to hospitals in the English National Health Service contain information about quality of care and to compare sentiment on Twitter about hospitals with established measures of patient experience quality	Mixed methods – volume and frequency of total tweets in study period, and content analysis Content analysis conducted on 1000 tweets	Journal article	UK	Twitter– open feed; connections via @-mentions Open access	NHS hospitals and their consumers	Twitter used as a care quality/ patient experience feedback mechanism
Harris (2014)[51]	To present case study and evaluative data on the implementation of a system to identify, respond to, and act on tweets about food poisoning in Chicago	Quantitative – Twitter and website analytics, outcomes of food safety inspections of restaurants 270 tweets, 193 website complaints, 133 restaurant inspections	Journal article	USA	Twitter– open feed; connections via key word search Open access	Chicago Department of Health and the general public in their service area	Twitter used to increase identification, reporting and public health response (inspections) to food poisoning reports
Harris (2017)[52], Harris (2018)[53]	To evaluate the performance of a system to identify, respond to, and act on tweets about food poisoning in St Louis	Mixed methods – Twitter and website analytics, outcomes of food safety inspections of restaurants (2017); interviews with stakeholders (2018) 193 relevant tweets identified, 7 interviews	Journal article	USA	Twitter – open feed; connections via key word search Open access	St Louis Department of Health and the general public in their service area	Twitter used to increase identification, reporting and public health response (inspections) to food poisoning reports
Harris and Moreland-Russell (2014)[54]	To examine the messages and tweet patterns in the social media response to the Chicago	Mixed methods – Twitter analytics and content	Journal article	USA	Twitter – open organisational feed; connections via @-mentions and	Chicago Department of Health and the general public	Twitter used to share information and facilitated communication

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Table 1. Continued.

First author (Year)	Study aim	Study design	Publication type	Region or country	Social media platform and features	Social media user population	Description of health service design and/or QI activity
	Department of Health e-cigarette campaign	analysis of tweets 683 included tweets			hashtags Open access		about vote on regulation of eCigarette use
Hawkins (2016)[55]	To assess the use of Twitter as a supplemental data stream for measuring patient perceived quality of care in US hospitals and compare patient sentiments about hospitals with established quality measures	Mixed methods – Machine learning classification of identified tweets, calculation of sentiment, surveys of representatives from included hospitals 4,04,065 tweets classified, 147 survey participants	Journal article	USA	Twitter– open feed; connections via @-mentions Open access	Hospitals and their consumers	Twitter used as a care quality/ patient experience feedback mechanism
Hedge (2011)[56]	To explore the effectiveness and specific challenges of a youth sexual health service evaluation project conducted via social media	Quantitative – survey ($n = 78$)	Journal article	UK	Facebook – public organisational page MySpace – open organisational page Bebo – open organisational page Hi5 – open organisational page Open access	Youth sexual health service and its consumers (aged 15–25)	Use of social media to engage service users in providing feedback and engagement in service improvement activities
Hildebrand (2013)[57]	To describe the participatory process used in a project to involve young people in the UNAIDS strategy planning.	Qualitative – thematic analysis of online and offline forum discussions ($n = 3479$)	Journal article	Regional forums for Africa, Latin America, Brazil, Asia Pacific, Eastern Europe, Central Asia, Middle East, North America, Caribbean, Central	Facebook – open forums Blog RenRen Vkontakte Purpose built website Open access	Young people (<30 years old), including people living with HIV, sex workers, men who have sex with men, people who inject drugs and the UNAIDS organisation	Use of online platforms to engage young people in UNAIDS strategy and planning process, and to facilitate offline events

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Table 1. Continued.

First author (Year)	Study aim	Study design	Publication type	Region or country	Social media platform and features	Social media user population	Description of health service design and/or QI activity
				Europe, China.			
Hoxworth (2012)[58]	To measure the impact that a collaborative of health providers has on the rates of Healthcare Onset and Healthcare Acquired Clostridium difficile infections (CDI) across participating health services in Colorado	Quantitative – pre- and post-intervention infection rates. 17 healthcare facilities participated	Conference abstract	USA	Purpose-built platform – registration required. Blog. Restricted access	Hospitals in the collaborative and the health professionals and non-clinical service providers working within them	Use of social media to coordinate and share knowledge and information about CDI prevention with the aim of decreasing hospital CDI rates
Khasnavis (2017)[59]	To use Twitter to assess public response to draft guidelines on lung cancer	Mixed methods – Twitter analytics, content and sentiment analysis. 172 included tweets	Journal article	USA	Twitter – open feed; connections via key word search. Open access	News organisations, general public, health professionals, professional medical organisations, businesses, government and research organisations	Using Twitter to gather public response to draft national guidelines for using low dose CT to screen for lung cancer
King (2013)[60]	To examine how Twitter influences or informs opinion on health policy, using the example of the Health and Social Care Bill in the UK	Mixed methods – Twitter analytics, sentiment analysis. 1,20,180 included tweets, 200 tweets included in sentiment analysis	Journal article	UK	Twitter– open feed; connections via key word search. Open access	General public and policy makers	Use of Twitter to influence decision making about National health policy while policy is under debate in parliament
Kleefstra (2016)[61]	To explore how patient reviews of hospitals on rating sites can contribute supervision of hospital care by healthcare inspectors	Qualitative – semi-structured interviews ($n = 10$)	Journal article	The Netherlands	Rate and review site. Open access	Health consumers, health service inspectors	Use of hospital rating site to provide additional patient experience information to hospital inspectors

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Table 1. Continued.

First author (Year)	Study aim	Study design	Publication type	Region or country	Social media platform and features	Social media user population	Description of health service design and/or QI activity
Lagu (2016)[62]	To learn whether social media could be used as a tool to engage patients and to identify opportunities for hospital quality improvement	Qualitative – thematic coding of Facebook posts 47 posts from 37 respondents	Journal article	USA	Facebook – public organisational page Open access	Hospital and their consumers	Using Facebook to gather patient experience narratives with the intention of improving quality of care through identifying patient experience issues
Lara (2017)[63]	To describe the development and implementation of two virtual communities of practice and assess participation and use during implementation	Mixed methods – site analytics, survey, case study ($n = 66$ in pilot phase; $n = 181$ post-launch)	Journal article	Spain	Forum, blog, wiki – registration required to view and post Purpose-built platform – registration required. Restricted access	Primary care nurses and GPs and hospital-based specialists and nurses	Virtual community of practice between hospital and community health professionals to improve patient outcomes through knowledge sharing and advice on patient care
Levine (2011)[64]	To describe the process of using social media to involve youth of colour in the design of programmatic content and formats for an Internet intervention	Qualitative – online focus groups ($n = 36$)	Journal article	USA	MySpace – Closed forum, chat Restricted access	Young people aged 16–24 and the organisation which services them	Social media to facilitate involvement of young people in the development of a HIV prevention intervention
Lopuhaa (2014)[65]	To explore the challenges and opportunities of using social media as a national, disease-specific non-government organisation	Qualitative – case study 8000 Facebook followers	Conference abstract	The Netherlands	Facebook – features undescribed Purpose-built platform – registration required. Restricted access and ? open access (unclear)	People with rheumatological disease, national rheumatological disease organisation	Community advocacy conducted through social media to influence changes in national health policy.
Martyn-Hemphill (2015)[66]	To evaluate the use of WhatsApp for communication among a urology team	Mixed methods – WhatsApp usage data, dialogue analysis of messages, focus groups 1051 messages included in analysis	Conference abstract	UK	What'sApp Restricted access	Health professionals in a hospital urology service	Use of WhatsApp to improve communication between health professionals particularly trainees and senior staff

Table 1. Continued.

First author (Year)	Study aim	Study design	Publication type	Region or country	Social media platform and features	Social media user population	Description of health service design and/or QI activity
Moorley (2014)[67]	To evaluate the development and growth of using Twitter to create an online nursing community.	Quantitative – Twitter analytics 7000 Twitter followers	Journal article	UK	Twitter– open feed; connections via hashtags Open access	Nurses	Use of Twitter to build a community of practice for nurses
Mukherjee (2013)[68]	To evaluate the use of social media to disseminate innovative video education for providers about asthma management guidelines	Quantitative – audit measuring rates of knowledge and use of clinical guidelines ($n = 58$ pre-intervention; $n = 55$ post-intervention)	Conference abstract	UK	YouTube Open access	Health professionals	Use of social media to disseminate QI education to health professionals leading to improved knowledge of acute asthma management guidelines
Norman (2012)[69]	To present the ways in which social media and digital audio-visual tools have been used to engage young people in the research and evaluation of social action and health projects	Mixed methods – two case studies Total number of participants not stated	Journal article	Canada	Facebook – open and closed groups, open organisational pages Twitter Ning – blogs, forums Flickr Purpose-built platform and website Restricted and open access	Young people aged 16-24 including young people who were newly arrived migrants, and the organisation that services them.	Using social media to collect data on youth experience of tobacco use to inform intervention design, and involve young people as health navigators and designers of an online tool for health navigation for newly arrived immigrants
O'Connor (2017)[70]	To explore nurses' views on future priorities for the profession and to examine social media as an engagement tool to aid policy communication and development	Mixed methods – Twitter analytics and thematic analysis ($n = 64$)	Journal article	UK (Scotland)	Twitter – open feed; connections via hashtags Open access	Clinical service providers, general public, health organisations	Use of Twitter to seek ideas, opinions and prioritising issues for future nursing strategy for Scotland
Owolabi (2014)[71]	To explore stakeholder views and justifications regarding the incorporation of Traditional Birth Attendants (TBAs)	Qualitative - thematic analysis ($n = 193$)	Journal article	Africa, North and South America, Europe	Forum - email communication forum with reader focused moderation Restricted access	Service providers with experience working with Traditional Birth Attendants and	Forum communication to gather views and experiences on role and use of TBAs and the degree to which TBAs should

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Table 1. Continued.

First author (Year)	Study aim	Study design	Publication type	Region or country	Social media platform and features	Social media user population	Description of health service design and/or QI activity
	into formal health systems					the organisation seeking views on TBAs.	be incorporated in formal health systems
Pisano (2014)[72]	To increase awareness of antimicrobial stewardship tools and care pathways for community acquired pneumonia among internal medicine residents through the use of social media communications	Quantitative – pre- and post-intervention survey (n = 39)	Journal article	USA	Facebook – public organisational page. Twitter – organisational feed. Open access	Internal medicine residents and the hospital they work at.	Use of social media to educate residents in antimicrobial stewardship and increase awareness of available treatment pathways
Porterfield (2017)[73]	To evaluate an online quality improvement communication platform for public health quality improvement professionals	Mixed methods – survey, interviews and platform analytics (n = 462 survey, n = 21 interview)	Journal article	USA	Forum – registration required to view and post. Purpose-built platform – registration required. Restricted access	Health setting-based QI professionals	Online community of practice for health quality improvement professionals to improve quality improvement practices and connectedness of QI workforce
Rackham (2017)[74]	To present a case study of a social media-based peer support and consumer representation group	Mixed methods – case study. Over 440 members across social media platforms	Conference abstract	UK	Facebook – Closed groups, Open groups. Twitter – organisational feed. Open and restricted access	Parents of neonatal ICU patients, service providers	Use of social media as a feedback mechanism to improve services within a neonatal ICU
Ramirez (2015)[75]	To evaluate how an online network impacts advocacy efforts around creating health policy to overcome the issue of childhood obesity in Latino populations	Quantitative	Journal article	USA	Facebook – public organisational page. Twitter – organisational feed. Blog. YouTube. Open access	Advocates, leaders, researchers, policy-makers and service providers within, or with interest in, the Latino community, and the organisation	Using social media to advocate for public health policy changes addressing high rates of childhood obesity in areas with large Latino populations

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Table 1. Continued.

First author (Year)	Study aim	Study design	Publication type	Region or country	Social media platform and features	Social media user population	Description of health service design and/or QI activity
						that services them	
Rizvi (2013)[76]	To describe the development of a youth cancer advocacy group who influence service design and health policy	Qualitative – case study 300 members of online forum	Conference abstract	Romania and Moldova	Forum – features undescribed Facebook – features undescribed Blog	Young people aged 14–29 with a history of cancer	Use of social media to advocate for service improvement and national policy changes around cancer in young people
Rushing (2018)[77]	To describe the process of designing a health website for American Indian and Alaskan Native Youth	Mixed methods – case study 32,000 users reached each week through online channels	Conference abstract	USA	Forum – features undescribed Facebook – public organisational page. Closed groups Twitter – features undescribed Instagram – features undescribed YouTube Open and restricted access	American Indian and Alaska Native youth aged 15–24, and the organisation that services them	Use of social media to involve young people in the development of youth health website and social media health promotion campaigns
Shields (2010)[78]	To describe a healthcare priority setting activity with residents and providers conducted across four social media platforms	Mixed methods – platform analytics, thematic analysis of written contributions >800 people	Journal article	Canada	Forum – features undescribed Facebook – features undescribed Blog YouTube Choicebook Open and ?restricted access (unclear)	Health service consumers, including those from remote, Aboriginal, seniors and hard to reach communities, their providers, and the public health organisation servicing their geographical area	Use of social media platforms to help set priorities for health service planning
Sperber (2016)[79]	To explore an online health community, and identify essential characteristics within the	Qualitative – ethnography of Twitter content and semi-structured	Dissertation	Global, most activity from USA and Europe	Twitter – open feed; connections via hashtags Open access	Health consumers with a history of breast cancer, health	Examining various ways that health professional-consumer partnership emerges through

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Table 1. Continued.

First author (Year)	Study aim	Study design	Publication type	Region or country	Social media platform and features	Social media user population	Description of health service design and/or QI activity
	community that may inform future development and support for patient-centred healthcare	interviews (n = 22)				professionals, advocates, researchers	their involvement in the online health community. These include reviewing content for publication, partnering on grant writing, being involved in policy making, being invited to consumer participation activities
Stokes (2015)[a,80]	To evaluate the effectiveness of online social media/social networks on consumer engagement in health	Systematic review 11 studies	Report	USA, Australia, Denmark, Sweden	Facebook page, group Twitter – undescribed Purpose-built platform – undescribed Open and restricted access	Various participants including young people (<26, 4 studies), Latino and Hispanic participants (2 studies) and men who have sex with men (1 study) and their service organisations.	Social media use to involve consumers in the design, delivery and evaluation of online health interventions
Sundstrom (2016)[81]	To examine the role of health as a connective narrative among individuals organizing collectively in an online advocacy community	Qualitative – content analysis of blog posts 1110 posts included in analysis	Journal article	USA	Tumblr Open access	People who identify with the Occupy Wall Street and 'We are the 99%' movements	Use of (Tumblr) to collect stories and experiences of inequity in healthcare with the aim of advocating for national health policy changes
Thynne (2014)[82]	To describe the processes of engaging young people in the design of a transition service for young people with diabetes	Mixed methods – case study Number of participants not stated	Conference abstract	UK	Unspecified – 'social media'	Young people (age not defined) with diabetes transitioning from paediatric to adult care.	Social media used to engage young people in the design of a diabetes transition clinic
Timimi (2015)[83]	To explore the use of a customised social	Mixed methods – surveys of knowledge	Journal article	USA		Health professionals and non-	Use of a purpose-built platform to enable

(continued)

Table 1. Continued.

First author (Year)	Study aim	Study design	Publication type	Region or country	Social media platform and features	Social media user population	Description of health service design and/or QI activity
	media platform to foster a culture of teamwork, accountability, and improve patient care	and awareness, platform analytics, thematic analysis of forum posts ($n = 254$)			Purpose-built platform – registration required. Open access	clinical service providers in a cardiovascular nursing care unit	sharing of performance metrics and quality improvement activities among service providers
Tursunbayeva (2017)[a,84]	To capture, classify, appraise and synthesize relevant evidence around how public sector health organisations are using social media for e-Government	Systematic review 22 studies	Journal article	USA, UK, Australia, Italy, Netherlands, Japan	Facebook – features undescribed, Twitter – features undescribed, YouTube, Unspecified – 'social media'	Hospitals, health departments, public health organisations	Various e-Government approaches including organisations using social media to: - crowdsource solutions to problems - co-produce activities - provide opportunities for democratic participation in decision making - evaluate activities
Waddell (2019)[85]	To describe and analyse social media content associated with three national nursing organizations during the month preceding the 2016 United States presidential election	Qualitative – content analysis of social media posts 2137 posts analysed	Journal article	USA	Facebook – public organisational page, Twitter – organisational feed, Open access	National nursing organisations, policy makers	Use of social media by national nursing organisations to influence or comment on national health policy in the lead up to an election

[a]Stokes (2015)[80] and Tursunbayeva (2017)[84] are both systematic reviews with some similarities in scope with this review. Stokes (2015)[80] had a focus on consumer engagement in the design, delivery or evaluation of interventions that targeted individual health outcomes (e.g. healthy eating, physical activity), rather than consumer engagement in a broader range of service design and QI activities which might have other impacts or outcomes on individuals or health organisations (such as improved patient experience). Additionally, the review only included randomised controlled trials. Tursunbayeva (2017)[84] focused on social media for consumer engagement in public health eGovernment, rather than looking at social media for consumer engagement across a range of health settings. Overall, both reviews had narrower inclusion criteria than this review.

Most authors did not identify or describe the specific features of platforms being used for health service design or QI activities. Of those studies which did, forums and blogs were the most commonly used features, with ten studies using forums[46,57,63,64,69,71,73,76–78] and seven using blogs.[57,58,63,69,75,76,78]

Privacy settings were a common feature cited in the literature. Twenty-one studies[50–57,59–62,67,68,70,72,75,79,81] conducted all their activities on social media platforms that were open to anyone visiting the site, such as open Twitter feeds or Facebook organisational pages. Seven studies[58,63,64,66,71,73,83] only used platforms that were private, with access restricted by password registration, invitation only or similar privacy mechanisms. Six studies[46,69,74,77,80,84] used a combination of open access and restricted access platforms for their service design or quality improvement activities.

For a full numerical summary of the social media platforms in the included studies, see 'RSQ1: Social media platforms' in Table 2.

RSQ2: What communication models are used in health service design or QI activities, or to influence changes in health service design? To categorise the communication models described within studies both the direction of the communication and the management of the social media spaces being used were considered.

In the included studies, two-way communication models were used in 22 studies,[46,54,56–58,62–67,69–74,77–80,83] one-way communication was used in 13 studies[49–53,55,59–61,68,75,81,85] and social listening was used in six studies.[51–53,59–61]

The administrators responsible for managing or curating the social media communications were primarily health organisations ($n = 20$;[49,54,56–58,62–65,69,71–75,77,78,80,83,85]) This included seven social media spaces managed by hospitals[49,58,62,63,72,74,83] and 12 studies[50–53,55,59–61,67,68,70,79] with communications occurring in a public and apparently unmanaged/moderated online space. Unmanaged/unmoderated spaces were primarily on Twitter, where communications occurred via hashtags, @-mentions and keyword searches. Only two studies[46,81] included consumer-managed spaces, and one study[66] included a health provider-managed space.

For a full numerical summary of the communication models used in the included studies, see 'RSQ2: Communication models' on Table 2.

RSQ3: Which populations of people are using social media in health service design or QI activities, or to influence changes in health service design? A finding of this review is that, rather than just being a setting where QI and communications activities took place, healthcare organisations were themselves active users of social media, presenting as a population group separate to their providers or consumers. Organisations had social media accounts in their organisational name, they had their own 'voice' and online presence, and the person or people responsible for running the account were generally not identifiable by other users on the platform. Other users interacting with an organisation on social media platforms communicated with the organisation as if it was an individual user, and organisations communicated directly with each other. Therefore, in this review, organisations were identified as a user population.

Social media users were primarily health organisations ($n = 25$;[49–59,62–65,69–72,75,77,78,80,84,85]) and hospitals accounted for seven of these organisations. Health service providers (either clinical or non-clinical) were users in 19 studies[46,47,49,58,59,61,63,66–68,70–75,78,79,83] and consumers were users in 20 studies.[46,48,50,55–57,61,62,64,65,69,74–82] Children or young people (aged <30) ($n = 9$;[48,56,57,64,69,76,77,80,82]) and people with a disability or chronic illness ($n = 6$;[46,57,65,76,79,82]) were the two most common consumer user populations in the included studies. Only eight studies[48,66–68,73,81–83] indicated one user population, and some of these studies were unclear in their reporting, so it is possible there were other user populations that were not identified.

For a full numerical summary of the user populations in the included studies, see 'RSQ3: Populations of users' on Table 2.

RSQ4: What types of health service design or QI activities are being undertaken/influenced through social media communications? Social media was used as a tool in government or international health policy/strategy/guidelines development in 13 included studies.[47,54,57,59,60,65,70,71,75,76,79,81,85] Examples of relevant activities include policy makers gathering public response to drafts of health policy through Twitter,[54,60] consumers or organisations using social media to organise and advocate for policy changes,[75,76,81] and organisations using social media platforms as a virtual space in which to conduct discussions and consultations on guidelines or strategy with stakeholders.[57,70,71]

Social media was used by health services to gather data from key stakeholders to inform their QI or design activities in 12 included studies.[47,48,50,55,56,61,62,74,78,79,82,84] Some of the ways hospitals and health services use social media for planning are by gathering QI-relevant data from posts made by individuals about their care experiences,[50,55] by using open social media platforms to invite feedback on services,[56,61,62] and by using private social media spaces to gather together stakeholders to discuss and provide feedback on service QI activities.[74,78]

Social media was used as a broadcast communication tool to disseminate resources or information which would prompt offline health service QI related actions

Table 2. Numerical overview of the frequency of which research sub-questions are addressed within included studies.

Research sub-question focus area	Number of studies (*n* (%)) reporting focus area of interest[a]
RSQ1: Social media platforms	**Platform used** Twitter = 20 (50%) Facebook = 13 (32.5%) Purpose-built site = 7 (17.5%) YouTube = 5 (12.5%) Instagram = 2 (5%) MySpace = 2 (5%) Other[c] = 9 (22.5%) Unspecified = 3 (7.5%) **Platform features** Forums = 10 (25%) Blogs = 7 (17.5%) Real-time chat = 2 (5%) Wikis = 1 (2.5%) Rate and review = 1 (2.5%) Moderators = 1 (2.5%) Unreported = 27 (67.5%) **Privacy** Open access only = 21 (52.5%) Restricted access only = 7 (17.5%) Both open and restricted access areas = 6 (15%) Unclear/not reported = 6 (15%)

RSQ2: Communication models	**Communication direction**
	Two-way = 22 (55%)
	One way = 13 (32.5%)
	Social listening = 6 (15%)
	Unclear categorisation = 4 (10%)
	
	Management of online spaces
	Online space managed by health organisation = 20 (50%)
	    Hospital = 7 (17.5%)
	    Other health organisation = 13 (32.5%)
	Communication in an unmanaged/moderated public online space = 12 (30%)
	Online space managed by consumers = 2 (5%)
	Online space managed by providers = 1 (2.5%)
	Unclear/not reported = 4 (10%)
	Various (systematic review) = 1 (2.5%)

RSQ3: Populations of social media users	**Country/region** USA = 16 (40%) UK = 10 (25%) Canada = 4 (10%) Netherlands = 2 (5%) Global reach (English language) = 1 (2.5%) Unspecified = 1 (2.5%) Other[b] = 6 (15%) **User populations** Health organisations = 25 (62.5%) Hospitals = 7 (17.5%)

(continued)

Table 2. Continued.

Research sub-question focus area	Number of studies (n (%)) reporting focus area of interest[a]

	Other health organisations (government, non-government) = 18 (45%)
	Consumers = 20 (50%)
	Children and young people (<30 years old) = 9 (17.5%)
	    People with disability or chronic illness = 6 (15%)
	    Culturally and Linguistically Diverse communities (in English speaking countries) = 4 (10%)
	    First Nation communities = 2 (5%)
	    Parents/carers = 2 (5%)
	    Health advocates and community leaders = 2 (5%)
	    Older people = 1 (2.5%)
	    Rural/remote = 1 (2.5%)
	    Uncategorised health service consumers = 5 (12.5%)
	Service providers (clinical or non-clinical) = 19 (47.5%)
	General public = 7 (17.5%)
	Policy makers = 2 (5%)

RSQ4: Intended health service change/QI activity	Government or international health policy/strategy/guidelines development = 13 (32.5%) Gathering data from key stakeholders to inform health service QI or design activities = 12 (30%) Disseminate resources/information to prompt QI actions = 7 (17.5%) Develop specific products, interventions, resources = 7 (17.5%) Develop community of practice/ease communication = 6 (15%) Improve how specific health issues are identified, reported and responded to = 4 (10%) Evaluation of activities = 2 (5%) Monitor organisational adherence to national quality standards = 1 (2.5%)

[a]The total number of studies against each focus area sub-category may not equal the number of included studies (n = 40) because some studies used multiple platforms, had a variety of target user populations, worked across more than one setting, or sub-categories were not described in the paper.
[b]The 'other' category includes two systematic reviews that only included studies from high income countries; one study which included participants from Africa, Latin America, Brazil, Asia Pacific, Eastern Europe, Central Asia, Caribbean, Central Europe and China; one study with participants from Africa, North and South America and Europe; one study from Spain; and one from Romania and Moldova.
[c]All platforms in the 'other' category were only used in one study. These included the platforms WhatsApp, Bebo, Tumblr, Choicebook, RenRen, High5, Vkontake, ZorgkaartNederland and an email moderated discussion forum.

in seven studies.[49,58,68,72,75,81,83] This was most commonly for providing professional development information to service providers aimed at increasing the number of providers following clinical guidelines.[49,58,68,72]

Social media was used as a tool to include stakeholders in the creation of specific interventions, products or resources in seven studies,[46,64,69,77,79,80,84] and as a platform to facilitate improved communication between service providers in six studies.[58,63,66,67,73,83] It was used to improve the identification, reporting and response to specific health issues in four included studies,[51–53,58] evaluation of activities in two studies[80,84] and to monitor health service adherence to national standards in one study.[61]

Most of the included studies reported on the experience or process of the QI, service design or change activity. Very few of the included studies demonstrated whether the activities improved the health service or had impact on patient experience or outcomes. Three studies used social media to educate staff about

existing guidelines or clinical pathways in an effort to standardise treatment approaches.[49,68,72] Two studies[68,72] showed improvements in staff knowledge and awareness of the available resources, while one showed no significant change in knowledge.[49] None of these studies measured patient outcomes or any changes in how treatment was delivered, so it is unknown whether the observed changes in staff knowledge and awareness led to changes at the service-delivery or patient level.

Harris et al.[52] aimed to increase reporting and improve the response to foodborne illness in St Louis, USA, through Twitter interactions between the public and the local health department. This change was demonstrated, with a higher frequency of reporting when the department used their Twitter reporting mechanism alongside their usual reporting mechanisms.[52] The outcomes of the reports (primarily the frequency and severity of food safety violations following inspection) was comparable between Twitter and non-Twitter reporting mechanisms.[52]

Finally, Hoxworth et al.[58] examined a virtual community of practice of healthcare providers and organisations in Colorado working together to share data and find collaborative approaches to reducing the rates of healthcare onset and healthcare acquired-community onset clostridium difficile infections (CDI). The goal was to reduce these CDI rates by at least 15% from baseline.[58] This was achieved, with the rates of the infections reducing by 17% over the study period.[58]

For a more detailed description of the health service design or QI activity within each included study, see 'Description of QI activity' on Table 2. For a full numerical summary of the health service design or QI activities in the included studies, see 'RSQ4: Intended health service change/QI activity' on Table 2.

Typology of social media use in QI and health service design

The importance of generating new theories and knowledge from the analysis of data from included studies – rather than just mapping the literature – is a feature of the qualitative content analysis method used in this scoping review.[43] By analysing the models of social media communication identified in the included studies alongside the platform features and user populations, several recurring methods or types of social media use were identified. Table 3 presents the results of this analysis, summarising how different user populations use social media platforms (and their associated features) to communicate for a variety of aims and within a range of different activity types. In the 'method of social media use' column, each method in the typology is named based on the direction of communication, whether communication occurs in public or privately, and who hosts or manages the online space.

Discussion

In this review we examined the various ways in which social media is used by health services, providers and consumers to contribute to service design or QI activities.

Main findings

Platforms and user populations. Commercially available platforms were used more often than purpose-built platforms, and these were most often used in public, openly accessible ways. Social media channels were most commonly managed by health services or occurred in largely unmanaged and unmoderated public spaces (such as Twitter), rather than being managed by provider or consumer groups. The most common user populations were organisations, consumers and service providers.

The findings in this review about who is using social media and how it is being used supports ideas proposed by previous authors that social media could be used to reach different audiences and engage diverse consumer communities in health service design and quality improvement.[19–21,86,87] In this review social media engagement methods were used to engage children and young people,[48,56,57,64,69,76,77,80,82] First Nations communities[77,78] and culturally and linguistically diverse communities in English-speaking countries.[64,69,75,78] However, within the included studies, users often identified as belonging to more than one population, or studies involved multiple user populations. In total, only 14 studies in the review included user populations who have been identified as at higher risk of experiencing health inequalities[37] or representative of groups that health programs often fail to reach.[88] Half of the included studies (n = 20) did not include health service consumers. These findings demonstrate that while social media use can be a successful strategy to engage communities in health service design and QI activities, the theoretical potential for using social media to reach groups of people which health services often fail to reach – or even health service consumers in general – may not yet be fully realised.

Only six studies included users who identified as having chronic illness or disability,[46,57,65,76,79,82] and in only four of these studies was the social media consumer community pre-existing.[46,65,76,79] Tapping into chronic illness and disability communities that are already well established online was viewed as an important potential benefit of social media use in QI and service design in some of the background literature which prompted this review.[22–24] Our results demonstrate that while some organisations and providers are working with existing online groups, this number is still small, and engaging with pre-existing groups of people who discuss their chronic illness or disability online may still be a largely untapped source of knowledge and experience that can be integrated into – or lead – health service design and QI activities in the future.

Models of communication. Past research of health service use has shown that social media is primarily used as a one-way broadcast medium.[89] In this review, most studies used two-way models of social media communication. Two-way communication is seen as one of the advantages of social media over other forms of online communication both generally[2] and specifically within health when engaging stakeholders in service design and QI.[22]

Table 3. Typology of social media use in health service design and QI.

Method of social media use	Description	Communication direction	Platforms and/or features	Who is using this in the scoping review?	Included studies using this model and one example
Covert social listening	One party searches for key words relevant to them which could reveal conversations/data that are not being directed to them but are relevant to their issue or service.	Use of searched data, no attempt at communication.	Key word search function, most platform users have open/public feeds (e.g., Twitter). May use artificial intelligence software to aid search and data gathering.	Organisations listening in to social media conversations involving their service users or the public to gather patient experience/quality of care data, feedback on policies, or surveillance data.	Studies:[51–53,59–61] Khasnavis et al.[59] used key word searching through Twitter to find tweets responding to the release of draft USA clinical guidelines which could be used for feedback and evaluation.
Non-targeted broadcast	Social media users broadcasting their communications in an undirected way in an unregulated, open, online space to share their experiences and opinions, and find others. Communication users may or may not aim to prompt changes in health services.	One way, undirected or directed to general public/existing contacts. Not aiming to get a reply from a specific individual or organisation.	Most platform users have open/public feeds, ability to share the communication to a wider/unrestricted audience (e.g., Twitter).	Consumers/general public sharing stories or opinions online about health. Without this communication style, there is no social listening.	Studies:[51–53,59,60] Twitter users posted perspectives on the 2012 Health and Social Care Bill while the Bill was before Parliament.[60]
Public communication aimed at a known audience	Purposeful attempt at sharing information with a group, organisation or individual in a public forum to address a specific interest, issue or concern.	One-way, directed, attempt to get a reply or prompt an action.	Most users have open/public feeds (e.g., Twitter) or organisations (or similar primary targets or originators of communication) have open social media pages (e.g., Facebook). Platform allows for hashtagging and/or tagging users.	Consumers, providers and organisations use this to: - share experiences, ideas and opinions in hope of influencing change (providing unsolicited feedback). - share information /education / call to action with a QI purpose (both advocacy and professional development examples from the included literature).	Studies:[49–53,55, 61,68,72,75,81,85] Health consumers shared their experiences of care at NHS hospitals on Twitter and tagged their treating hospital in the tweet.[50]

Table 3. Continued.

Method of social media use	Description	Communication direction	Platforms and/or features	Who is using this in the scoping review?	Included studies using this model and one example
Public consultation	Call for information, advice or feedback in a public online space. Communications may be intended for a certain audience only, but can be viewed and responded to by anyone on the platform. Either unmanaged/ unmoderated or managed/moderated by the organisation conducting the consultation.	Two-way	Most users have open/ public feeds (e.g., Twitter) or organisations (or similar primary targets or originators of communication) have open social media pages (e.g., Facebook). Platform allows for hash-tagging and/or tagging users.	Organisations consulting with consumers or providers on an issue.	Studies:[55,57,62,69, 70,74,77,78] Bayside Medical Centre, a tertiary hospital in the US, asked patients to share narrative feedback about patient experience on the hospital Facebook page over a three-week period in 2014, to inform QI.[62]
Private consultation	Creation of restricted access spaces in which organisations or individuals seek information, advice or feedback from a specific audience, to inform organisational change/QI projects.	Two-way	Restricted access pages (through registration or invitation) and/or moderated pages (e.g., Facebook organisational pages or closed/private groups; discussion forums; purpose-built platforms).	Organisations consulting with consumers or providers on an issue. Organisations appear as a user in the space and have a voice, act as administrator to curate and facilitate the discussion and seek information.	Studies:[64,69,71,77,80] Young people were invited to participate in online focus groups held in a private MySpace discussion forum, to design a HIV intervention.[64]
Public conversation	Ongoing communication between two or more users in a public forum, using hashtags, tagging or happening on public social media pages etc. Either unmanaged/ unmoderated or managed/moderated by participants in the conversation.	Two-way	Most users have open/ public feeds (e.g., Twitter) or organisations (or similar primary targets or originators of communication) have open social media pages (e.g., Facebook). Platform allows for hash-tagging and/or tagging users.	Online communities of practice/support groups in open forums; responses to consultative activities, initiating advocacy activities.	Studies:[46,67,79] An online breast cancer community of consumers and providers hosted an ongoing public conversation on Twitter using the #BCSM hashtag to inform QI and research.[79]

Table 3. Continued.

Method of social media use	Description	Communication direction	Platforms and/or features	Who is using this in the scoping review?	Included studies using this model and one example
	Communications may be intended for a certain audience only, but can be viewed and responded to by anyone on the platform.				
Organisation hosted collaborative space	Organisation creates a space in which participants can discuss, share and create new knowledge and decide on QI/change projects together. If the organisation has a presence in the space, it is as a an equal participant with other users.	Two-way	Restricted access pages, accessible through registration or invitation (e.g., closed/private Facebook group; WhatsApp; discussion forums; purpose-built platforms). Able to be moderated.	Organisations providing spaces for their providers to engage together.	Studies:[58,63,73,83] Local government of Catalonia, Spain hosted a virtual community of practice for pulmonary and endocrinology specialists and nurses.[63]
Provider initiated and managed private space	Providers creating private spaces. Providers act as moderators/managers of spaces.	Two-way	Restricted access pages, accessible through registration or invitation (e.g., closed/private Facebook group; WhatsApp; discussion forums; purpose-built platforms). Able to be moderated.	Providers using WhatsApp to increase communication efficiency. No examples which include consumers in this review.	Study:[66] WhatsApp used by urology doctors within a hospital to improve support for, and communication between, trainee doctors.[66]
Consumer initiated and managed private space	Consumers creating private spaces. Consumers acting as moderators/managers of spaces.	Two-way	Restricted access pages, accessible through registration or invitation (e.g., closed/private Facebook group; WhatsApp; discussion forums; purpose-built platforms). Able to be moderated.	Example shows both consumer connection and consumer-provider connection when providers come (or are invited) into the space for consultation purposes.	Study:[46] Private consumer-led and moderated online discussion forums for people with pan-disabilities and/or spinal cord injury.[46]

Reporting who was responsible for management of the social media spaces in the included studies emerged through the analysis as an important feature of the social media communication models being used. Responsibility for management reflects who has 'control' of the space. This is important in a context of stakeholder engagement in health services because being aware of who has 'control' enables us to consider issues of power and participation in social media spaces, can inform the development of new ways to categorise of social media use in QI and health service design, and may also help to identify models that support more meaningful consumer engagement in QI activities.[89] In half of the included studies the social media spaces were managed by a health organisation. This creates an 'invited space' where an organisation (often with greater power than the stakeholders) owns and structures how people participate.[90] Participation within an invited space can result in tokenistic participation,[91] due to constraints on engagement that are either intentionally created by the managing organisation, or through unintentionally creating power imbalances between the manager of the space and the people participating.[90] In the typology we have developed (Table 3) the 'public consultation', 'private consultation' and 'organisation-hosted collaborative space' communication methods are examples of invited spaces where the organisation establishing the space controls how the stakeholders participate.

Social media could also provide opportunities for expanding beyond existing models of stakeholder participation in closely curated and moderated 'invited spaces'. In our typology (Table 3), 'covert social listening', 'non-targeted broadcast', 'public communication aimed at a known audience' and 'public conversation' methods all happen in public, largely unmoderated or unmanaged social media spaces (e.g., Twitter). Additionally, social media allows stakeholder groups with common interest or experience to establish their own communities, and in this review there are two studies where spaces were managed by consumers,[46,81] and one study where the space was managed by providers.[66] Groups that sit outside of invited spaces are typically less marked by differences in power and control between members, give members the opportunity to develop their own approaches to the issues they face, and can include people that are either not invited into, or are unwilling to participate in, spaces created by organisations.[90] The spaces that sit outside organisational control have the potential to uncover insights which could inform QI and service design which would not necessarily be shared within organisation-controlled spaces. Additionally, within these types of groups there is more likelihood of achieving a 'citizen power' model of participation.[91]

Types of QI and design activities. The most common QI or design activities undertaken through social media were the development of health policy, strategy or guidelines ($n = 13$;[47,54,57,59,60,65,70,71,75,76,79,81,85]) and gathering data from key stakeholders to inform QI or design activities at the hospital or health service level ($n = 12$;[47,48,50,55,56,61,62,74,78,79,82,84]).

Social media was generally used either as a way for organisations to gather data to inform QI and design activities, or as a virtual meeting space for people to collaborate on projects or advocate for change. When used as a data gathering tool, communication methods such as covert social listening, and public and private consultation were common (see Table 3). When used as a meeting space, public conversation, organisation hosted collaborative spaces and consumer- or provider-initiated spaces communication methods were favoured. Cycles of data gathering and meetings of stakeholders to discuss and decide on actions based on the available data are a common feature of QI models[92,93] and based on our review social media can be used as a place for these activities to be undertaken.

However, the use of social media as a source of data is an area of ongoing debate. Some researchers believe that social media posts made on public sites can be used without consent, and consent is only necessary where posts are made in private, password protected or invitation-only, groups.[94] Other researchers believe that consent should be gained for the use of any social media posts,[94] or that historical social media content is not an appropriate source of data at all.[95] A study of user views about the ethics of social media research[96] demonstrated that what was seen as 'ethical' or 'unethical' by study participants was determined by a large range of different factors – including, but not limited to, the mode of the posts (e.g., written, photos), the subject matter (e.g., sensitive, 'mundane'), the type of platform being used (e.g., social, professional), the original audience for the post (e.g., private, public), and the nature of the research (e.g., research purpose, research affiliation) and the participant's individual views about social media. In general, participants in this study felt that the passive use of data without the user's consent or knowledge (e.g., social listening, data mining) raised ethical concerns even when posts were made on public sites, whereas actively participating in research activities through forums or groups raised fewer ethical concerns.[96]

These ethical questions may be even more complex in the area of health service QI, where the requirements for ethical oversight are not always clear.[97] This complexity highlights the need for people conducting service design and QI activities to involve target audiences in the design of social media-based engagement

activities, and include discussions of ethical concerns as part of this design process.

Gaps in the literature and opportunities for future research

This review identified several areas where there are potential gaps in the existing literature.

Service and practitioner rating sites (e.g, CareOpinion,[98] PatientOpinion[99]) are considered social media and a number of articles on service rating sites were found through the literature search but did not meet the inclusion criteria because they examined the validity/reliability of patient ratings compared to other measures rather than the use of rating sites to inform QI or design activities. Only one article about rating sites met the inclusion criteria of this review.[61] The experience of using rating sites and the use of rating site data to inform QI and service design activities could be an emerging area of research, particularly if rating sites expand their coverage across more institutions and more locations.

There were few included studies from low- and middle-income countries (LMICs). However, we know from the digital disruption literature that it is likely that people in these countries are adopting digital technologies to overcome issues relating to access to health care, data collection and the economics of health.[100–102] It is possible that consumer and community input into health service design and QI via social media is already happening in LMICs and is published in languages other than English or is yet to be published. As a result, there may be a need for specific research into how health services and stakeholders in LMICs use social media to engage in health service QI, design and change activities, particularly in the context of rapid uptake of digital technologies.

Finally, while most of the studies examined the process of QI or service design, and the experience of participants using social media (to be presented in a future publication), very few included studies measured either patient or health service outcomes arising from the QI, service design or change activities. There is an opportunity for future research into the impacts of QI and design activities on patient and service outcomes, and to compare activities conducted either solely or partially on social media platforms with those undertaken through more 'traditional' methods of engagement.

Limitations

As this is a scoping review, no assessment of quality was conducted on included studies. This means that no conclusions can be drawn about how robust or generalisable the findings of individual studies are, and no

weighted evidence around the various approaches to social media use can be produced.[34] Additionally, non-English publications were excluded from the review. As a result, some studies – particularly those which addressed the gap of evidence from LMICs – may have been excluded during the search stage. Finally, it must be noted that only one author (LW) was responsible for the bulk of the screening and selection of included studies. This approach differs from the JBI methods which state that "source selection ... is performed by two or more reviewers, independently".[32] As this scoping review forms the literature review component of a PhD project, a decision was made that the PhD candidate (LW) would do the bulk of the screening and selection of studies, with NH and SH providing input only when inclusion was unclear. This approach may have introduced bias into the selection of included studies which may impact the quality of the scoping review findings.

Conclusion

This review addressed the overarching question 'how is social media being used as a tool for health service design and QI activities' and demonstrated that social media is used in a range of ways in health service design, QI and change activities. Engagement through open-access platforms was more common than restricting access through passwords or registration. Social media has been most commonly used as tool for engagement in national or international health policy or strategy design, and in design/QI projects in individual health services. Communication was most often two-way, but social media spaces are often managed by organisations, which may have implications for the quality of stakeholder engagement.

This review demonstrates that social media platforms are suitable for engaging health stakeholders in the cycles of data gathering and planning/implementation meetings that characterise most QI models. More importantly, it shows the diversity of participation and engagement approaches that are possible through social media, including using the different platforms and communication models in strategic ways to engage a range of social media users in QI and service design activities. The diversity of potential communication approaches available through using social media creates new opportunities for innovation in designing and trialling new ways of engaging stakeholders in QI and health service design.

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