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# BMJ Open

## A scoping review protocol on the use of social media for health research purposes

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## A scoping review protocol on the use of social media for health research purposes

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## **Abstract:**

**Introduction:** More than a third of the world population uses at least one social media. Since their advent in 2005, health-oriented research based on social media data has largely increased. The objective of this scoping review is to provide an evidence map of the various uses of social media for health research purposes, their fields of applications and their analysis methods.

**Methods and analysis:** This scoping review will follow the Arskey and O'Malley methodological framework (2005) as well as the Joanna Briggs Institute Reviewer's manual. Relevant publications will be first searched on the PudMed/MEDLINE database and then on Web of Science. We will focus on literature published between January 2005 and April 2020. All articles related to the use of social media or networks for health-oriented research purposes will be included. First, a manual search will be conducted with some keywords in order to identify relevant articles. After identifying the research strategy, a two-part study selection process will be systematically applied by two reviewers. The first part consists in screening titles and abstracts found thanks to the search strategy to define the eligibility of each article. In the second part, the full texts will be screened and only relevant articles will be kept. Data will finally be extracted, collated and charted to summarize all the relevant methods, outcomes and key findings in the articles.

**Ethics and dissemination:** This scoping review will provide an extensive overview of the use of social media for health research purposes. Opportunities as well as future ethical, methodological and technical challenges will also be discussed based on our findings to define a new research agenda. Results will be disseminated through a peer-reviewed publication.

## **Strengths and limitations of this study:**

- This will be the first scoping review about the overall use of social media for health research purposes.
- The evolution of social media interest in health research, the different use cases and fields of application of social media use for research purposes and the different methodologies for social media data analysis will be discussed in the review.
- Our scoping review will conform to the rigorous methodology manual by the Joanna Briggs Institute.
- The identification and synthesis of data will be limited to published articles found on the PubMed/MEDLINE and Web of Science databases and snowball references.

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- Because the present scope is focused on health research, other major uses of social media by patients, associations, organizations and healthcare professionals will not be included as such, but only put in perspective in the discussion.

### **Introduction:**

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Social media (SM) are interactive “mobile and web-based technologies” which allow discussion, creation and sharing of information between individuals, online communities and networks [1]. General platforms such as Facebook, Twitter and YouTube have emerged around 2004-2006 and many others since. SM are now increasingly used by a large proportion of the global population, estimated to 2.61 billion users worldwide in 2018 [2],[3]. To date, the most popular SM platform is Facebook with more than 2.41 billion monthly active users in 2019 [2],[4]. In 2018, the average time spent by users daily on SM is about 142 minutes while it was 90 minutes in 2012 [5].

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Thus, the broad use of SM around the world offers numerous applications. SM users continuously generate large amounts of data that can for instance be studied in the political, business or even policy contexts [6]. Most importantly, data generated by SM 1) are of high potential for medical research purposes [6],[7],[8], 2) can help healthcare professionals and scientists to keep being informed about the latest scientific discoveries or remotely follow medical conferences [9],[10], and 3) can reshape the way patients interact with their peers and exchange health related information and tips to manage their disease [11],[12]. For physicians, SM can improve their knowledge and abilities as well as their interactions with patients [13]. It has also been shown that, somehow, people use SM to fulfill the need to belong to one or several social groups, reflecting our primary biological needs and survival instinct [14]. People can interact with their friends, family and audiences of potentially unlimited sizes. Hence, patients can easily interact with their peers on SM about their conditions, search for support or even try to sensitize others with prevention and storytimes [15],[16]. Such digital space with no obvious hierarchy between users opens the door to new discourses as well as access and sharing of medical information about the patient’s health, feelings, symptoms, that would have been impossible to collect in a face-to-face setting with a physician or research investigator.

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In 2010 in the US, 80% of adults used the internet to search for health-related information and 11% of SM users posted comments, queries or information about health or medical content [17]. “Health research” refers to all kinds of research performed to learn more about human health, prevent or treat disease, test ideas, improve treatments and answer questions [18],[19]. Among all sub-fields of

health and medical research, epidemiology and public health are the two most important disciplines that can potentially benefit from the use of SM. “Infodemiology” is a recent term which describes a new approach for public health based on Big Data monitoring [20],[21]. Public Health, as the science of improving, protecting the health and the well-being of people and communities from a population-level perspective, can directly and easily benefit from accessing large datasets of health-related information on large samples [18]. Tracking health, treatment and feelings related posts or discussions on SM can develop new methods to improve healthcare [22],[23],[24],[25]. Not only have SM improved researchers communication with individuals and peers, but it also has a high potential to improve their research (eg, collecting data, understanding public perceptions) and their impact [26,27].

### **Protocol design:**

This scoping review will follow the methodological framework introduced by Arskey and O’Malley in 2005 [28] and the methodology manual published by the Joanna Briggs Institute for scoping reviews [29]. The present protocol and future corresponding scoping review are reported in accordance with the PRISMA Extension for Scoping Review (PRISMA-ScR) guidelines [30]. Thus, this review will follow five of these six stages: (1) identification of the research question, (2) identification of relevant studies; (3) selection of eligible studies; (4) charting the data; (5) collating, summarizing, and reporting of the results; and (6) consultation with relevant stakeholders (optional).

#### **Stage 1: Identification of the research questions**

Through consultation with the clinical research team, the overall research questions are:

- (1) How SM have modified or complemented traditional health research?
- (2) What are the different fields of application of this approach?
- (3) What are the different methodologies for SM data analysis?

#### **Stage 2: Identifying relevant studies**

This review will use the PCC (Population, Concept, Context) framework suggested by the Joanna Briggs Institute [29]. We will base our search strategy on the PCC framework described on Table 1.

<b><u>PCC Element</u></b>	<b><u>Definition:</u></b>	<b><u>Example:</u></b>
Population	All humans (no restrictions)	NA

Concept	Use of SM	Extracting Twitter data and metadata related to a specific keyword of interest
Context	Health research	Public health

**Table 1** : PCC framework of our scoping review

For the scoping review, we do not have any restriction on the population of interest, we will take any relevant publications regardless of the age, the origin or the gender of the studied populations. The concept is the use of SM. We are looking for any potential benefits related to the use of SM, such as using the online-available data or the features developed by SM. Lastly, both these elements have to be linked with health research.

The databases chosen for this review are PubMed/MEDLINE and Web of Science. An initial search strategy based on the PCC framework will be developed on PubMed to determine some relevant terms and articles. Database and other searches will combine terms from two themes: SM (eg, Twitter, Facebook) and health research (eg, medicine). The MeSH terms will be screened, sorted by pertinence and frequency. Figure 1 shows the most frequent MeSH terms found in the articles before any selection. A second search strategy will be developed thanks to the most relevant MeSH terms. Some keywords will be searched both in the title, abstract and subject headings (eg, MeSH) on PubMed and as topics on Web of Science. Other terms such as “Humans” and “Clinical trial” might further be used as filters. We will focus on articles published in English between January 2005 and April 2020. The pilot search strategy is shown in appendix A. Lastly, reference lists from the retrieved reviews on related topics will be used as an additional source for snowball searching for additional articles.

### Stage 3: Selection of eligible studies

All papers derived from the search process will be uploaded to Endnote in order to remove all duplicates. Then, a two-step screening will be performed. The first part consists in screening titles and abstracts thanks to the research strategy in order to define the eligibility of each article. Publications with title or abstract not meeting the eligibility criteria will be excluded. During the second part, the full texts having passed the first step will be screened and only relevant articles will be kept. The remaining ones will get full text screened. Screening will be conducted with CADIMA [31], a free web tool to facilitate the conduct and the documentation of literature reviews [32]. Two reviewers will screen articles independently and consistency checks will be performed. In cases of inconsistency, CADIMA will prompt each reviewer to review the article a second time.



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3 Studies will be included if they describe the use of SM for health or medical research purposes. Articles  
4 will be excluded if they deal with the use of SM among patients, patient associations, organizations,  
5 healthcare professionals for their day-to-day practice. Studies about non-human subjects and grey  
6 literature will be excluded as well. Papers will be excluded if not one of the following: clinical study,  
7 journal article, letter, observational study. This exclusion criteria might change depending on the  
8 relevance of the studies.  
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#### 13 14 15 Stage 4: Charting the data

16 Still using CADIMA, two independent reviewers will conduct this process. First, relevant studies will be  
17 selected from all the remaining papers in order to develop agreement on what information should be  
18 extracted. We will focus on the different fields of application of SM use by health researchers as well  
19 as the developed tools to achieve data collection and analysis. Then, data extraction will be performed  
20 after defining critical appraisal criteria and results will be stored in a table. The data extraction table  
21 produced will include at least the following key elements:  
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- 26 1. Author(s),
- 27 2. Year of publication,
- 28 3. Origin /country of origin,
- 29 4. Aims /purpose,
- 30 5. Type of study
- 31 6. Studied population(s) (eg, young adults)
- 32 7. Type on SM studied,
- 33 8. Methodology / methods,
- 34 9. Outcomes and details of these (eg, symptoms surveillance, medical concepts),
- 35 10. Key findings that relate to the scoping review questions (eg, tools used or developed, quality  
36 of SM use domains).  
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#### 48 Stage 5: Collating, summarizing, and reporting of the results

49 The purpose of this scoping review is to collect the findings and present an overview of the research  
50 rather than to evaluate the quality of the studies. As a result, our overall assessment of the strength  
51 of the evidence will be narrative instead of quantitative. The results of the previous stages will be  
52 synthesized to describe the progress of research thanks to SM from 2005 to 2020, all the research  
53 fields where SM are helpful and the methods to collect and analyse data. The PCC inclusion criteria  
54 will guide the map of the data. Thus, at least two tabulars will be carried out to introduce the data.  
55 The first tabulate will be a bubble plot describing the number of research publications published per  
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3 year on PubMed from 2005 to 2019 considering first, SM in their totality and then specific SM (eg,  
4 Twitter, Facebook). The second one will summarize the different approaches to collect SM data and  
5 the developed processes to investigate it. A descriptive summary will accompany the tabulated results  
6 and describe how the results apply to our scoping review questions. Results will then be classified into  
7 categories depending on the research field they link to.  
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### 15 **Dissemination and ethics:**

16 Results of this scoping review will provide a one-of-its-kind overview of all the applications in health  
17 research of the use of SM. Thus, it will be informative for various stakeholders: researchers, data  
18 scientists, public health agencies and governments will easily capture the big picture of the field and  
19 have an extensive presentation of the benefits, usefulness and potential of SM. Results will be  
20 disseminated through a peer-reviewed publication.  
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23 Since the scoping review methodology consists of reviewing and collecting data from publicly available  
24 materials, this study does not require ethics approval.  
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### 30 **Abbreviations:**

31 SM: Social media  
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44 **Contributors:** Design of protocol: CB, SS, CD, GF Draft of manuscript: GF, CB Review and final  
45 approval of manuscript: CB, SS, GF, AA, CP  
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50 **Competing interests:** None declared.  
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52 **Patient consent for publication:** Not required.  
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54 **Word count:** Abstract: 279, Total : 1660  
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#### **Figure/legend caption:**

56 **Figure 1:** Word Cloud of the most found MeSH terms in the manually found publications  
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Figure 1: Word Cloud of the most found MeSH terms in the manually found publications

361x270mm (72 x 72 DPI)

**Appendix A : Pilot search strategy for a scoping review protocol on the use of social media for health research purposes**

The pilot search strategy is developed on the PubMed/MEDLINE database.

Step	Search terms / description
1	<p>((("Social Media"[MH]) OR ("Social Media"[TW])) AND ((("Biomedical research"[MH]) OR ("Medical research"[TW] OR "Biomedical research"[TW]) OR ("Health research"[TW] OR "Health services research"[TW]) OR ("Nursing research"[TW]) OR (Research[OT]))) OR (((("Social networking"[MH]) OR ("Social network"[TW] OR "Social networks"[TW] OR "Social networking"[TW])) AND ((("Biomedical research"[MH]) OR ("Medical research"[TW] OR "Biomedical research"[TW]) OR ("Health research"[TW] OR "Health services research"[TW]) OR ("Nursing research"[TW]) OR (Research[OT]))))</p> <p><b>Filters:</b> From 2000/01/01 to 2020/04/09, Clinical Study; Journal Article; Letter; Observational Study; Humans; English</p>
2	Manual search in the reference lists of the relevant studies
3	Iterative refinements of stage 1
4	Adapting the final research strategy to Web of Science

## **PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist**

Adapted checklist for use with protocol submissions to Systematic Reviews from Table 3 in Moher D et al: Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. Systematic Reviews 2015 4:1

Section/topic	Item #	Checklist item	Information reported		Page
			Yes	No	
<b>ADMINISTRATIVE INFORMATION</b>					
<b>Title</b>					
<b>Identification</b>	1a	Identify the report as a protocol of a systematic review	x		1
<b>Update</b>	1b	If the protocol is for an update of a previous systematic review, identify as such			NA
<b>Registration</b>	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number			NA
<b>Authors</b>					
<b>Contact</b>	3a	Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author	x		1
<b>Contributions</b>	3b	Describe contributions of protocol authors and identify the guarantor of the review	x		9
<b>Amendments</b>	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments			NA
<b>Support</b>					

<b>Sources</b>	5a	Indicate sources of financial or other support for the review	x		9
<b>Sponsor</b>	5b	Provide name for the review funder and/or sponsor	x		9
<b>Role of sponsor/funder</b>	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol			NA
<b>INTRODUCTION</b>					
<b>Rationale</b>	6	Describe the rationale for the review in the context of what is already known	x		4
<b>Objectives</b>	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	x		4
<b>METHODS</b>					
<b>Eligibility criteria</b>	8	Specify the study characteristics (e.g., PICO, study design, setting, time frame) and report characteristics (e.g., years considered, language, publication status) to be used as criteria for eligibility for the review	x		4-5
<b>Information sources</b>	9	Describe all intended information sources (e.g., electronic databases, contact with study authors, trial registers, or other grey literature sources) with planned dates of coverage	x		5



<b>Search strategy</b>	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	x		Appendix A
<b>Study records</b>					
<b>Data management</b>	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	x		5
<b>Selection process</b>	11b	State the process that will be used for selecting studies (e.g., two independent reviewers) through each phase of the review (i.e., screening, eligibility, and inclusion in meta-analysis)	x		5-6
<b>Data collection process</b>	11c	Describe planned method of extracting data from reports (e.g., piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	x		6
<b>Data items</b>	12	List and define all variables for which data will be sought (e.g., PICO items, funding sources), any pre-planned data assumptions and simplifications	x		6
<b>Outcomes and prioritization</b>	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	x		6-7

<p><b>Risk of bias in individual studies</b></p>	<p>14</p>	<p>Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis</p>	<p>x</p>		<p>7</p>
<b>Data</b>					
<p><b>Synthesis</b></p>	<p>15a</p>	<p>Describe criteria under which study data will be quantitatively synthesized</p>		<p>x</p>	<p>Not performed</p>
	<p>15b</p>	<p>If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g., <math>I^2</math>, Kendall's tau)</p>			<p>NA</p>
	<p>15c</p>	<p>Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression)</p>			<p>NA</p>
	<p>15d</p>	<p>If quantitative synthesis is not appropriate, describe the type of summary planned</p>			<p>NA</p>
<p><b>Meta-bias(es)</b></p>	<p>16</p>	<p>Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies)</p>			<p>NA</p>
<p><b>Confidence in cumulative evidence</b></p>	<p>17</p>	<p>Describe how the strength of the body of evidence will be assessed (e.g., GRADE)</p>			<p>NA</p>

# BMJ Open

## A scoping review protocol on the use of social media for health research purposes

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## **A scoping review protocol on the use of social media for health research purposes**

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## **Abstract:**

**Introduction:** More than a third of the world population uses at least one form of social media. Since their advent in 2005, health oriented research based on social media data has largely increased as discussions about health issues are broadly shared online and generate a large amount of health related data. The objective of this scoping review is to provide an evidence map of the various uses of social media for health research purposes, their fields of applications and their analysis methods.

**Methods and analysis:** This scoping review will follow the Arskey and O'Malley methodological framework (2005) as well as the Joanna Briggs Institute Reviewer's manual. Relevant publications will be first searched on the PudMed/MEDLINE database and then on Web of Science. We will focus on literature published between January 2005 and April 2020. All articles related to the use of social media or networks for health-oriented research purposes will be included. A first search will be conducted with some keywords in order to identify relevant articles. After identifying the research strategy, a two-part study selection process will be systematically applied by two reviewers. The first part consists in screening titles and abstracts found thanks to the search strategy to define the eligibility of each article. In the second part, the full texts will be screened and only relevant articles will be kept. Data will finally be extracted, collated and charted to summarize all the relevant methods, outcomes and key findings in the articles.

**Ethics and dissemination:** This scoping review will provide an extensive overview of the use of social media for health research purposes. Opportunities as well as future ethical, methodological and technical challenges will also be discussed based on our findings to define a new research agenda. Results will be disseminated through a peer-reviewed publication.

## **Strengths and limitations of this study:**

- This will be the first scoping review about the overall use of social media for health research purposes.
- The evolution of social media interest in health research, the different use cases and fields of application of social media use for research purposes and the different methodologies for social media data analysis will be discussed in the review.
- Our scoping review will conform to the rigorous methodology manual by the Joanna Briggs Institute.
- The identification and synthesis of data will be limited to published articles found on the PubMed/MEDLINE and Web of Science databases and snowball references.

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3 - Because the present scope is focused on health research, other major uses of social media by  
4 patients, associations, organizations and healthcare professionals will not be included as such,  
5 but only put in perspective in the discussion.  
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### 8 **Introduction:**

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10 Social media (SM) are interactive “mobile and web-based technologies” which allow discussion,  
11 creation and sharing of information between individuals, online communities and networks [1].  
12 General platforms such as Facebook, Twitter and YouTube have emerged around 2004-2006 and many  
13 others since. SM are now increasingly used by a large proportion of the global population, estimated  
14 to 2.61 billion users worldwide in 2018 [2],[3]. To date, the most popular SM platform is Facebook  
15 with more than 2.41 billion monthly active users in 2019 [2],[4]. In 2018, the average time spent by  
16 users daily on SM is about 142 minutes while it was 90 minutes in 2012 [5].  
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23 Thus, the broad use of SM around the world offers numerous applications. SM users continuously  
24 generate large amounts of data that can for instance be studied in the political, business or even policy  
25 contexts [6]. Most importantly, data generated by SM 1) are of high potential for medical research  
26 purposes [6],[7],[8], 2) can help healthcare professionals and scientists to keep being informed about  
27 the latest scientific discoveries or remotely follow medical conferences [9],[10], and 3) can reshape  
28 the way patients interact with their peers and exchange health related information and tips to manage  
29 their disease [11],[12]. For physicians, SM can improve their knowledge and abilities as well as their  
30 interactions with patients [13]. It has also been shown that, somehow, people use SM to fulfill the  
31 need to belong to one or several social groups, reflecting our primary biological needs and survival  
32 instinct [14]. People can interact with their friends, family and audiences of potentially unlimited sizes.  
33 Hence, patients can easily interact with their peers on SM about their conditions, search for support  
34 or even try to sensitize others with prevention and storytimes [15],[16]. Such digital space with no  
35 obvious hierarchy between users opens the door to new discourses as well as access and sharing of  
36 medical information about the patient’s health, feelings, symptoms, that would have been impossible  
37 to collect in a face-to-face setting with a physician or research investigator.  
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50 In 2010 in the US, 80% of adults used the internet to search for health-related information and 11%  
51 of SM users posted comments, queries or information about health or medical content [17]. It is  
52 possible to join virtual communities, to participate in research, to receive moral support and to track  
53 personal progress [9]. Such actions generate data that can be used notably in health research. “Health  
54 research” refers to all kinds of research performed to learn more about human health, prevent or  
55 treat disease, test ideas, improve treatments and answer questions [18],[19]. Among all sub-fields of  
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3 health and medical research, epidemiology and public health are the two most important disciplines  
4 that can potentially benefit from the use of SM. “Infodemiology” is an early 2000s term [20] which  
5 describes a new approach for public health based on Big Data monitoring [21],[22]. Public Health, as  
6 the science of improving, protecting the health and the well-being of people and communities from  
7 a population-level perspective, can directly and easily benefit from accessing large datasets of health-  
8 related information on large samples [18]. Researchers can recruit study participants on SM [23,24]  
9 to collect data [25] and to disseminate research [26]. Moreover, tracking health, treatment and  
10 feelings related posts or discussions on SM can develop new methods to improve healthcare  
11 [27],[28],[29],[30]. Not only have SM improved researchers communication with individuals and  
12 peers, but it also has a high potential to improve their research (eg, collecting data, understanding  
13 public perceptions) and their impact [31,32]. Still, using SM for research may raise ethical issues such  
14 as getting consent of online users, protecting users’ privacy or preserving anonymity of study  
15 participants [33,34].

### 26 **Protocol design:**

27 This scoping review will follow the methodological framework introduced by Arskey and O’Malley in  
28 2005 [35] and the methodology manual published by the Joanna Briggs Institute for scoping reviews  
29 [36]. The present protocol and future corresponding scoping review are reported in accordance with  
30 the PRISMA Extension for Scoping Review (PRISMA-ScR) guidelines [37]. Thus, this review will follow  
31 five of these six stages: (1) identification of the research question, (2) identification of relevant studies;  
32 (3) selection of eligible studies; (4) charting the data; (5) collating, summarizing, and reporting of the  
33 results. There is an optional stage 6 (consultation with stakeholders) in order to identify additional  
34 references about potential studies to include and to collect feedback about the findings uncovered by  
35 the review but we will not include it because of time constraint.

#### 36 Stage 1: Identification of the research questions

37 Through consultation with the clinical research team, the overall research questions are :

- 38 (1) How SM have modified or complemented traditional health research?
- 39 (2) What are the different fields of application of this approach?
- 40 (3) What are the different methodologies for SM data analysis?

#### 41 Stage 2: Identifying relevant studies

42 This review will use the PCC (Population, Concept, Context) framework suggested by the Joanna Briggs  
43 Institute [36]. We will base our search strategy on the PCC framework described on Table 1.



<u>PCC Element</u>	<u>Definition:</u>	<u>Example:</u>
Population	All humans (no restrictions)	NA
Concept	Use of SM	Extracting Twitter data and metadata related to a specific keyword of interest
Context	Health research	Public health

**Table 1** : PCC framework of our scoping review

For the scoping review, we do not have any restriction on the population of interest, we will take any relevant publications regardless of the age, the origin or the gender of the studied populations. The concept is the use of SM. We are looking for any potential benefits related to the use of SM, such as using the online-available data or the features developed by SM. Lastly, both these elements have to be linked with health research.

The databases chosen for this review are PubMed/MEDLINE and Web of Science. An initial exploratory search strategy based on the PCC framework will be developed on PubMed to determine some relevant terms and articles. Database and other searches will combine terms from two themes: SM (eg, Twitter, Facebook) and health research (eg, medicine). The MeSH terms will be screened, sorted by pertinence and frequency.

A second search strategy will be developed thanks to the most relevant MeSH terms. Some keywords will be searched both in the title, abstract and subject headings (eg, MeSH) on PubMed and as topics on Web of Science. Other terms such as “Humans” and “Clinical trial” might further be used as filters. We will focus on articles published in English between January 2005 and April 2020. The pilot search strategy is shown in appendix A. Lastly, reference lists from the retrieved reviews on related topics will be used as an additional source for snowball searching for additional articles.

### Stage 3: Selection of eligible studies

All papers derived from the search process will be uploaded to Endnote in order to remove all duplicates. Then, a two-step screening will be performed. The first part consists in screening titles and abstracts thanks to the research strategy in order to define the eligibility of each article. Publications with title or abstract not meeting the eligibility criteria will be excluded. During the second part, the full texts having passed the first step will be screened and only relevant articles will be kept. The

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3 remaining ones will get full text screened. Screening will be conducted with CADIMA [38], a free web  
4 tool to facilitate the conduct and the documentation of literature reviews [39]. Two reviewers will  
5 screen every article independently and consistency checks will be performed. In case of inconsistency,  
6 CADIMA will display the rating differences and prompt each reviewer to review the article a second  
7 time. In case of disagreement, both reviewers will discuss the relevance of the article to decide if it  
8 should be included or not.  
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13 Studies will be included if they describe the use of SM for health or medical research purposes. Articles  
14 will be excluded if they deal with the use of SM among patients, patient associations, organizations,  
15 healthcare professionals for their day-to-day practice. Studies about non-human subjects and grey  
16 literature will be excluded as well. Papers will be excluded if not one of the following : clinical study,  
17 journal article, letter, observational study. This exclusion criteria might change depending on the  
18 relevance of the studies.  
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#### 24 25 Stage 4: Charting the data

26 Still using CADIMA, two independent reviewers will conduct this process. First, relevant studies will be  
27 selected from all the remaining papers in order to develop agreement on what information should be  
28 extracted. We will focus on the different fields of application of SM use by health researchers as well  
29 as the developed tools to achieve data collection and analysis. Then, data extraction will be performed  
30 after defining critical appraisal criteria and results will be stored in a table. The data extraction table  
31 produced will include at least the following key elements:  
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- 36 1. Author(s),
- 37 2. Year of publication,
- 38 3. Origin/country of origin,
- 39 4. Aims/purpose,
- 40 5. Type of study
- 41 6. Studied population(s) (eg, young adults)
- 42 7. Type on SM studied,
- 43 8. Methodology / methods,
- 44 9. Outcomes and details of these (eg, symptoms surveillance, medical concepts),
- 45 10. Key findings that relate to the scoping review questions (eg, tools used or developed, quality  
46 of SM use domains).
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#### Stage 5: Collating, summarizing, and reporting of the results

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3 The purpose of this scoping review is to collect the findings and present an overview of the research  
4 rather than to evaluate the quality of the studies. As a result, our overall assessment of the strength  
5 of the evidence will be narrative instead of quantitative. The results of the previous stages will be  
6 synthesized to describe the progress of research thanks to SM from 2005 to 2020, all the research  
7 fields where SM are helpful and the methods to collect and analyse data. The PCC inclusion criteria  
8 will guide the map of the data. Thus, at least two tabulars will be carried out to introduce the data.  
9 The first tabulate will be a bubble plot describing the number of research publications published per  
10 year on PubMed from 2005 to 2019 considering first, SM in their totality and then specific SM (eg,  
11 Twitter, Facebook). The second one will summarize the different approaches to collect SM data and  
12 the developed processes to investigate it. A descriptive summary will accompany the tabulated results  
13 and describe how the results apply to our scoping review questions. Results will then be classified into  
14 categories depending on the research field they link to.

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25 **Patient and Public Involvement:** No patient involved.

### 26 27 28 **Dissemination and ethics :**

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30 Results of this scoping review will provide an overview of all the applications in health research of the  
31 use of SM. Thus, it will be informative for various stakeholders: researchers, data scientists, public  
32 health agencies and governments will easily capture the big picture of the field, the different SM uses  
33 and methodologies for health research and have an extensive presentation of the benefits, usefulness  
34 and potential of SM. Ethical issues will also be outlined as they remain fundamental in health research.  
35 In terms of dissemination activities, the scoping review will be submitted for publication in a scientific  
36 journal. Overall, it will help future researchers to better shape their future projects using social media  
37 data or for other researchers to consider this source of information as a valuable option to answer  
38 their research question.

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40 Since the scoping review methodology consists of reviewing and collecting data from publicly available  
41 materials, this study does not require ethics approval.

### 42 43 44 **Abbreviations :**

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51 SM: Social media  
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#### **Footnotes:**

**Contributors:** Design of protocol: CB, SS, CD, GF Draft of manuscript: GF, CB Review and final approval of manuscript: CB, SS, GF, AA, CP

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**Word count:** Abstract : 298, Total : 2000

**Appendix A : Pilot search strategy for a scoping review protocol on the use of social media for health research purposes**

The pilot search strategy is developed on the PubMed/MEDLINE database.

<u>Step</u>	<u>Search terms / description</u>
1	<p>((("Social Media"[MH]) OR ("Social Media"[TW])) AND ((("Biomedical research"[MH]) OR ("Medical research"[TW] OR "Biomedical research"[TW]) OR ("Health research"[TW] OR "Health services research"[TW]) OR ("Nursing research"[TW]) OR (Research[OT]))) OR (((("Social networking"[MH]) OR ("Social network"[TW] OR "Social networks"[TW] OR "Social networking"[TW])) AND ((("Biomedical research"[MH]) OR ("Medical research"[TW] OR "Biomedical research"[TW]) OR ("Health research"[TW] OR "Health services research"[TW]) OR ("Nursing research"[TW]) OR (Research[OT])))</p> <p><b>Filters:</b> From 2000/01/01 to 2020/04/09, Clinical Study; Journal Article; Letter; Observational Study; Humans; English</p>
2	Manual search in the reference lists of the relevant studies
3	Iterative refinements of stage 1
4	Adapting the final research strategy to Web of Science

## **PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist**

Adapted checklist for use with protocol submissions to Systematic Reviews from Table 3 in Moher D et al: Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. Systematic Reviews 2015 4:1

Section/topic	Item #	Checklist item	Information reported		Page
			Yes	No	
<b>ADMINISTRATIVE INFORMATION</b>					
<b>Title</b>					
<b>Identification</b>	1a	Identify the report as a protocol of a systematic review	x		1
<b>Update</b>	1b	If the protocol is for an update of a previous systematic review, identify as such			NA
<b>Registration</b>	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number			NA
<b>Authors</b>					
<b>Contact</b>	3a	Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author	x		1
<b>Contributions</b>	3b	Describe contributions of protocol authors and identify the guarantor of the review	x		10
<b>Amendments</b>	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments			NA
<b>Support</b>					



<b>Sources</b>	5a	Indicate sources of financial or other support for the review	x		10
<b>Sponsor</b>	5b	Provide name for the review funder and/or sponsor	x		10
<b>Role of sponsor/funder</b>	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol			NA
<b>INTRODUCTION</b>					
<b>Rationale</b>	6	Describe the rationale for the review in the context of what is already known	x		3
<b>Objectives</b>	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	x		4
<b>METHODS</b>					
<b>Eligibility criteria</b>	8	Specify the study characteristics (e.g., PICO, study design, setting, time frame) and report characteristics (e.g., years considered, language, publication status) to be used as criteria for eligibility for the review	x		4-5
<b>Information sources</b>	9	Describe all intended information sources (e.g., electronic databases, contact with study authors, trial registers, or other grey literature sources) with planned dates of coverage	x		5

<b>Search strategy</b>	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	x		Appendix A
<b>Study records</b>					
<b>Data management</b>	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	x		5
<b>Selection process</b>	11b	State the process that will be used for selecting studies (e.g., two independent reviewers) through each phase of the review (i.e., screening, eligibility, and inclusion in meta-analysis)	x		5-6
<b>Data collection process</b>	11c	Describe planned method of extracting data from reports (e.g., piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	x		6
<b>Data items</b>	12	List and define all variables for which data will be sought (e.g., PICO items, funding sources), any pre-planned data assumptions and simplifications	x		6
<b>Outcomes and prioritization</b>	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	x		6-7

<b>Risk of bias in individual studies</b>	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	x		7
<b>Data</b>					
<b>Synthesis</b>	15a	Describe criteria under which study data will be quantitatively synthesized			NA
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g., $I^2$ , Kendall's tau)			NA
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression)			NA
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned			NA
<b>Meta-bias(es)</b>	16	Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies)			NA
<b>Confidence in cumulative evidence</b>	17	Describe how the strength of the body of evidence will be assessed (e.g., GRADE)			NA