The value of social media analysis for adverse events detection and pharmacovigilance: a Scoping Review

Su Golder, Karen O'Connor, Yunwen Wang, Ari Klein, Graciela Gonzalez Hernandez

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Abstract

Background: Adverse drug events pose a significant public health burden leading to hospitalisation, disability, and death. Even those adverse events categorised as non-serious can severely impact on patient quality of life, adherence, and persistence. Monitoring medication safety is challenging. Online patient reports on social media may be a useful supplementary source of real-world data. Despite the growth of sophisticated techniques for identifying adverse events using social media data, a consensus has not been reached as to the value of social media in relation to more traditional data sources.

Objective: To evaluate and characterise the utility of social media analysis in adverse drug event detection and pharmacovigilance as compared to other data sources (such as spontaneous reporting systems and the clinical literature).

Methods: In this scoping review, we searched 11 bibliographical databases and Google Scholar, followed by handsearching and forward and backward citation searching. Each records was screened by two independent reviewers at both title/abstract stage and the full-text screening stage. Studies were included if they 1) used any type of social media (such as Twitter or patient forums) to detect any adverse event associated with any drug medication and 2) compared the results ascertained from social media to any other data source. Study information was collated using a piloted data extraction sheet . Data were extracted on 1) the adverse events and drugs searched for and included, 2) the methods used (such as machine learning), 3) social media data source, 4) volume of data analysed, 5) limitations of the methodology, 6) availability of data and code, 7) comparison data source and comparison methods, 8) results, including the volume of adverse events, and how adverse events found compared to other data sources in their seriousness, frequencies, and expectedness/novelty (new vs. known knowledge) and 9) conclusions.

Results: Of the 6538 unique records screened, 73 publications representing 60 studies and a wide variety of methods met our inclusion criteria. The most common social media platforms used were Twitter and online health forums. The most common comparator data source was spontaneous reporting systems, although other comparisons were made such as with scientific literature and product labels.
Although similar patterns of adverse event reporting tended to be identified, the frequencies were lower in social media. Social media data were found useful in identifying new or unexpected adverse events and adverse events in a more timely manner.

Conclusions: There is a large body of research comparing adverse events from social media to other sources. Most studies advocated the use of social media as an adjunct to traditional data sources. Some indicated the value of social media in understanding patient perspectives such as the impact of adverse events, which could be better explored.

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Although similar patterns of adverse event reporting tended to be identified, the frequencies were lower in social media. Social media data were found useful in identifying new or unexpected adverse events and adverse events in a more timely manner.

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Keywords: adverse events; pharmacovigilance; social media; real-world data; scoping review

Introduction

Adverse drug events (ADE) can lead to increased morbidity, mortality, and economic burden within the healthcare system [1, 2]. Moreover, ADEs can result in patients prematurely discontinuing treatment or being hesitant to initiate drug therapies, depriving them of potentially beneficial treatment [3]. Despite efforts to detect ADEs before a drug is marketed, some will go undetected, underscoring the importance of continuous safety surveillance and monitoring.

Post-marketing pharmacovigilance relies on spontaneous reporting to regulatory agencies, but such systems have limitations, including time delays and underreporting [4-7]. The insufficient rate of reporting has prompted researchers to explore alternative data sources.

Social media data analysis has been applied in various health research areas, such as, disease surveillance, and health outcomes research [8-10] . Safety outcomes, in particular, have been extensively studied [8-10], and patient reports of ADEs are found abundantly within this content-rich resource [11]. The utilization of social media as a supplementary data source may hold immense value, as it can capture the perspectives of patients from diverse demographics, including those who are typically not reached in traditional pharmacovigilance channels. The synthesis of ADEs reported in different data sources, including social media, may increase the representativeness and comprehensiveness of drug safety signals.

The potential value of extracting drug safety data from social media was recognized as early as 2010 [11]. Social media data was believed to have the potential to identify new signals or detect signals earlier than conventional methods [12]. To manage the vast amounts of text-based information posted on social media, ongoing advancements in natural language processing (NLP) and machine learning (ML) methods have facilitated automatic detection of relevant mentions [13, 14]. These methods face numerous challenges, such as the highly informal language used on social media, and extracting user-expressed ADE concepts which are usually descriptive and nontechnical [15, 16]. NLP has played a crucial role in overcoming some of these barriers encountered in

identifying ADE mentions [13, 14]. While technological methods continue to advance [17-21], the practical utility of social media for identifying adverse events requires further demonstration [22], leading to an ongoing debate regarding what social media can bring to pharmacovigilance.

Numerous papers have concluded that social media holds the potential to improve pharmacovigilance, while others, including the well-known Web-RADR study [23], have argued against it, stating that signal detection in Twitter and Facebook '*performs poorly and cannot be recommended at the expense of other pharmacovigilance activities'* [24]. However, these studies often make conclusions based on case studies, which necessarily present a limited perspective, particularly given the selection and the comparative analysis methods used for their case study may have impacted the outcomes. The general question of whether social media can enhance pharmacovigilance may be more complex and nuanced than, a simple "yes" or "no" answer. Instead, we propose to focus this study on establishing how social media data can contribute to pharmacovigilance.

Between 2015 to 2021, seven systematic reviews were published aiming to evaluate the potential use of social media in pharmacovigilance [25-30]. These reviews focused on various aspects such as the frequency of adverse event reports or the detection of safety signals [25-30]. Despite the inclusion of a substantial number of articles, these reviews generally concluded that the research was still in its infancy and that further investigations were required. Nonetheless, some of the reviews did note that social media may be more suitable for identifying mild symptomatic ADEs, gaining patient perspectives of notable events and their impact, or detecting adverse event signals earlier than regulatory agencies. Since the publication of these reviews, there has been significant progress in methods used to extract data from social media and numerous additional studies.

Given the breadth of original studies conducted since these systematic reviews were published, our aim was to provide an updated summary of the current literature regarding the value of detecting

ADEs from social media data as compared to other (traditional) sources. Thus, we narrowed our review to studies that included a comparison of ADEs found in social media to another (traditional) data source and excluded studies primarily focused on the technical aspects of extracting ADE reports. Considering the extensive landscape of literature in this area and our objective to map the evidence comprehensively, we chose to conduct a scoping review using the Arksey and O'Malley [31] framework. Specifically, our review aimed to address the following questions.

1. What recent (post 2017) research has been conducted on the large-scale detection of adverse events from social media?
2. What types of drugs and adverse events have been studied using social media data to date, and what are the findings?
3. How do the types and frequency of ADEs identified from social media differ from those identified from other sources (such as regulatory data or clinical trials)?
4. What methods are used to identify and extract ADEs from social media data, and could the choice of methods impact the results?

Methods

This scoping review is reported in line with PRISMA extension for Scoping Reviews (PRISMA-ScR) checklist [32] and followed a pre-specified published protocol [33]. The inclusion and exclusion criteria are listed in Table 1. The inclusion criteria were necessarily broad in nature to provide an understanding of the volume and diversity of the research in this area.

Table 1. Inclusion and exclusion criteria for studies on identifying adverse drug events data from social media in comparison to other data sources.

Inclusion Criteria	Exclusion Criteria
Population (P)	
Any person (including pregnant persons, young and older adults) with or without any condition or disease type (chronic or acute) who states that they have taken any drug intervention (including vaccines) used in diagnosis, treatment or prevention (as defined by the Food and Drug Administration [FDA]) and experienced an adverse event.	Reports by healthcare professionals. People reporting diagnosis, treatment, or prevention with a non-medical intervention (such as medical devise, surgery, supplements, or natural remedy). People not reporting experience of an adverse event.
Intervention(s) (I)	
Any type of social media, defined as any computer-mediated tools for users to create, share or exchange information, ideas, or content via text, images and audio (e.g., message postings, pictures and videos) in virtual communities and networks (such as message boards, social networks, patient forums, Twitter,	Simple, non-social internet-based interventions (i.e., web 1.0). Studies using social media to recruit participants.

Reddit, blogs and Facebook).	
Comparator(s) (C)	
Any data source other than social media (such as spontaneous reporting systems of the FDA or MHRA, clinical trials or summary of product characteristics) is eligible as a comparator (see Supplementary Table S1: Description of comparator resources used in included studies).	No comparison undertaken to any non-social media data source.
Outcome(s) (O)	
Primary outcomes: Data on the type and frequency of adverse drug events data (such as muscle ache, headache or rash) are required from social media and at least one other data source. Secondary outcomes: Data on the application of the adverse drug events data (such as pharmacovigilance, hypothesis generation).	We are concerned with the properties of interventions under normal use. We therefore did not consider papers where the primary aim was to assess events such as intentional and accidental poisoning (i.e., overdose), drug abuse, errors or non-compliance. Drug–drug interactions are not eligible where they are the primary objective of the paper due to the different techniques required in identifying interactions as opposed to adverse events under normal use. Papers focused on identifying patient perspectives of adverse events (such as fear or impact on quality of life) and papers on subsequent patient behaviours as a result of adverse events are also ineligible.
Study design (S)	
Any type of assessment.	Discussion papers, purely technical papers and papers that only contain examples of posts from social media.
Any date or language limits	
Published 2017 onwards in English, Spanish, or French or in any language with an English translation available.	Anything published before 2017 and anything published since 2017 that is not in either English, Spanish, or French or in another language with no available English translation.

Search Methods

Eleven databases covering a range of topic areas, including health and medical research, nursing, information and computer science and grey literature were searched (Table 2 and Supplementary Table S2: Database search results). We also searched Google Scholar, however, due to the immense number of hits this search engine retrieves we only sifted the first 300 records. Searching in databases may not retrieve all relevant available studies as there are delays in indexing, they may not have been indexed adequately (particularly where the database does not index using full-text or uses automated methods) or they may have a lack of detail in titles and abstracts. We, therefore, conducted handsearching of the most common journal titles from a previous review [25]: Drug Safety; Journal of Medical Internet Research (JMIR) and Pharmacoepidemiology and Drug Safety (2017 to 2023) (Table 2).

Table 2. Sources searched for included studies

Databases
ACM Digital Library
Conference Proceedings Citation Index – Science (CPCI-S)
Emerging Sources Citation Index (ESCI)
Embase
IEEE Xplore
Library, Information Science & Technology Abstracts (LISTA)
MEDLINE
OpenDissertations
Proquest Dissertations & Theses: UK & Ireland
PsycINFO
Science Citation Index Expanded (SCI-Expanded)
Internet search engine
Google Scholar (first 300 records sifted).
Handsearching of journals
Drug Safety (2017-2023)
Journal of Medical Internet Research (2017-2023)
Pharmacoepidemiology and Drug Safety (2017-2023)

The database search strategies consisted of just two facets – “social media” and “adverse events” (see Supplementary Material for full search strategies in all databases). A date restriction of 2017 onwards was placed on the searches as this review updates seven previous reviews [25-30], the most recent of which is more focused than our review [29]. No language restrictions were placed on the searches, although financial and logistical restraints did not allow translation from all languages.

We also conducted forward and backward citation searching by checking the references of all included studies and forward citation searching using CitationChaser [34] to identify papers that have cited our included studies or that our cited by our included studies (Supplementary Table S3: Citation searching using CitationChaser). We noted any related systematic reviews during our full-text screening stage and carried out forward citation searches on these reviews.

The search results were entered into an Endnote library with the duplicates removed. Title and abstract screening were undertaken independently by two reviewers in Covidence with any disagreements resolved by discussion or if necessary, a third reviewer. Full-text screening was again undertaken in Covidence by two independent reviewers.

Data Extraction

A data extraction spreadsheet was designed and piloted for this review in Covidence. The form recorded study characteristics of existing papers on using social media data to identify potential adverse drug events. Two reviewers (SG, KO) extracted descriptive data independently, with findings compared and agreed through discussion and consensus with a third person where required. The following data was extracted from the included studies:

1) Details on the type of social media platform used.
2) Details on the primary aim of the study.
3) Brief details of the methods used to extract data from social media including which drugs or adverse events are searched for and how.
4) Whether the study distinguished between personal and non-personal mentions, and whether it accounted for the influence of bots or non-individual accounts.
5) The type and frequency of adverse events data identified for each drug and which drug.
6) Comparator data source(s) along with any comparisons of the data collected.
7) Conclusions of the original investigators.
8) Lastly, whether code or annotated or raw data are made available by the authors.

As this is a scoping review, we did not assess the methodological quality (risk of bias assessment) of the studies or conduct any evidence synthesis. Nevertheless, we did briefly summarise whether the methods were reported, and any issues raised.

Ethical Considerations

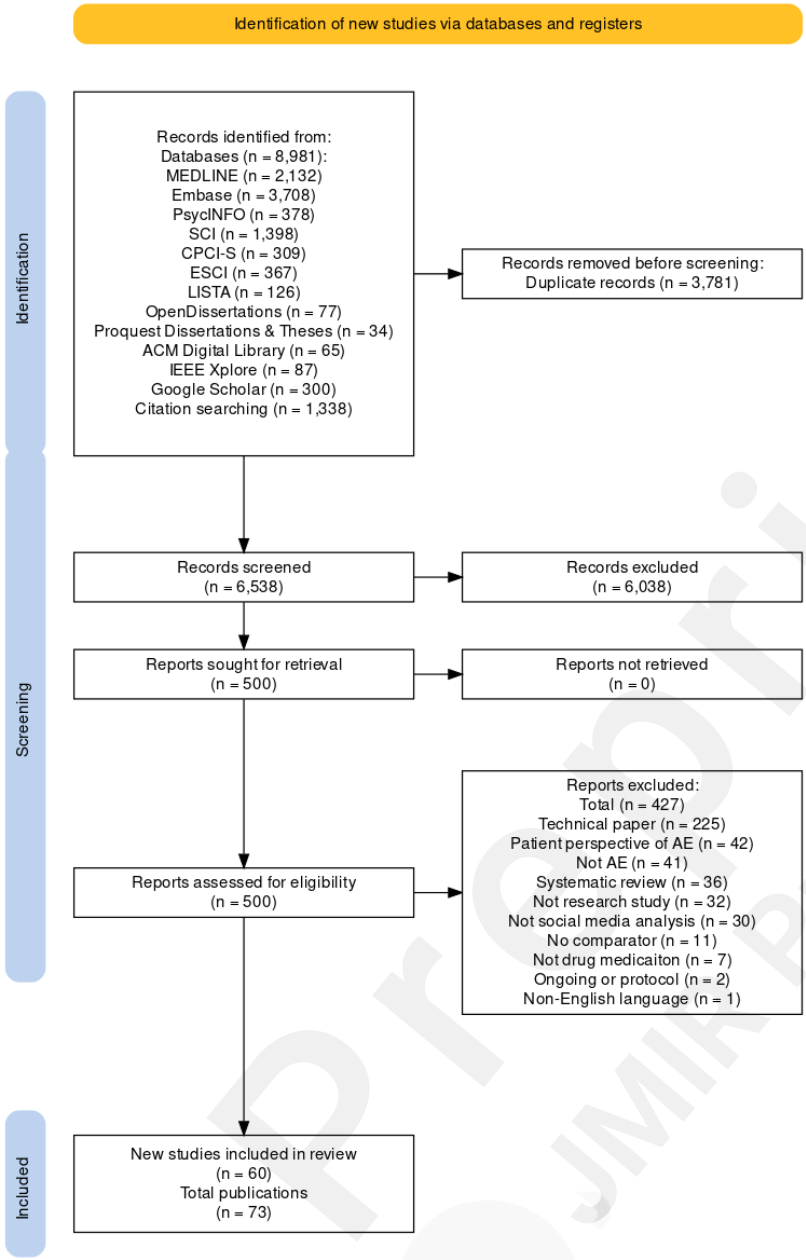
Since the scoping review methodology consists of reviewing and collecting data from publicly accessible materials, this study does not require ethical approval.

Results

After screening 6538 unique records, the full text of 500 were examined and 73 publications representing 60 studies included (Figure 1: PRISMA Flow Diagram for included studies and Supplementary Table S4: Data extracted from all included publications). Those excluded at the full-text stage fell in to ten categories; Technical papers (n=225), patient perspective of adverse event (n=42), not adverse events (n=41), systematic review (n=36), not research study (n=32), not social media analysis (n=30), no comparator (n=11), not drug medication (n=7), ongoing or protocol (n=2) and non-

English language (Portuguese).

FIGURE 1: Flow Diagram for Included Studies



A brief overview of the included studies can be found in Table 3. The full details of the extracted information for each publication are in the Supplementary Table S4.

Table 3. Overview of included publications/studies and their findings when comparing the adverse event extracted from social media to other data sources.

Publication (Author-Year)	Study name	Social media source used	Reported finding on adverse events found in social media*
Abbasi 2019 [35]		Twitter, health forums, drug review sites	Unexpected, earlier
Audeh 2020 [36]	Vigi4Med	Twitter, health forums, drug review site	Less serious, unexpected
Bellet 2018 [37]	Vigi4Med	Twitter, health forums, drug review site	Less serious, unexpected

Boeuf 2017 [38]	Vigi4Med	Twitter, health forums, drug review site	Less serious, unexpected, less informative
Karapetiantz 2018[39]	Vigi4Med	Twitter, health forums, drug review site	Less serious, unexpected
Karapetiantz 2018 [40]	Vigi4Med	Twitter, health forums, drug review site	Less serious, unexpected
Karapetiantz 2019 [41]	Vigi4Med	Twitter, health forums, drug review site	Less serious
Karapetiantz 2019[42]	Vigi4Med	Twitter, health forums, drug review site	Less serious, unexpected
Barakat 2022[43]		Health forums	New, similar, more frequent
Bennett 2022 [44]		Twitter	Not reported
Bhattacharya 2017[45]		Twitter, Reddit, health forums	Less serious, similar, less frequent
Blaser 2017 [46]		Health forums	Less frequent
Borchert 2019 [47]		Drug review site	Similar
Bratti Correia 2019[48]		Twitter, Instagram	Similar
Campillos-llanos 2019[49]		Health forums	New
Caster 2018 [24]	WEB-RADR	Twitter, Facebook, health forums	Less frequent, no value
van Stekelenborg 2019 [50]	WEB-RADR	Twitter, Facebook, health forums	Not earlier, no value
Chen 2018 [51]		Health forums	New, similar
De Langen 2017 [52]		Twitter, health forums	Less serious, different pattern
Den Hollander 2022 [53]	Den Hollander 2022	Facebook	Similar
Dirkson 2022 [54]	Den Hollander 2022	Facebook	New
De Rosa 2021 [55]		Twitter	Similar
Dreyfus 2017[56]		Twitter, Facebook, blogs, health forums	Similar
Eslami 2020 [57]		Health forums	New, less frequent
Farooq 2020 [58]		Twitter	Underreported
Ferawati 2022 [59]		Twitter	Less frequent
Gavrielov-Yusim 2019 [60]		Health forums	Earlier, new, similar
Golder 2021 [61]		Twitter	Less serious, similar
Han 2020 [62]		Drug review site	Similar, less frequent
Harpster 2018 [63]		Twitter	Less frequent
Hoang 2018 [64]		Twitter	New, similar
Hussain 2022 [65]		Twitter, Facebook	Similar
Jarynowski 2021[66]		Health forums	Similar
Jiang 2020[67]		Twitter	New, unexpected, similar
Khademi Habibabadi 2023[68]		Twitter	Similar
Kim 2020 [69]		Drug review site	Similar
Koutkias 2017 [70]		Twitter	Similar
Kurzinger 2018a[71]	Kurzinger AB	Health forums	Earlier
Kurzinger 2018b[72]	Kurzinger AB	Health forums	Earlier, new
Lardon 2018 [73]		Twitter	Less serious, unexpected
Lebanova 2019 [74]		Health forums	Similar
Lee 2023 [75]		Naver	Similar
Li 2019 [76]		Health forums	Similar
Li 2020 [77]		Twitter	Similar, less frequent, less serious
Lian 2022 [78]		Twitter	Similar, less serious
Liu 2017 [79]		Twitter, health forums	Earlier, more frequent, less serious
Mackinlay 2017 [80]		Twitter	New, less serious

Maskell 2017 [81]		Twitter, Facebook	Different patterns
Matsuda 2017 [82]	Matsuda AB	Health forums	Similar, less serious
Matsuda 2017 [83]	Matsuda AB	Health forums	Similar, less serious
Natsiavas 2017 [84]		Twitter	New
Nguyen 2017 [85]		Twitter, Reddit, blogs	Similar
Nikfarjam 2019 [86]	Nikfarjam and Ransonhoff	Health forums	Earlier, similar
Ransohoff 2018 [87]	Nikfarjam and Ransonhoff	Health forums	Earlier, new, similar
Ransohoff 2018 [88]	Nikfarjam and Ransonhoff	Health forums	Earlier, new
Oyebode 2023 [21]		Health forums	Similar
Pan 2018 [89]		Health forums	New, similar, less frequent
Park 2022 [90]		Drug review site	New, unexpected
Patel 2018 [91]		Twitter	Less serious
Pathak 2023 [92]		Twitter	Earlier, new, similar
Pierce 2017 [93]		Twitter, Facebook	Earlier
Powell 2022 [94]		Twitter, health forums	Similar, less frequent
Rees 2018 [95]		Twitter, health forums	Less serious
Sadeghi 2017 [96]		Health forums	Less serious
Salamun 2020 [97]		Reddit	Other
Sampathkumar 2017 [98]		Health forum, drug review site	Earlier, new, similar
Smith 2018 [99]		Twitter	Similar, different rates
Song 2021 [100]		Drug review site	Similar
Xia 2022 [101]		Drug review site	Earlier, new
Yahya 2022 [102]	Yahya AB	Health forum, drug review site	Similar, less frequent
Yahya 2022 [103]	Yahya AB	Health forum, drug review site	Similar, less frequent
Yu 2022 [104]		Twitter	New, similar
Zhou 2020 [105]		Twitter	New, similar

*as compared to comparator source used

Characteristics of Included Studies

The most commonly used social media platform was Twitter (34 studies) [24, 35-42, 44, 45, 48, 50, 52, 55, 56, 58, 59, 61, 63-65, 67, 68, 70, 73, 77-81, 84, 85, 91-95, 99, 104, 105] followed by various health forums (26 studies) [21, 24, 35-43, 45, 46, 49-52, 56, 57, 60, 69, 71, 72, 74, 76, 79, 82, 83, 85-89, 94-96, 98, 102, 103], drug reviews sites (9 studies) [21, 35, 47, 62, 90, 98, 100-103], Facebook (6 studies) [36-38, 41, 42, 53, 54, 56, 65, 81], Reddit (3 studies) [45, 85, 97], blogs (3 studies) [56, 75, 85] other social media platforms (2 studies) such as Telegram [66], and Instagram [48]. Table 4 provides an overview of these characteristics, along with references, as well as those for the remainder of this section. In those that reported on the number of drugs included this ranged from

1 to 4888, with some studies searching for any or all named drugs in the corpus – and in many cases not all the drugs were named. This made any detailed analysis by type of drug too challenging. 33 studies searched for data for 10 or less named drugs, 14 studies searched for 11 – 200 named drugs, and 7 studies searched for or extracted all named drugs in their collected corpus. Five studies did not report the exact number of drugs searched or extracted. One study searched for posts of interest using 4 named adverse events and then extracted drugs mentioned in these posts. The majority did not restrict their search or analysis to any named adverse events (50 studies), whilst the other 10 studies named adverse events (such as fever or cutaneous adverse events) [44, 46, 56, 65, 68, 70, 84, 92-94]. The large numbers of drugs and adverse events included and the lack of detail in naming them meant that we could not conduct any additional analysis by type of drug or type of adverse event.

The volume of data analysed varied between 130 posts to 230 million, whereas the volume of adverse events mentions varied between 14 and 1,191,767. In general, studies that used Twitter or Facebook analysed a large number of posts, while studies that used medication reviews or health forums analysed a small number of posts.

Table 4. Characteristics of included studies (including social media platforms selected, number of drugs searched and whether named adverse events were searched)

Category	Sub-Category (No. of Studies)	References*
Social Media Platform	General social media (38)	[24, 35-42, 44, 45, 48, 50, 52, 53, 55, 56, 58, 59, 61, 63-68, 70, 73, 77-81, 84, 85, 91-95, 99, 104, 105]
	Drug review site (9)	[21, 35, 47, 62, 90, 98, 100-103]
	Online health forums (26)	[21, 24, 35, 36, 38-43, 45, 46, 49-52, 56, 57, 60, 69, 74, 76, 79, 82, 83, 85-89, 94-96, 98, 102, 103]
	Blogs (3)	[56, 75, 85]
Number of Drugs Searched	1-10 (33)	[7, 36-45, 47, 49, 51, 53-56, 59, 61-63, 65-68, 70-72, 74-

		76, 78, 86-88, 91, 93, 94, 97, 99, 100, 105]
	11-200 (14)	[21, 24, 35, 46, 48, 50, 57, 58, 64, 69, 73, 79, 92, 95, 102, 103]
	All Named (7)	[17, 18, 36, 60, 71, 80, 98]
	Not Reported (5)	[52, 81-83, 90, 96]
	Searched AEs (1)	[84]
Only Named Adverse Events	Yes	[44, 46, 56, 65, 68, 70, 84, 92-94]
	No	[21, 24, 29, 35-43, 45, 47-55, 57-64, 66, 67, 69, 71-74, 76-83, 85-91, 95-101, 104, 105]

*Includes all publications

Methods of Included Studies

Seven studies [35, 44, 52, 57, 63, 89, 96] did not describe their methods in enough detail to identify any issues with their methodology. A further seven studies [21, 24, 45, 50, 55, 56, 81, 95] used third party software to detect or extract ADE mentions. For 17 studies [48, 51, 58, 64, 65, 69, 70, 75, 80, 82, 83, 85, 94, 97, 98, 102-105] some methodological issues were identified such as (1) lack of reproducibility [45], (2) no mention of manual validation of ADE mentions [58, 85], (3) missing key information such as the volume of social media data from which the ADE signals were extracted or analysed [70-72], and (4) using lexical match for ADE detection or extraction [43, 48, 50, 58, 64, 69, 86, 89, 93, 98]. For the remaining 29 studies [36-43, 46, 47, 49, 53, 54, 59-62, 66-68, 73, 74, 76-79, 84, 86-88, 90-93, 99-101]we did not identify any methodological issues.

Only six studies [36-42, 45, 67, 82, 83, 93, 95] mentioned that they attempted to exclude bots (or spam content) from the final set of posts and 15 studies [21, 36-42, 51, 53, 54, 61, 64, 67, 71, 72, 77, 78, 80, 82, 83, 90, 94, 105]

attempted to remove non-personal accounts (such as organizations or companies). 13 studies [30, 36-42, 53, 54, 58, 60, 61, 64, 68, 71, 72, 78, 79, 94, 105] attempted to distinguish between personal experience of the adverse event(s) from non-personal mentions.

Data Source for Comparison

The most common comparison (42 studies) was made with spontaneous reporting systems (such as FAERS, MHRA or VigiBase), this was followed by comparisons to product labels (21 studies), scientific literature (18 studies), or online medical sites (5 studies), Other comparisons included drug information databases (DID), reference standards and an internal database. Table 5 reports the details of these data sources used and their references.

Table 5. Data sources for adverse events compared to social media

Data Source (no. of studies)	Source Name (no. of studies)	References
Spontaneous reporting system (42)	FAERS (23)	[35, 45, 47, 56, 58, 61-63, 67, 70, 76, 77, 79, 80, 90, 93-95, 97, 99, 100, 102, 103, 105]
	Vigibase (5)	[24, 50, 51, 60, 71, 72, 81]
	MHRA (4)	[61, 65, 91, 92]
	FPVD (3)	[36-42, 73, 96]
	KAERS (2)	[75, 100]
	VAERS (2)	[44, 78]
	JADER (1)	[82, 83]
	Medeffect (1)	[58]
	SAEFVIC (1)	[68]
	Argentinian SRS (1)	[66]
Product labels (21)	SPL/SPC (12)	[24, 36-42, 45, 46, 49-51, 53, 54, 56, 69, 73, 74, 98]
	SIDER (9)	[21, 43, 48, 57, 64, 77, 79, 85, 102, 103]
Scientific Literature (18)	Scientific literature (7)	[21, 52, 69, 70, 86-89, 102, 103]
	Clinical trials (6)	[53, 54, 59, 66, 67, 69, 86-88]
	Systematic reviews (3)	[61, 67, 99]
	PubMed (2)	[55, 67]
Medical Web Sites (4)	MedlinePlus (2)	[67, 104]
	Drug Bank (1)	[84]
	Drugs.com (1)	[58]
	WebMD (1)	[57]
Other (12)	DID (4)	[36-42, 61, 73, 99]
	Safety communications (3)	[67, 101]
	Reference standards (2)	[24, 50, 77]
	Administrative claims (1)	[56]

	Internal ADE database (1)	[45]
	Surveys (1)	[53, 54]

Method of Comparison

The most common method of comparing adverse events was by frequency (33 studies)[24, 36-47, 50, 53, 54, 57, 59-63, 65-67, 73, 74, 78, 79, 81-83, 85-92, 94, 96, 99, 105], followed by type of adverse events (30 studies) [16, 21, 30, 36-42, 47-49, 51-54, 57, 58, 63, 64, 66, 70-72, 77, 80-83, 86-90, 93, 95, 96, 98, 100, 102-104], rank order of adverse events (11 studies) [43, 45, 47, 53, 54, 61, 68, 75, 76, 78, 82, 83, 99] and timing of adverse event identification (10 studies) [24, 35, 50, 71, 72, 79, 86-88, 93-95, 98, 101]. Other methods included disproportionality analysis, or comparing correlation/agreement, proportion, and proportional reporting ratios (PRR) (15 studies) [36-43, 46, 51, 55, 61, 68, 71, 72, 77, 85-88, 90, 92, 95, 99], which are used to detect more frequently reported drug-ADR pairs or to detect potential safety signals. In addition, precision [35, 92, 102, 103] and recall [35], among other metrics such as sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV) [56] of the detection were sometimes compared between different data sources to evaluate detection accuracy and specificity.

Results of Comparison

Many of the publications state that similar patterns of adverse events were reported in social media as compared to other traditional pharmacovigilance data sources [35-43, 47, 48, 51-56, 60-62, 64-70, 74-78, 82, 83, 85-89, 92, 94, 98, 99, 102-105]. However, some studies [24, 45, 46, 50, 57, 59, 62, 89, 94, 102, 103] detected fewer numbers of adverse events on social media.

Another limitation noted of social media data was that no serious adverse events were detected [36-42, 45, 52, 61, 73, 77-80, 82, 83, 91, 95, 96]. De Langen 2017 noted that serious adverse events were only identified in the literature [52].

The main advantages noted were that social media data included unexpected or new adverse events [35-43, 49, 51, 53, 54, 57, 60, 64, 67, 71-73, 80, 84, 86-90, 92, 98, 101, 104, 105] (24 studies)

and that adverse events could be identified earlier [35, 60, 71, 72, 79, 86-88, 92, 93, 98, 101] (9 studies) in social media as compared to those reported in spontaneous reporting systems [35, 71, 72, 76, 79, 93] , search query logs from search engines [35], drug safety communications [101] and scientific literature [76, 86-88]. In contrast, 3 out of the 60 studies suggested that routine surveillance of social media would *not* aid in earlier identification of ADE signals [24, 50, 95] , while one stated it will not be useful to confirm previously identified safety signals [45] and another one that certain social media platforms (such as online health forums) may be timelier in signal detection while others (Twitter) will not [35].

Regarding evaluation metrics, findings from these publications were inconsistent. One study concluded that social media had a generally higher recall but lower precision in ADE detection than other data sources such as search query logs [35]. However, this conclusion was noted to be context-specific, since different social media channels had performed better or worse depending on for which event type they were tasked to detect the signals [35]. Meanwhile, social media was also found to be more sensitive in detecting ADE than administrative claims, but less sensitive than the spontaneous reporting system of FAERS [56]. And, social media detection was found to be more specific, able to yield higher PPV and similarly low NPV as other data sources [56].

Data and Code Availability

Only 15 studies stated that their data was available: five studies [53, 54, 62, 75, 92, 102, 103] stated that the data would be available upon request, and the other 10 [24, 46, 49, 50, 58, 59, 61, 64, 65, 75, 77, 94] either provided data as supplemental material or a link to a repository. In two cases [39, 64], the links were no longer working when checked as part of this review.

Five studies [53, 54, 64, 65, 86-88] stated that their code was available. All links were validated, and one [64] was found to no longer work.

Author Conclusions

Overall, out of the selected 60 studies, 47 were supportive of the use of social media as an adjunct to traditional pharmacovigilance (Table 6). Of the rest, eight studies stated that there may be potential value in the use of SM in pharmacovigilance, but more research is required to improve methods. Only 5 out of the 60 studies were not supportive of the use of data from social media for pharmacovigilance, however, one of the 5 noted that usefulness may be improved with advances in techniques used to identify ADEs in social media posts.

Table 6. Author's conclusions on the use of social media for pharmacovigilance

Author's conclusion (no. of studies)	References
Support – as complementary resources (47)	[21, 35, 44, 46-49, 52-61, 63-68, 71, 72, 74-76, 78, 81-84, 86-92, 96-105]
Support – with more research to improve methods (8)	[36-43, 51, 62, 73, 79, 80, 93]
Unsupportive (4)	[45, 77, 94, 95]
Unsupportive – may be improved with more research (1)	[24, 50]

Discussion

This review identified 60 studies published on the potential utility of social media in pharmacovigilance by comparing social media data to other sources since 2017. This demonstrates that the subject of using social media in adverse events detection is still prolific. Indeed, many more studies were identified that analysed social media for the purpose of identifying adverse events but were done without comparison and where thus excluded from this study.

The Web-RADR study [24, 50], which is probably the most cited research on the utility of social media in pharmacovigilance, recommends that social media data not be used for broad statistical signal detection at the expense of other pharmacovigilance activities. However, the authors acknowledged several limitations with their approach, including shortcomings in their adverse event recognition algorithm. It was noted that the method for automatic extraction of adverse event mentions used in their study (primarily based on string matching) is an extremely basic approach, even for the time when the study was conducted, a choice that severely impacts the validity of their

conclusion. Nonetheless, the study also noted that for certain underrepresented areas of pharmacovigilance, such as drug exposure during pregnancy, social media data could provide a valuable resource of information.

Vigi4Med Project is another well-known study of social media analysis for pharmacovigilance [36-42]. This study searched for all adverse events related to six drugs in 22 French medical forums. They extracted 60 million posts and validated 5149 posts manually. The main comparison was to the French pharmacovigilance database (FPVD), although for one drug they also carried out a comparison to SPC/Product labels. They concluded that even though the information in forums was less informative, less serious, and contained fewer signals, it could be complementary as forums contained more unexpected AEs than the FPVD.

Whilst the above two studies are probably the most well-known, there are a large number of other studies, as we have demonstrated.

As exemplified by these studies, the identification of ADEs and the choice of drug or comparator source can significantly influence the conclusions drawn from a study. It is crucial to consider these factors when evaluating the results. Particularly, the methods employed for detecting ADEs may result in overestimation or underestimation of the reports from social media. Our findings indicate that only a few studies distinguished personal reports of ADEs from other general mentions, potentially introducing biases. While this may be less problematic in moderated patient health forums, it becomes more challenging when general social media platforms are used, where various factors can lead individuals to mention drug-related adverse events that are not based on personal experiences. Additionally, it is important to implement filters or rules in ADE detection to ensure that mentions are not negations, feared ADEs, or unrelated signs and symptoms, such as indications for a drug that do not represent an ADE. Failure to incorporate these measures may result in an inflated number of captured ADEs.

Detection of ADEs can be limited by certain methods. Many studies [24, 43, 48, 50, 58, 64,

69, 71, 72, 89, 93, 98] (notably, Web-RADR) relied on dictionary-based or lexical matching systems to identify ADE mentions. These methods may overlook a great number of mentions due to the descriptive idiomatic and non-technical language used by patients to describe their symptoms. The lexicons used by these systems were typically curated from traditional sources like drug labels or SIDER, which do not capture the full range of patient expressions. While incorporating consumer-generated terms, such as those from consumer health vocabularies or previous social media mentions, expands the number of matches, a lexical match method still primarily identifies frequently reported ADEs. In contrast, studies utilizing advanced NLP and ML techniques, such as deep learning, have demonstrated superior performance in ADE recognition, including rare and previously unknown ADEs. For instance, Xia 2022 [101] developed a historical awareness multi-level framework that leverages transfer learning from prior review embeddings and utilizes BERT-based sentence and word embeddings with an attention mechanism. This approach achieved state-of-the-art performance with an impressive F-1 score of 0.944.

In several studies it was observed that the frequency of drug mentions in social media varied depending on the specific drug [24, 50, 101, 105]. It was reported that drugs ranked in the top 100 by sales generated more posts compared to other drugs. Therefore, the selection of drugs for study can impact the conclusions regarding the use of social media for pharmacovigilance. Additionally, the use of a single comparator can introduce further issues. For instance, SIDER, a database of ADEs extracted from product labels, lacks coverage for many drugs and has not been updated since 2015, potentially missing newly reported ADEs on updated labels or reported in the literature. Interestingly, two studies [21] noted the number of new ADEs identified in social media was higher than with SIDER. However, fewer new ADEs are identified in social media if a comparison is made to more uptodate sources such as clinicaltrials.gov, FDA data and Pubmed or MEDLINEPlus[46].

Future Research Directions

The question as to the utility of social media analysis in identifying adverse events does not appear to be resolved. Future research, particularly with the advancement of artificial intelligence should be welcomed. It may be, however, that we should not be asking social media to replace spontaneous reporting systems but more as an adjunct and to develop social media listening skills akin to those used in businesses. For example, social media is increasingly being recognized as a source for patient perspectives, and this was evident in our included studies as many [36-42, 45-47, 51-54, 57, 60, 61, 68, 78, 91, 95, 98, 99] discussed the application of social media data for identifying quality of life issues, adherence behaviour or coping mechanisms [106]. Research into the value of social media to identify trends in the public discourse, public concerns, and patient perspectives could prove useful.

Summary of and Comparison with Previous Systematic/Scoping Reviews

In our previous systematic review in 2015 we identified 29 studies comparing social media adverse events data to another source of data [61]. These studies focused on using discussion forums whereas in our review the dominant platform used was Twitter, followed by discussion forums. We now include other platforms such as Reddit and WebMD which were not identified in our previous review. The sources used to compare against were similar to those noted in this review. Previously we found that social media data had general agreement with other data sources for patterns of adverse events but showed the potential to identify adverse events earlier (one included study), and to identify new or unexpected adverse events - particularly symptomatic ‘mild’ symptoms. This agrees with this review, with more studies now investigating the timeliness of social media data.

Our 2015 review [26] identified 22 technical papers on the extraction of adverse events data, but such papers were excluded in our current review if they did not compare the results to an existing data source. The large number of technical papers that we excluded indicates that many more papers have been published since 2015 for the purpose of extraction. Interestingly, only 6 of 22 studies in

the review by Sarker [26] made their annotations publicly available, a ratio comparable to our review.

The review by Lardon [30] focused on summarizing methods used for identifying, extracting, and evaluating the quality of medical information from social media. They found that works about identification tend to not accurately assess the completeness, quality, and reliability of the social media data being analyzed; whereas works about extraction had limited generalizability to new sites and data sources [30]. Given the limited information found through 24 publications, they concluded that the studies they reviewed were inadequate for precisely determining the role of social media data in pharmacovigilance.

Tricco [12] reviewed 19 works which compared AEs reported through social media to validated data. According to Tricco [12], previous research showed that social media data has potential to supplement regulatory data as they allow for earlier detection of AEs and detection of less frequently reported AEs. But Tricco [12] questioned the validity and reliability of these systems that use social media data for ADE detection, as none of the works they reviewed reported on these two important dimensions. Based on these findings, Tricco [12] concluded that the use of social media data for pharmacovigilance was “in its infancy” (p. 1) at the time of their reporting.

Based on the 38 studies Convertino 2018 [27] reviewed, it was found that social media data occasionally—but not always—allowed for identification of serious and unexpected proto-adverse drug events, but that social media was lower in information quality compared to spontaneous reporting databases, with causal relationships rarely evaluated in the detected events. Overall, Convertino did not recommend the use of social media signal detection for routine pharmacovigilance as of the end of 2017 [27].

Pappa and Stergioulas [28], a more recent review of 100 articles, compared different approaches to using social media data in pharmacovigilance. It concluded that in its use for pharmacovigilance, social media data had both advantages and limitations in population coverage,

usefulness, accessibility, and processability; advantages in timeliness; and limitations in quality [28]. Similarly to what we found in this review, Pappa and Stergioulas [28] argue that within the big umbrella term of social media data (or social data), different types of social media data sources can vary in specific evaluative dimensions. For example, data from generic social networking sites (such as Twitter) tends to raise more quality concerns and requires more quality control as compared to data from specialized healthcare social networks and forums (such as WebMD or What to Expect). The latter have more relevant data and lengthier postings that have the potential for broader analysis. Lee [29] had a more specific focus, looking at the use of social media data in detecting new black box warnings, labeling changes or withdrawals in advance. There were 2 studies [24, 93] included in the review by Lee that were published from 2017 onwards and both these reviews are included in our scoping review. These studies were two of the four studies that reported negative or modest results. A further 9 studies in Lee 2021 were positive. This can be compared to the 10 studies in our review that measured timeliness of adverse events detection, of which 9 were positive.

Strengths and Limitations

There are two main strengths to our study. First, different experts in the fields of NLP, ML, systematic review methodology and information science participated in the planning and development of the study. Second, we have already identified seven previous systematic reviews or scoping reviews on which we can build our methods. Unlike our review, none of the previous reviews considered whether, for studies that used social media data, the authors detected and/or removed bots. Neither did they evaluate if previous works had distinguished non-personal social media accounts (e.g., business, organizations) when detecting ADE reports.

The main limitations of our study are the exclusion of studies published in languages other than English, French, or Spanish and the use of Anglo dominated databases. However, we only identified one paper in a non-English language which we could not translate that is likely to have met

our inclusion criteria. This is also a fast-paced area of research meaning that the applicability of our findings may change over time. Indeed, the social media platforms themselves are rapidly changing in terms of use and access, and the technological developments to extract data from social media are rapidly evolving. The time period in which each included study was undertaken may have an impact on their findings.

It was also impossible to identify any patterns of results in relation to the type of medication studied or the types of adverse events sought. This was due to a combination of poor reporting of the drug names and adverse events and the large number of drugs (up to 4888) included in some studies.

As this is a scoping review, we also did not conduct any formal risk of bias assessment to ensure the validity of the results. It should be noted that any risk of bias assessment will be challenging given the lack of a validated tool for the types of studies included.

The interpretation of the results and the authors conclusions extracted from the included studies are subjective, the primary authors may be biased as to their initial objective, their funding, and the impact of the results on their career progression.

Whilst we limited our review to studies with a comparison to gain a better understanding of the potential utility of social media analysis it is important to note that utility is an ambiguous concept – what may be useful to regulatory agencies may differ to patients or clinicians for example. We should also be mindful of false positives within any system measuring case reports of adverse events given that causality cannot be proven. False positives may, however, still be important to identify given the potential impact on uptake and adherence of medication.

Conclusions

The results of this study may help inform current recommended practices and the future

direction of research in this area. Most studies concluded that social media can be a useful adjunct to traditional sources. It was apparent from our study that social media data may prove most fruitful for more timely hypothesis generation of new or unexpected adverse events and for detecting reports of mild symptomatic events. Knowledge of mild symptomatic events is difficult to quantify and has been shown through social media to play a role in adherence patterns [107, 108] and coping strategies [106]. Future research that uses state-of-the-art NLP methods to identify personal experiences of adverse events from a range of platforms and that can directly capture reports of medication change alongside the reasons for change poses to bring the best return-on-investment for the incorporation of social media data with other traditional data sources.

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Conflict of Interest

None declared

Data Availability

All the included studies are published and available via the internet. The search results library can be made available on request. Data sharing is not applicable to this article.

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Supplementary Files

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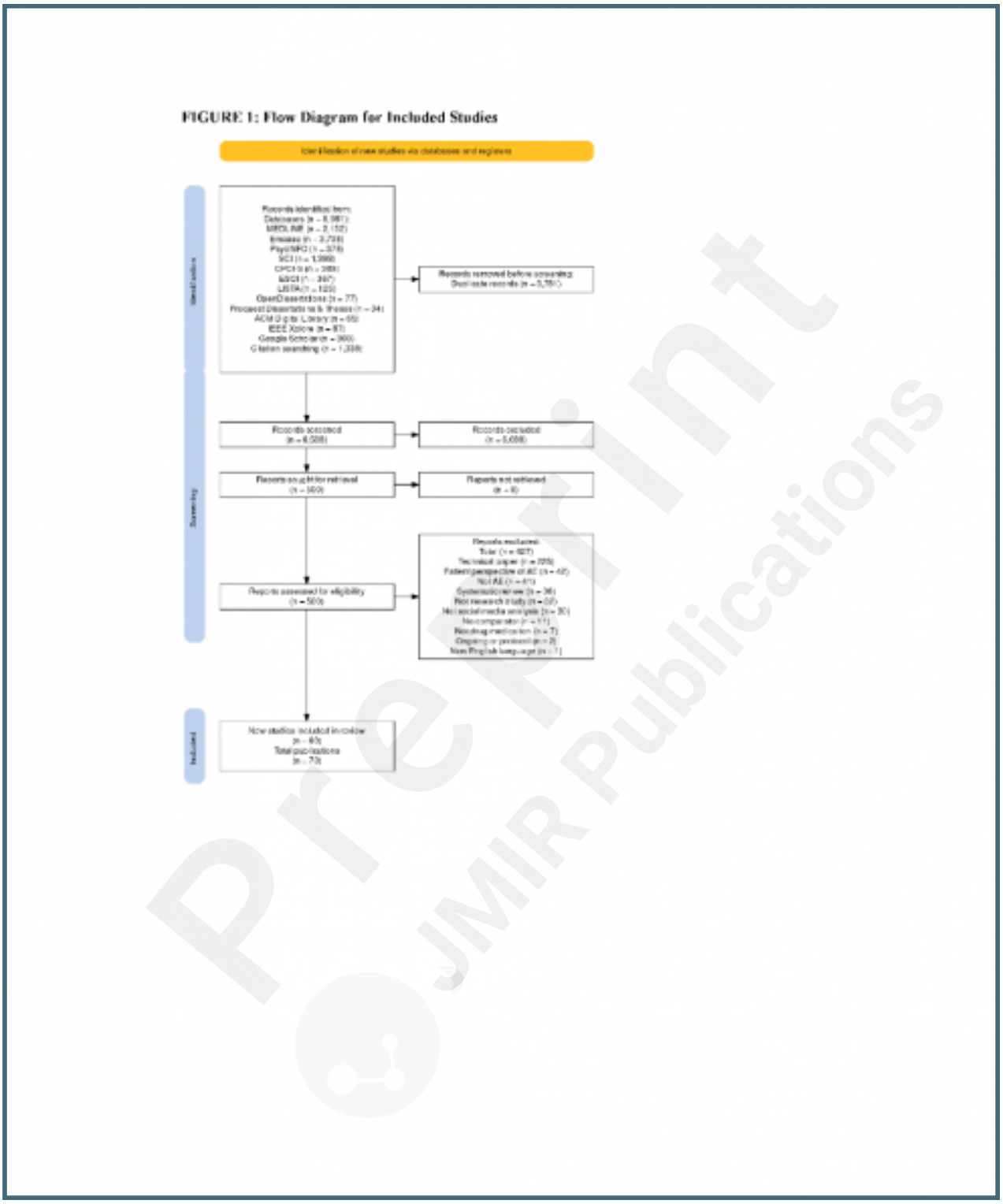
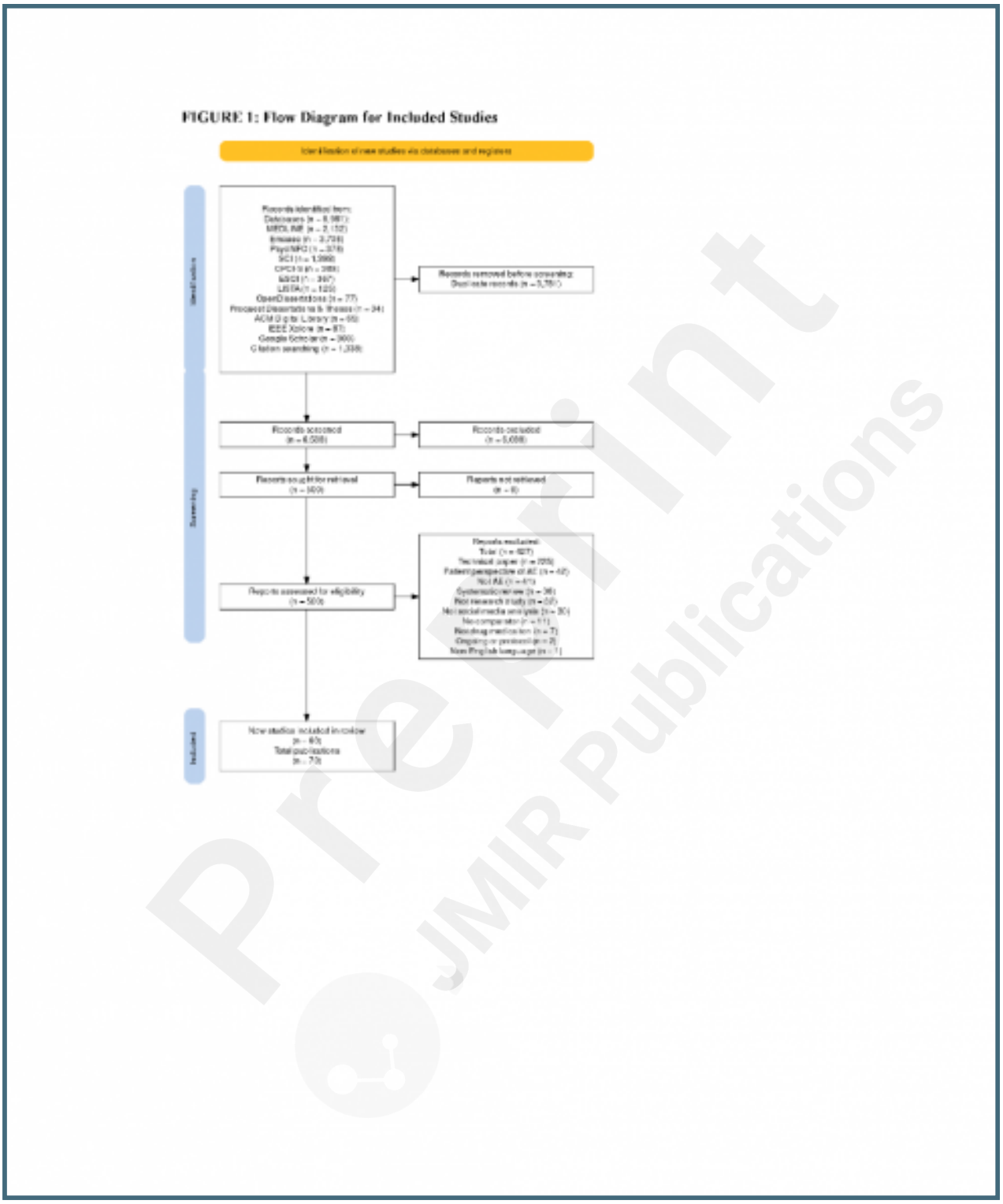


Figures

Flow diagram for included studies.



Multimedia Appendixes

Supplementary material tables.
URL: http://asset.jmir.pub/assets/d8753cbe9e7fbbc093a21349a76e0977.docx

CONSORT (or other) checklists

PRISMA-ScR checklist.
URL: http://asset.jmir.pub/assets/9acab849d74855a2247d04b6377226ee.pdf