



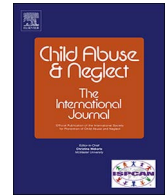
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Research article

The potential use of social media and other internet-related data and communications for child maltreatment surveillance and epidemiological research: Scoping review and recommendations[☆]



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ABSTRACT

Collecting child maltreatment data is a complicated undertaking for many reasons. As a result, there is an interest by child maltreatment researchers to develop methodologies that allow for the triangulation of data sources. To better understand how social media and internet-based technologies could contribute to these approaches, we conducted a scoping review to provide an overview of social media and internet-based methodologies for health research, to report results of evaluation and validation research on these methods, and to highlight studies with potential relevance to child maltreatment research and surveillance. Many approaches were identified in the broad health literature; however, there has been limited application of these approaches to child maltreatment. The most common use was recruiting participants or engaging existing participants using online methods. From the broad health literature, social media and internet-based approaches to surveillance and epidemiologic research appear promising. Many of the approaches are relatively low cost and easy to implement without extensive infrastructure, but there are also a range of limitations for each method. Several methods have a mixed record of validation and sources of error in estimation are not yet understood or predictable. In addition to the problems relevant to other health outcomes, child maltreatment researchers face additional challenges, including the complex ethical issues associated with both internet-based and child maltreatment research. If these issues are adequately addressed, social media and internet-based technologies may be a promising approach to reducing some of the limitations in existing child maltreatment data.

1. Introduction

Collecting child maltreatment data is a complicated undertaking for many reasons (World Health Organization, 2016). Although governmental and other official data records are the gold standard for the data of many disciplines, official data records for child maltreatment have several significant issues. First, the definition of child maltreatment differs substantially depending on the geographic region, agency or organization, and purpose for data collection. For example, Section 3 of the United States Child Abuse Prevention and Treatment Act (CAPTA) defines child abuse and neglect as, “at a minimum, any recent act or set of acts or failure to act on the part of a parent or caretaker, which results in death, serious physical or emotional harm, sexual abuse or exploitation, or an

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act or failure to act, which presents an imminent risk of serious harm” (Children’s Bureau, 2010). States and other jurisdictions are free to develop their own definition, so long as it meets or exceeds the federal definition (Child Welfare Information Gateway, 2016). These differing definitions result in inconsistent reporting to The National Child Abuse and Neglect Data System (NCANDS), the official government data source in the United States for child abuse and neglect reports (Children’s Bureau, 2016). The NCANDS is also subject to changes in the jurisdictional definitions over time (Children’s Bureau, 2016). Thus, it is difficult to draw firm conclusions about trends over time or across geographical areas from official data reports. It is particularly difficult to create estimates that are sensitive enough to assess the impacts of broader social trends or interventions on child maltreatment.

Official reports are also associated with other forms of bias, including report and investigation bias. It is well-established in the literature that many factors, beyond presence of child maltreatment, contribute to referral to and investigation by the child protection system (Bunting, Lazenbatt, & Wallace, 2010; Drake, Lee, & Jonson-Reid, 2009; Lane & Dubowitz, 2007; Widom, Czaja, & DuMont, 2015). Estimates suggest that between fifty and eighty percent of child maltreatment victims are not officially reported so even without concerns about bias in the data, official reports underestimate the prevalence of child maltreatment and may not represent the true experience of children who are maltreated (Fallon et al., 2010). As a result of the introduction of these biases, the use of these data for research or evaluation is complicated.

Surveys of parents or children avoid some of the pitfalls associated with official data but introduce other issues. Approaches that require participant disclosure, whether retrospective or prospective, are subject to both random and systematic bias (Kahneman et al., 2000). Human memory is a function of various heuristic strategies so participant reports are influenced not only by characteristics of the event in question but also the experiences before, during, and after the event (Kahneman et al., 2000; Smallwood & O’Connor, 2011). In addition to these general issues with self-reported data, studies of child maltreatment may face additional limitations due to the sensitive nature of the questions. Individuals may intentionally withhold information related to child maltreatment due to social desirability, embarrassment, or concerns about confidentiality and the repercussions of reporting abuse (Everson et al., 2008). Concerns about repercussions may be especially prominent when talking to parents about their children’s experiences because many institutional review boards and universities require researchers to report suspected child maltreatment to child protective services. Researchers may also directly ask minors about their experiences. This approach reduces the issues associated with retrospective report but is debated because children may not have the necessary perspective to recognize their experiences as abusive or to critically process the potential costs and benefits of disclosure (International Society for the Prevention of Child Abuse & Neglect, 2016). In addition, infants and very young children, who are unable to report experiences to researchers, have the highest rates of maltreatment so child-reported research is not possible with the subpopulation at the highest risk of maltreatment (U.S. Department of Health, and, & Human Services, 2017).

Some approaches to self-reported studies also have issues related to social changes in engagement with research and technology. Historically, survey samples drawn via random digit dialing could provide reliable measures of population health indicators (Lee et al., 2011). As cell phones have increased in popularity, more people are unreachable through a landline number. In addition, cell phone service has not been equally adopted across the population so random digit dialing is likely to miss young people, people with low socio-economic status, and males (Lee et al., 2011). In addition to these potential biases, increased telemarketing, screening calls through caller ID, and call blocking present additional challenges to an adequate, representative response (Lee et al., 2011). Because of these changes, it is difficult to adequately access a sample that is representative of the population.

Finally, child maltreatment data may be collected from child welfare professionals and other key informants. The National Incidence Study of Child Abuse and Neglect (NIS), which is conducted in the United States, works with child welfare agencies to identify children served during the three-month study period, then solicits reports from other professionals who regularly engage with children (Sedlak et al., 2010). Using complex methodology, duplicate reports are removed so the final database includes abused children who were and were not known to child welfare to provide a more comprehensive view of the prevalence of child maltreatment (Sedlak et al., 2010). The NIS funding does not allow for frequent data collection and it has only been conducted four times since 1974 (Fallon et al., 2010). Cost is a significant limitation to this data collection approach and without substantial funding increases, timeliness of the data and inability to regularly monitor trends across time are significant limitations (Fallon et al., 2010). In addition, this method relies upon professionals’ knowledge of child maltreatment so it is likely that many maltreated children are not detected.

As a result of these complexities, there is an interest in developing methodologies for child maltreatment epidemiological research and approaches to the triangulation of data resources (Leeb & Fluke, 2015). Each potential data source has relative strengths and weaknesses, but, relying on any single source of information provides an incomplete and potentially biased view of the issue of child maltreatment (Afifi et al., 2015). Researchers in other areas of health, such as infectious disease, have readily adopted social media and internet-based approaches to triangulation. These approaches may be particularly relevant to child maltreatment researchers as 98% of young people in the United States access the internet at least weekly and 93% use at least one social network site (Lenhart, 2015). However, there have been notable lapses in accuracy for some of these approaches, which highlight the importance of rigorous evaluation and validation of these new approaches, prior to adoption and throughout the process of utilization (Olson, Konty, Paladini, Viboud, & Simonsen, 2013). To that end, the field is beginning to explore how techniques that rely on the use of social media may or may not be applicable to child maltreatment epidemiology and research.

Because this is a new and rapidly developing area, we have conducted a scoping review to provide an overview of social media methodologies for health surveillance or related epidemiologic research, to report results of evaluation and validation research on these methods, and to highlight studies with potential relevance to child maltreatment research and surveillance. Scoping reviews differ from systematic reviews in that they focus on the extent, range, and nature of research in the topic area for the purpose of summarizing and disseminating findings, evaluating the feasibility of conducting a systematic review, or identifying gaps in the

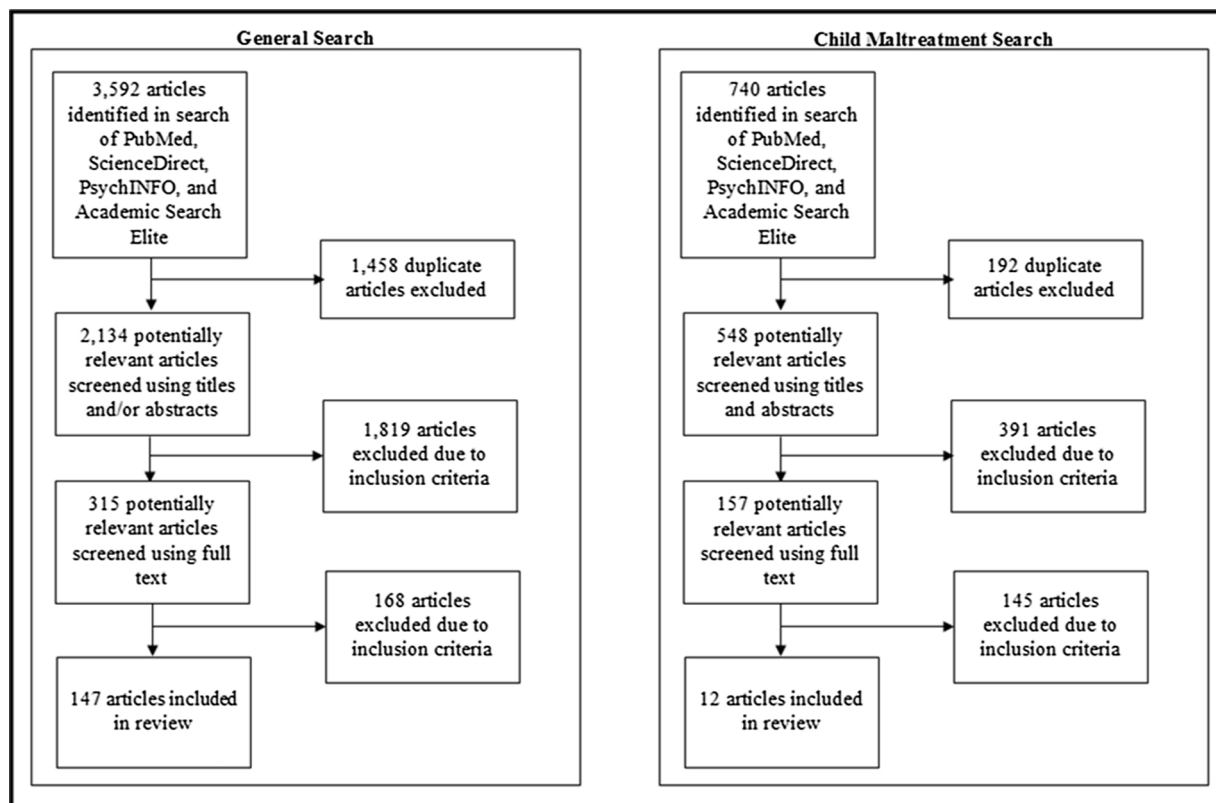


Fig. 1. Search processes for general and child maltreatment literature search.

literature (Levac, Colquhoun, & O'Brien, 2010). This type of review is ideal for topics with emerging evidence, where it would be difficult to complete a systematic review or meta-analysis (Levac et al., 2010).

2. Literature review methods

We searched PsychInfo, PubMed, ScienceDirect, and Academic Search Elite using two search frameworks. The first framework was broadly focused on how social media and other forms of internet-based technology were used for health surveillance, which also included some broader epidemiologic research. The second framework focused on the use of social media for child maltreatment research. For each framework, one author reviewed the title and, if available, the abstract of all articles found through the search framework. Articles were considered possibly relevant if social media or internet-based approaches to health research or surveillance were discussed in the abstract. Articles with possibly relevant content were downloaded and the full text of the article was reviewed. For this review, social media was conceptualized using the Bright, Margetts, Hale, and Yasserli (2014) definition as “a means of communication, based around a website or internet service, where the content being communicated is produced by the people using the service.”

The search terms for the general health framework included, “social media” OR “social media surveillance” OR crowdsourcing OR crowdsource OR “internet surveillance” OR “online surveillance” OR Facebook OR Twitter OR Google OR Tumblr OR YikYak OR Instagram OR Youtube OR apps OR “mobile app” AND “public health surveillance” OR “bio-surveillance” OR “health surveillance”. Articles were included in this portion of the review if data collection was conducted using social media or an internet-based technology and the study focused on a health-related issue. Commentaries on the use of social media, articles in languages other than English, articles without relevance to human disease or disability (i.e., plant/animal disease), and technical reports without application to human research were excluded. In total, 2134 possibly relevant articles were identified through this process (Fig. 1). Of these, 147 relevant articles were included in this review. Articles were most commonly excluded because they were commentaries or they focused on the computer science aspects of technology.

The search terms for the child maltreatment portion of the search included all the technology search terms, but included “child abuse OR “child neglect” OR “child maltreatment”, instead of the surveillance search terms. Articles were included in this portion of the review if data collection was conducted using social media or an internet-based technology and the study focused on a child maltreatment-related issue. As with the first review, commentaries, articles without human relevance, and technical reports were excluded. A total of 740 articles were considered for this review (Fig. 1). Of these, 12 articles were found to be related to social media or internet-based surveillance or research. Articles were commonly excluded because they were not directly relevant to child

Table 1
Summary of Social Media and Internet-based Approaches to Surveillance or Epidemiologic Research.

Method	Example Topics Studied	Strengths	Weaknesses
Active Data Collection			
Crowdsourcing	Infectious disease: influenza; malaria; dengue Non-infectious disease: cancer; asthma Health behavior/environment: availability of tobacco; cost of diverted prescriptions	Cost-effective; easy recruitment; geographical diversity; access to some hidden/rare subpopulations; research-driven data	Underrepresentation of people of color; volunteer bias; requirement for internet access; poor sustained participant engagement
Online Recruitment	Infectious disease: respiratory infection Non-infectious disease: respiratory distress; diabetes	Access to previously unreachable population; research-driven data	Volunteer bias; requirement for internet access;
Passive Data Collection			
Internet Search Query	Infectious disease: influenza; dengue fever; malaria; listeria; HIV; norovirus; hepatitis; tuberculosis; Non-infectious disease: cancer; multiple sclerosis Mental health: depression; anxiety; suicide Health behavior/environment: availability of tobacco; vaccination; drug use; preconception care	Low cost; some support for real-time validity	Questionable validity; poor sustained predictive ability; limited ability to control for confounders
Media Reports	Infectious disease: H1N1 Health behavior/environment: drowning; sudden cardiac death	Real-time availability; curated databases searchable by disease, location, source, and date	Resource intensive collection of reports by individuals; potential bias due to media sensitivity
Internet death notices	Mortality data	High correspondence to death records; nearly real-time data availability	Only applicable to mortality research
Forums	Infectious disease: foodborne illness Non-infectious disease: diabetes	Low cost	Limited information; potential lack of generalizability
Restaurant reviews	Infectious disease: foodborne illness	Low cost; real-time data availability	Potential confounding
Flexible or Combined Approaches			
Twitter	Infectious disease: influenza; H1N1; Middle East Respiratory Syndrome Coronavirus Health behavior/environment: e-cigarettes; dental pain; cardiac arrest; drug use; suicide; vaccination	Low cost; large number of observations; real-time data availability	Potentially missing covariates; potentially limited generalizability to overall population
Facebook	Health behavior/environment: obesity; general physical health; autism; water fluoride Mental health: autism; depression; alcohol abuse	Low cost; large number of observations; real-time data availability	Potentially missing covariates; potentially limited generalizability to overall population

maltreatment (i.e., internet-based pedophilia; peer-to-peer harassment) or did not use social media and/or internet-based approaches for data collection purposes (i.e., only online dissemination of findings; participant self-reported use of social media).

The initial searches for this review were completed in March of 2016. The child maltreatment-related search was repeated in August of 2017 with no additional articles found. The general health research search was not repeated because the March 2016 search results provided a comprehensive overview of methods for conducting this type of research and it was unlikely there were significant advances in these methods.

3. Results

Most of the studies and methods found through this scoping review were focused on physical health, which may be least applicable to child maltreatment research and surveillance. In the interest of brevity, we have provided an overview of the approaches, strengths, and weaknesses in Table 1 with references throughout the text. For mental health and health behavior related studies, we have provided some additional detail on the topic and approach in the text.

3.1. Active data collection methods

Active data collection methods include direct interaction with research participants. Although contact with participants is facilitated through the internet, the process of designing the measurement tool, collecting data through interaction with participants, and analyzing the data are similar to traditional data collection methods.

3.1.1. Crowdsourcing

Crowdsourcing is the process of obtaining services, ideas, or content from a large, undefined group of volunteers or part-time workers through a flexible open call. The volunteers and part-time workers have varying degrees of experience, knowledge, and skills. Most often, researchers use crowdsourcing to complete large, monotonous tasks or recruit large numbers of survey participants. Amazon Mechanical Turk, Google Consumer Surveys, and proprietary systems or websites are the most common methods of crowdsourcing. Amazon Mechanical Turk is an online multi-use crowdsourcing platform hosted through Amazon where users are recruited to answer surveys or complete repetitious tasks for a small amount of money. Google Consumer Surveys is another crowdsourcing platform used to recruit a large number of participants for short surveys (< 10 questions) (Sell, Goldberg, & Conron, 2015). Samples may be constructed to be nationally-representative based on age, gender, and geographic distribution of respondents. However, participants tend to be younger and more technologically savvy than the general population. Participants who complete surveys receive micropayments (\$1 or less) in the form of Google Play Store credit. Crowdsourcing tends to be cost-effective, facilitate easy recruitment, and allow for access to a geographically diverse sample. However, there may be bias in the results of studies using Amazon Mechanical Turk and Google Consumer Surveys related to varying access to the internet within a population so older adults, individuals with lower socioeconomic status, and others may be underrepresented (Bethlehem, 2010).

Crowdsourcing has been used to collect information on a range of physical health issues (Adler, Eames, Funk, & Edmunds, 2014; Alqahtani et al., 2014; Camacho, Eames, Adler, Funk, & Edmunds, 2013; Candido Dos Reis et al., 2015; Chunara, Chhaya et al., 2012; Harber & Leroy, 2015; Ilakkuvan et al., 2014; Kim, Lieberman, & Dench, 2015; Lwin et al., 2015; Mandl et al., 2014; Norr, Albanese, Oglesby, Allan, & Schmidt, 2015; Nyman & Biener, 2016; Paolotti et al., 2014; Smolinski et al., 2015; Zhang, Ho, Fang, Lu, & Ho, 2014). Crowd sourcing has also been used to study several health behaviors, including pedestrian behavior (Hipp, Adlakha, Eyler, Chang, & Pless, 2013); public awareness and knowledge about ovarian cancer (Carter, DiFeo, Bogie, Zhang, & Sun, 2014); and the cost of diverted prescription opioid analgesics (Dasgupta et al., 2013).

3.1.2. Online recruiting

Numerous studies have used websites and social media to recruit participants (Adler et al., 2014; Altshuler, Gerns Storey, & Prager, 2015; Barratt et al., 2015; Bauermeister et al., 2012; Ben-Ezra et al., 2013; Camacho et al., 2013; Chaulk & Jones, 2011; Dal Moro, 2013; Harris et al., 2014; Hernandez-Romieu et al., 2014; Janiec, Zielicka-Hardy, Polkowska, Rogalska, & Sadowska-Todys, 2012; Jones, Saksvig, Grieser, & Young, 2012; Klein, Thomas, & Sutter, 2007; Moreno, Grant, Kacvinsky, Egan, & Fleming, 2012; Schumacher et al., 2014; Stein et al., 2014; Sueki, 2015; Thomas, Heysell, Houghton, Moore, & Keller, 2014; Turbow, Kent, & Jiang, 2008; van Genderen, Slobbe, Koene, Mastenbroek, & Overbosch, 2013; Zhang, Bi, Hiller, & Lv, 2008; Zheluk, Quinn, & Meylakhs, 2014). Online recruitment is a convenient method of reaching samples for rare outcomes (Schumacher et al., 2014) or hidden or difficult to reach populations (Barratt et al., 2015; Hernandez-Romieu et al., 2014). However, online recruitment may introduce bias in the sample due to disparities in technology use among minority race/ethnic groups, low socioeconomic status groups, and older adults (Bauermeister et al., 2012).

3.2. Passive data collection methods

Passive data collection methods are more similar to secondary data analysis methods than to traditional data collection. In these methods, data are created for purposes other than research. Through a variety of methods, researchers gather the existing data, manipulate it into analyzable form, and analyze it. As these data may include millions of records, novel analytic techniques and software programs, often known as big data analytics, have been developed to handle these large sets.

3.2.1. Internet search query

Internet search query analysis, specifically Google Search Trends, is one of the most common forms of online public health surveillance. Google Search Trends, a regularly updated database of aggregated search queries, provides the relative search volume of terms selected by the researcher. The relative search volume scale normalizes queries to a scale of 1–100 where 100 is the highest search proportion and 1 the lowest search proportion. In one of the earliest studies of internet search trends, Yahoo! and Google searches for cancer related terms in the US were significantly associated with estimated incidence and mortality rate of cancer (Cooper, Mallon, Leadbetter, Pollack, & Peipins, 2005). This study and another also found significant associations between cancer-related internet search and the volume of related news coverage, which may suggest at least some of the correlation is due to media coverage prompting online searches (Cooper et al., 2005; Fazeli Dehkordy, Carlos, Hall, & Dalton, 2014). For example, searches for multiple sclerosis in Italy are highest in the geographical areas with the highest rates of multiple sclerosis but may also be attributed to increased media reports in the region (Brigo, Tezzon, Lochner, & Nardone, 2014). A review from 2013 found internet search query surveillance often had comparable findings to traditional surveillance methods (Bernardo et al., 2013). However, false positive and false negative results were a common problem in many of the reviewed studies. The review authors concluded internet search query data should be used to support, rather than replace, traditional surveillance methods.

Internet search query analysis has been used to study a range of mental health issues and health behaviors, including correlations between mental health-related searches and times of economic stressors (Ayers et al., 2012); seasonality of depressive symptoms (Ayers, Althouse, Allem, Rosenquist, & Ford, 2013); suicide (Bruckner, McClure, & Kim, 2014; Page, Chang, & Gunnell, 2011); use of tobacco, e-cigarettes, and vaping (Ayers, Ribisl, & Brownstein, 2011; Ayers, Althouse, Ribisl, & Emery, 2014; Ayers et al., 2016; Cavazos-Rehg et al., 2015); vaccine use (Barak-Corren & Reis, 2015); provider prescribing behaviors (Simmering, Polgreen, & Polgreen, 2014); bath salts use (Yin & Ho, 2012); prenatal care (D'Ambrosio et al., 2015); and krokodil use (an extremely dangerous

street drug) (Zheluk et al., 2014). Internet search query analysis has also been used to predict or estimate many physical health conditions (Althouse, Yih Yng, & Cummings, 2011; Carneiro & Mylonakis, 2009; Chan, Sahai, Conrad, & Brownstein, 2011; Cho et al., 2013; Cook, Conrad, Fowlkes, & Mohebbi, 2011; Cooper et al., 2005; Desai et al., 2012; Dugas et al., 2012, Dugas et al., 2013; Fazeli Dehkordy et al., 2014; Gluskin, Johansson, Santillana, & Brownstein, 2014; Martin, Xu, & Yasui, 2014; Min, Haojie, Jianfeng, Rutherford, & Fen, 2013; Ocampo, Chunara, & Brownstein, 2013; Ortiz et al., 2011; Patwardhan, Bilkovski, & Goldstein, 2012; Samaras, García-Barriocanal, & Sicilia, 2012; Timpka et al., 2014; Wilson & Brownstein, 2009; Zheluk, Quinn, Hercz, & Gillespie, 2013; Zhou et al., 2013, Zhou, Ye, & Feng, 2011).

Wikipedia, an online encyclopedia where the online community creates, edits, and modifies articles, has also been used for a modified internet search query analysis. Across several influenza seasons, the number of page views associated with influenza was significantly associated with CDC influenza diagnosis reports (McIver & Brownstein, 2014).

Despite the large number of studies supporting the use of internet search trends to predict infectious disease, search term algorithms may not perform well in the long-term. Google Flu Trend failed to predict the A/H1N1 pandemic in 2009 and greatly overestimated the A/H3N2 epidemic in 2012/2013, which may suggest changes in internet search behavior, geographical heterogeneity, and differences in age-distribution of the epidemic significantly influence the predictive power of the algorithms (Olson et al., 2013).

3.2.2. Media reports

Online media reports may also be used for public health surveillance. Individual researchers may monitor online reports or researchers may use databases that are automatically created or curated by other researchers. Examples of automated databases include HealthMap (Barboza et al., 2014; Brownstein et al., 2010; Chanlekha & Collier, 2010; Collier, 2010, 2012; Freifeld, Mandl, Reis, & Brownstein, 2008; Lyon, Nunn, Grossel, & Burgman, 2012); GENI-DB (Collier & Doan, 2012); Project Argus (Nelson, Li, Reilly, Hardin, & Hartley, 2012; Torii et al., 2011); ProMed-mail (Zhang, Dang, Chen, Thurmond, & Larson, 2009); MITAP (Zhang et al., 2009); and BioCaster (Lyon et al., 2012).

In addition to existing databases, researchers may use text mining (Collier, 2011) or human analysts to identify media reports (Collier, 2011; Nerlich & Koteyko, 2012). Text mining of media reports may reduce the resources required for identification of articles but may not perform as well as human analysts (Collier, 2011). Human analysts have also been used to identify newspaper and website articles associated with drowning or near-drowning (Ferretti, De Angelis, Donati, & Torre, 2014; Zhu, Jiang, Li, Li, & Chen, 2015) and sudden cardiac death in athletes (Choi, Pan, Pock, & Chang, 2013).

3.2.3. Other passive data collection methods

Several other possible passive data collection methods have been examined in the literature, including internet death notices as a source of mortality surveillance data (Boak, M'ikanatha, Day, & Harrison, 2008), forum postings (Kate, Negi, & Kalagnanam, 2014; Weitzman, Adida, Kelemen, & Mandl, 2011) and restaurant reviews and reservations (Harrison et al., 2014; Nsoesie, Kluberg, & Brownstein, 2014; Nsoesie, Buckeridge, & Brownstein, 2014)

3.3. Active or passive data collection methods

Several data collection methods may be used for active, passive, or combined types of data collection.

3.3.1. Twitter

Twitter is a microblogging site where users post messages (tweets) that are 140 characters or less. Users may “follow” other users to see their posts on the front page. Users may also respond to tweets posted by other users, share (retweet) messages posted by other users, or approve (like) other posts. Users may use hashtags to categorize their messages. When a large number of users are posting with a hashtag, the hashtag is listed on the Twitter front page and is said to be “trending.”

There are multiple methods of conducting research with Twitter, including both active and passive data collection methods. As a passive data collection method, researchers may download existing information from Twitter. Alternatively, researchers may use Twitter as a platform for reaching participants. Regardless of the collection method, there are several ways Twitter data may be used for research and surveillance. The content of individual tweets may be examined to determine how people are discussing topics and changes in trending hashtags may be examined to determine how discussions around topics change over time. Social network analysis, examination of the relationships between users, may also be conducted to determine how information moves through networks. These analytic methods can be implemented by automated algorithms (Cao et al., 2015; Denecke et al., 2013; Odlum & Yoon, 2015; Paul & Dredze, 2014; Prieto, Matos, Alvarez, Cacheda, & Oliveira, 2014; Yom-Tov, Borsa, Cox, & McKendry, 2014) or by human analysts.

These research methods are complicated by the microblogging (140-character limit) aspect of Twitter because the syntax and spelling are often altered to fit within the limit. Since these changes to language vary across users, it may be difficult for researchers to accurately categorize or recognize health information. However, Twitter recently doubled the character limit in many languages so issues with syntax and spelling may also change (Castillo, 2017). Twitter data may also be difficult to work with because they are unstructured and created at a very rapid rate. To address some of these issues, MappyHealth was created to simplify data management and analysis (Boicey, 2013). At the time of writing, it appears MappyHealth has been discontinued as the website and Twitter account are no longer active.

Twitter has been used to examine a range of health behaviors, including e-cigarettes and tobacco use (Aphinyanaphongs, Lulejian,

Brown, Bonneau, & Krebs, 2016; Jo, Kornfield, Kim, Emery, & Ribisl, 2015; Myslín, Zhu, Chapman, & Conway, 2013; Sofean & Smith, 2013; Step, Bracken, Trapl, & Flocke, 2016); drug use and abuse (Cavazos-Rehg, Krauss, Gruzca, & Bierut, 2014; Daniulaityte et al., 2015; Hanson et al., 2013; Katsuki, Mackey, & Cuomo, 2015); suicide (O’Dea et al., 2015); and HPV vaccination (Zhou et al., 2015). It has also been used to study a range of physical health outcomes (Aslam et al., 2014; Bosley et al., 2013; Broniatowski, Paul, & Dredze, 2013; Chew & Eysenbach, 2010; Chorianopoulos & Talvis, 2015; Collier, Son, & Nguyen, 2011; Fung et al., 2013; Gesualdo et al., 2013; Heavilin, Gerbert, Page, & Gibbs, 2011; Jain & Kumar, 2015; Nagel et al., 2013; Signorini, Segre, & Polgreen, 2011; Velardi, Stilo, Tozzi, & Gesualdo, 2014).

It was rare in these studies to compare Twitter data to other sources of surveillance data so the validity of inferences based on Twitter data was not clear. However, three studies found the characteristics or number of tweets on a specific subject were associated with at least one validated measure of the subject (Ireland, Schwartz, Chen, Ungar, & Albarracin, 2015; Jashinsky et al., 2014; Widener & Li, 2014).

3.3.2. Facebook

Facebook is an online social networking site where users create a profile, add other users to their network, send messages to their network connections, and post messages to their profiles. Users may also join common-interest groups and communicate with businesses. Similar to Twitter, Facebook may be used for active or passive data collection. It has frequently been used to recruit participants (Altshuler et al., 2015; Barratt et al., 2015; Bauermeister et al., 2012; Ben-Ezra et al., 2013; Hernandez-Romieu et al., 2014; Schumacher et al., 2014; Stein et al., 2014; Thomas et al., 2014; van Genderen et al., 2013), but the information created by users has also been used for research.

Facebook users have the option of listing interests, such as movies, books, sports teams, or activities, on their profile. In one study, obesity prevalence in communities was predicted using Facebook interests (Chunara, Bouton, Ayers, & Brownstein, 2013). Geographical areas where a higher proportion of users endorsed activity-related interests, such as health and wellness or outdoor fitness activities, and a lower proportion of users endorsed interests in sedentary behaviors, particularly television watching, tended to have lower rates of obesity. Facebook “likes”, users’ expressions of interest or approval of posts, may also be used to predict health behaviors. The proportion of users by zip code who “like” certain categories of information is available through the advertising program interface. These data were significantly associated with life expectancy and many health conditions reported in the Behavioral Risk Factor Surveillance System (Gittelman et al., 2015).

The content of Facebook groups may also be used to assess individual health behavior. Posts, comments, and photos in Facebook profiles and groups have been used to assess social support seeking among caregivers of children with autism spectrum disorder (Mohd Roffeei, Abdullah, & Basar, 2015), depressive symptoms (Moreno et al., 2011), alcohol use (Ridout, Campbell, & Ellis, 2012) and. One study of nine public anti-fluoridation groups examined the connectedness between these groups and the extent to which individuals in these groups shared or endorsed posts (Seymour, Getman, Saraf, Zhang, & Kalenderian, 2015).

3.3.3. Combined approaches

Some research suggests combining multiple approaches may reduce the limitations associated with each of the single approaches. For example, media reports of outbreaks or unusual events may drive increases in social media activity as awareness increases in the population so studies may combine the two approaches to evaluate the potential effects of traditional media (Chunara, Andrews, & Brownstein, 2012). One evaluation found that models predicting influenza rates from internet-based surveillance were most accurate when they accounted for newspaper and television reports (de Lange et al., 2013). Another evaluation found the number of social media messages was more strongly correlated with the number of online news articles than the number of reported measles cases, which supports social media as a measure of public opinion, rather than disease detection (Mollema et al., 2015). The limitations associated with social media and internet-based approaches were also demonstrated during the Ebola outbreak in the US. Social media posts and internet searches increased due to the public panic surrounding the outbreak, rather than due to a high incidence of the disease (Towers et al., 2015).

Despite these limitations, social media may provide important context not available in traditional forms of surveillance and combined approaches may reduce some of the limitations associated with each approach (Powell et al., 2016). Models including Twitter data, Google search trends, and environmental sensors were able to accurately predict, in nearly real-time, asthma-related emergency department visits in the US with 70% accuracy (Ram, Zhang, Williams, & Pengetnze, 2015). Another study found models based on Twitter data, Google search trends, and a crowdsourced survey were able to create robust weekly influenza predictions (Santillana et al., 2015). A third study found the combination of Twitter and internet search data was able to estimate the influenza rate with a correlation of 0.72 to officially reported influenza diagnoses (Santos & Matos, 2014).

3.4. Approaches used for child maltreatment

There has been limited application of social media and internet-based approaches to child maltreatment surveillance (Table 2). The most common use found in the literature was recruiting participants or engaging existing participants through a variety of online methods. One study recruited participants through listservs, websites, groups, organizations, and clubs targeting lesbian, gay, and bisexual populations to retrospectively assess their exposure to child maltreatment (Balsam, Lehavot, Beadnell, & Circo, 2010). Another study tracked existing participants in a study of child maltreatment through social media (Nwadiuki, Isbell, Zoloto, & Kotch, 2011). Other studies have recruited adults to report their experiences or their children’s experience of childhood abuse (Brian, Schier, Schulz, Dragan, & Hardt, 2014; Caldas & Bensey, 2014; Parkinson & Bromfield, 2013; Schaefer, Mundt, Ahlers, & Bahls, 2012). A final

Table 2
Summary of Social Media and Internet-based Approaches for Child Maltreatment Surveillance or Epidemiological Research.

Author	Year	Population	Research Purpose	Recruitment Method/Study Design
Online recruitment				
Balsam, Lehavot, Beadnell, Circo	2010	LGB Adults	Examine relationships between child abuse and adult mental health	<ul style="list-style-type: none"> ● Online questionnaire ● Invitations sent to LGB listservs, websites, groups, organizations, and clubs in all states, specifically targeted LGB people of color ● Participants asked to forward to other eligible individuals/groups
Parkinson, Bromfield	2013	Young Adults	Determine if Facebook is viable for recruiting for studies on child maltreatment	<ul style="list-style-type: none"> ● Online questionnaire ● Invitation via Facebook
Schaefer, Mundt, Ahlers, Bahls	2012	Not restricted	Examine psychosocial impairment associated with sexual abuse	<ul style="list-style-type: none"> ● Online questionnaire ● Invitation on initiators' website, Twitter, references from political activists, contact through victim support groups
Brian, Schier, Schulz, Dragan, Hardt	2012	Not restricted	Estimate the prevalence of childhood abuse and neglect in Germany and Poland	<ul style="list-style-type: none"> ● Online questionnaire ● Recruited through an online market research firm
Caldas, Betsy	2014	Child with disability or caregiver of child with disability	Determine risk factors and consequences of sexual maltreatment of children with disabilities	<ul style="list-style-type: none"> ● Online questionnaire ● Invitations sent via weekly email for nine months to groups or individuals who had "publicized interest" in child sexual maltreatment or children with disabilities
Maier, Mohler-Kuo, Landholt, Schnyder, Jud	2013	Child sexual abuse agencies in Switzerland	Estimate the prevalence of child sexual abuse reported to agencies	<ul style="list-style-type: none"> ● Initial contacts asked to forward to other groups/individuals ● Ongoing reports of child sexual abuse for six months ● Online access to secure server for reporting number of cases ● Based on publicly available data, agencies related to child sexual abuse were identified and selected using a stratified random sample framework
Nwadiako, Isbell, Zolotor, Hussey, Korch	2010	Existing cohort study participants	Evaluate Facebook and Myspace as supplementary methods of subject follow-up	<ul style="list-style-type: none"> ● Follow-up to existing cohort study ● Facebook and Myspace search for participants by name and location; profile created with study or PI name; message sent to subject asking for verification
Electronic News Media				
Lonne, Gillespie	2014	Media reports of child abuse	Compare media reports of child maltreatment to official reports	<ul style="list-style-type: none"> ● Analysis of content of media reports ● Electronic search of 10 newspapers with the largest readership in Australia using search terms: child*, AND abuse*, neglect, protection, safety, OR pedophile* OR aedophil* OR parent neglect, OR harm, OR maltreatment
Walklate, Petrie	2013	Media reports of filicide-suicide	Explore the nature of reporting on filicide-suicide in Britain and Ireland	<ul style="list-style-type: none"> ● Analysis of online newspaper reports ● Lexis Nexis search using search terms: murder-suicide, family tragedy, or family death
Nambu, Nasu, Nishimura, Nishimura, Fujiwara	2011	Media reports of fatal child abuse cases	Determine if fatal child abuse perpetrators are more harshly punished than other homicide perpetrators	<ul style="list-style-type: none"> ● Analysis of reports from three major newspaper articles ● Search of newspaper databases using search terms: abuse, fatal, prosecutor-suggested sentences, court sentence
Caregiver Blogs				
Brown, Gonzalez, Wiester, Kelley, Feldman	2014	Perpetrators of medical abuse	Evaluate caregiver blogs as a source of information about caregiver-fabricated illness	<ul style="list-style-type: none"> ● Case study comparison of information presented on caregiver blog about illness to information provided by medical providers ● Interest search for blogs of potential cases of caregiver-fabricated illness
Social Networks				
Noll, Shenk, Barnes, Haralson	2013	Adolescent females	Determine differences in online sexual behaviors between adolescent females with and without maltreatment	<ul style="list-style-type: none"> ● Maltreatment youth recruited through child protective services, control youth recruited through flyers at local hospital ● Online questionnaires and review of social network profiles ● Content coding of publicly available profile pages

study surveyed professionals at child protection agencies to establish the rates of reported sexual maltreatment (Maier, Mohler-Kuo, Landolt, Schnyder, & Jud, 2013).

Media reports have also been used to research aspects of child maltreatment, but similar to other health topics, there may be some bias in media reports. Researchers have found that media reports tend to disproportionately focus on physical and sexual abuse with limited reporting on emotional abuse and neglect (Lonne & Gillespie, 2014) and often present a simplified version of the events (Walklate & Petrie, 2013). Another study used media reports to examine perpetrator, victim, and context variations in sentences for fatal child abuse (Nambu, Nasu, Nishimura, Nishimura, & Fujiwara, 2011).

There have been two other novel examples of social media and internet-based assessment of child maltreatment characteristics. One novel assessment of child maltreatment was an evaluation of caregiver blogs in caregiver-fabricated child illness (Brown, Gonzalez, Wiester, Kelley, & Feldman, 2014). Researchers found that blogs created by these caregivers tended to distort and exaggerate the medical information shared by the doctors. There were also visually graphic images of the children and frequent discussions of fundraising and charity. Although the study was limited in size, the findings suggested physicians and child protective service providers may be able to evaluate caregiver blogs for these patterns. Another study examined the profiles of youth with and without substantiated maltreatment reports to determine if there were differences in risky online behaviors and found maltreated youth tended to engage in more provocative self-presentation (Noll, Shenk, Barnes, & Haralson, 2013).

In sum, online recruitment or follow-up of participants was the most common technology-based approach to child maltreatment research. Six recent studies have used online methods to recruit participants to self-report past childhood maltreatment experiences or the more recent experiences of their children or of children with whom they have had professional contact. Child maltreatment-related internet media reports have also been examined, but there were clear biases in reporting that suggest the use of media for surveillance would be problematic. Two innovative studies about child maltreatment using social media addressed very narrow questions about the risk behaviors of a subset of children who have been maltreated and about detecting risk for child maltreatment by examining the social media of caregivers of seriously ill children. At the time of writing, there was very little peer-reviewed published work related to social media and other internet-based approaches in the study of child maltreatment.

4. Implications for child maltreatment research

From the broad technology and health literature, social media and internet-based approaches to surveillance and epidemiologic research appear promising. Several strengths were identified in the reviewed literature. First, many of the approaches are relatively low cost and easy to implement without extensive infrastructure. This is particularly true for well-established social media environments, such as Twitter, where there are existing tools for accessing and analyzing data. Second, social media may present an opportunity to reach communities or populations that would be otherwise difficult to reach through traditional approaches. Many researchers promote this claim in their work, and a small number of researchers across disciplines have conducted parallel studies using traditionally-created and online samples to compare the findings (Rindfuss, Choe, Tsuya, Bumpass, & Tamaki, 2015; Simon Rosser, Oakes, Bockting, & Miner, 2007; Temple & Brown, 2011). Although all authors agree there are some differences in the findings depending on the recruitment methods, there is disagreement about which approach best represents the underlying population. Finally, many of the technology-based approaches allow for continuous data collection in real-time or nearly real-time, which may facilitate the identification of trends or evaluation of national or community interventions.

A range of limitations for each method were also identified in the literature. Across methods, there was a mixed record of validation and sources of error in estimation were not yet understood or predictable. Studies of internet search query trends suggested that methods operated well for a time but often failed extended tests of validation. Crowdsourcing methods, which may be another source of continuous data, appeared to suffer from substantial attrition of users over time. Media reporting seemed to incur observer effects that may have created short term issues with estimates. Media reports also caused issues for other types of online surveillance because increased public awareness may contribute to inflated estimates. Other concerns included changes over time in the technology or the way the technology is used. Although not explicitly raised in the literature captured in this review, misrepresentation on social media or other internet-based methods may also result in issues with the data (Whitehead, 2007).

Overall, validation of social media and internet-based methods is a challenge across all methods. To some extent, these issues may be of little concern if social media methods are combined and correlated with other established methods. That is, so long as these new methods are part of a triangulation approach, rather than replacing existing approaches, they may have much to offer.

The use of social media methods for child maltreatment surveillance and research is promising, but there has been limited implementation, relative to other health outcomes. Based on the methods, strengths, and limitations identified in the reviewed literature, we propose several considerations for future research focused on child maltreatment. First, the strengths of social media and internet-based technologies may be leveraged to improve child maltreatment surveillance. The capacity to introduce these techniques anonymously into a range of social and professional environments (schools, community agencies, etc.) makes them potentially ideal for studying populations that are difficult to reach through traditional methods. Further, the ability to have access to these populations on a continuous basis creates the opportunity for long term monitoring, which may facilitate the identification of trends or evaluation of national or community interventions.

Validation of the epidemiological use of child maltreatment data collected via social media or other internet-related technologies poses challenges. In addition to the problems relevant to the application of these approaches to other health outcomes, child maltreatment researchers face additional challenges. Unlike many other health issues addressed in this review, complete data about child maltreatment are rarely available. For example, influenza researchers in the United States can validate their technology-based research through FluView, a weekly influenza surveillance report prepared by the Centers for Disease Control and Prevention (2017).

FluView provides weekly information on influenza virus type reported by public health laboratories, mortality information, proportion of outpatient visits for influenza-like illness, and information about the geographic spread of influenza ([Centers for Disease Control & Prevention, 2017](#)). This detailed, timely information allows for reliable assessment of the underlying influenza trends and gold standard data for validity assessment. In contrast, it is well known that child maltreatment reported to authorities is not indicative of the true prevalence and other sources of data using traditional methods are rarely repeated with sufficient frequency. Further, the use of official statistics based on reported maltreatment and other existing maltreatment data to evaluate the accuracy of estimates drawn from social media is not straightforward. On the other hand, the ability to create consistently available, timely information about incidence may be the key promise of social media and internet-based methodologies, assuming issues of validity can be addressed.

Another critical consideration is the ethical issues of child maltreatment research, which are further complicated by the ethical challenges associated with social media and internet-based research. The Association of Internet Researchers suggests researchers engaging in internet-based research consider several ethical questions before beginning a study ([Buchanan, 2004](#)).

- How are the researchers accessing the participant/data and what expectations are established by the method (e.g., social media site, blog, forum)?
- Who is creating the data and what vulnerabilities may exist that create an obligation for the researcher to protect the data?
- Should the researcher obtain informed consent and how should it be collected?
- How will the data be used and could these uses create new or additional risks for participants?

In addition to these basic guidelines, a recent update to the recommendations from the Association of Internet Researchers suggests researchers consider several additional questions ([Markham & Buchanan, 2012](#)).

- What is the primary purpose of the study?
- How are data managed, stored, and analyzed during the study?
- How are findings presented?
- Who might be harmed or benefit from this study?

In reviewing and considering these questions, the Association of Internet Researchers suggest researchers broadly consider several ethical considerations that are important in all research but may be particularly challenging in technology-based studies ([Markham & Buchanan, 2012](#)). The first challenge surrounds the definition of human subjects. Regulatory bodies have often used interaction with human subjects as an indicator of need for institutional ethical review ([Markham & Buchanan, 2012](#)). Since many technology-based studies, particularly passive data collection studies, do not directly engage with human subjects, these studies have been carried out without ethical review. It may be prudent, however, to engage with the institutional review board, an ethical regulatory body, or an external advisory committee to critically process the potential harms, vulnerabilities, benefits, and so forth, even if the research does not directly engage with human subjects and thus, does not explicitly require intuitional ethics review. In addition, it may be necessary to reevaluate what constitutes engaging with a human subject ([Markham & Buchanan, 2012](#)). Direct connection with individual-level data has historically been considered engagement with a human subject, while studies with aggregated or de-identified data were not. However, recent research suggests deidentified datasets often contain sufficient personal information to potentially identify individuals ([Markham & Buchanan, 2012](#)). As a result, it may be necessary to develop an ethical review process, with or without institutional oversight, for research that involves person-based data without direct human contact. These ethical review processes should focus on reducing potential harms and vulnerabilities while balancing the benefits of the research.

The second challenge relates to definitions of public and private space ([Markham & Buchanan, 2012](#)). These expectations are often ambiguous and frequently change. As such, it is important to critically examine the potential harms and vulnerabilities associated with the context and data used in each study. Researchers must carefully consider the expectations of the individuals who are creating the data. In active data collection methods, the researcher has contact with the participants and may follow the standard informed consent process so individuals expect their data are being used for research. However, in passive data collection methods, the individual may have no knowledge that their data are being used for research. The researcher must consider if the individuals likely considered their data to be public or private. The creator of a public blog or social media profile which is viewable by anyone may have a lower expectation of privacy than in a private forum that requires log-in by members. Researchers must also consider the level of risk to participants and the potential benefits of the research to participants and other individuals. As child maltreatment is a particularly sensitive topic, it is likely that many participants would be embarrassed, hurt, or angry if their expectation of privacy did not match with that of the researcher. In addition, if the researcher has access to identifiable information and learns of child maltreatment, there may be an institutional requirement to report to child protection authorities, which has the potential to impact data collection. The researcher should also consider the expectations around research within the participants' culture. Although it is now relatively simple to conduct online research in communities across the world, it is necessary to understand the cultural norms around research and privacy within the participants' culture, as they may be different from those of the researcher. In some instances, communities have come together to define how non-community members should engage with them around research. In Canada, a First Nations Steering Committee representing diverse communities participating in a longitudinal health survey developed the OCAP principles (Ownership, Control, Access, Possession). OCAP is "a set of standards that establish how First Nations data should be collected, protected, used, or shared" ([First Nations Information Governance Centre, 2017](#)). Even when this type of guidance is available, it may be challenging for researchers from outside the community to fully understand the cultural expectations. When this

type of explicit guidance is not available, it may be even more challenging for researchers to understand cultural norms so careful attention must be given to understanding and following community expectations.

The final ethical challenge relates to how the field will choose to make ethical decisions around social media and internet-based technology research (Markham & Buchanan, 2012). In some aspects of research, there are tensions between regulation-driven and context-specific ethical decision making. Regulations are often intended to encourage ethical research and practice, but when applied universally without consideration, regulations may inadvertently restrict important, necessary research. In child maltreatment research, ethics regulations are rarely based on empirically derived information regarding the degree to which ethical concerns emerge (International Society for the Prevention of Child Abuse & Neglect, 2015). As technology-based research moves forward, it will be important to establish firm ethical boundaries for some clearly defined issues, while encouraging flexibility and situation-based ethical decision-making for ethically grey areas.

Despite these ethical challenges, the complexity of research in child maltreatment necessitates the development and validation of novel data collection approaches. Although social media and internet-based data collection should not, due to the current limitations, replace other traditional forms of data collection, it is possible that these methods may complement existing methodologies to address the current limitations for the field. For example, analysis of child maltreatment-related internet search queries that account for media recognition may be a novel way to collect in-the-moment trends that could be used to inform tailoring and targeting of just-in-time interventions. However, these approaches should be carefully validated prior to wide scale implementation and continuously monitored for reliability and validity. Although it would be difficult to validate these approaches for child maltreatment on a large-scale due to existing data limitations, it may be possible to begin to validate in specific subpopulations. Official child protection data from a school or other geographically confined area could be paired with self-reported surveys and analysis of youth Facebook or Twitter postings during a specific time. Using this approach would reduce the limitations associated with each type of collection and could create a better source of validation data. Replicating this type of validation in other subpopulations could provide the research support for an eventual wide scale implementation based on small-area data compilation.

4.1. Limitations

This review had several limitations. First, the review excluded articles that were not published in English so important work conducted in other languages would not be included in this review. This limitation is common among reviews conducted by researchers from majority native English-speaking countries; yet, future reviews may benefit from including other languages. Second, it was possible to define social media, internet-based technology, and surveillance in various ways. Differing definitions may have resulted in a different literature base to review. Finally, the search framework resulted in the inclusion of a variety of research designs, health outcomes, and technology approaches. This variety prevented quantitative comparisons across studies. However, as previously noted, that type of analysis is outside the scoping review framework, which focused on the extent, range, and nature of research with respect to a focused topic, as well as the identification of gaps in the literature. As also noted, scoping reviews are ideal for topics with emerging evidence, such as social media.

5. Conclusions

Social media and internet-based technologies may be a promising approach to address the existing issues with child maltreatment data collection. However, it is necessary to account for the issues within each type of data collection approach and carefully validate the approach. In addition, researchers should thoughtfully consider the ethical issues associated with both child maltreatment research and internet-based research and take steps to protect participants before conducting future studies.

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