Systematic scoping review on social media monitoring methods and interventions relating to vaccine hesitancy
This report was commissioned by the European Centre for Disease Prevention and Control (ECDC) and coordinated by Kate Olsson with the support of Judit Takács.

The scoping review was performed by researchers from the Vaccine Confidence Project, at the London School of Hygiene & Tropical Medicine (contract number ECD8894). Authors: Emilie Karafillakis, Clarissa Simas, Sam Martin, Sara Dada, Heidi Larson.

Acknowledgements
ECDC would like to acknowledge contributions to the project from the expert reviewers: Dan Arthus, University College London; Maged N Kamel Boulos, University of the Highlands and Islands, Sandra Alexiu, GP Association Bucharest and Franklin Apfel and Sabrina Cecconi, World Health Communication Associates.

ECDC would also like to acknowledge ECDC colleagues who reviewed and contributed to the document: John Kinsman, Andrea Würz and Marybelle Stryk.


Stockholm, February 2020

ISBN 978-92-9498-452-4
doi: 10.2900/260624
Catalogue number TQ-04-20-076-EN-N

© European Centre for Disease Prevention and Control, 2020
Reproduction is authorised, provided the source is acknowledged
Contents

Abbreviations .......................................................................................................................... iv
Glossary .................................................................................................................................... iv
Executive summary .................................................................................................................. 1
Introduction and background ................................................................................................. 1
  Aims ...................................................................................................................................... 1
  Methods ............................................................................................................................... 1
  Results .................................................................................................................................. 1
  Discussion ............................................................................................................................ 2
1 Introduction ......................................................................................................................... 4
2 Background ........................................................................................................................ 5
3 Goals and objectives .......................................................................................................... 7
4. Review methods ................................................................................................................. 8
  4.1. Search strategy and database search .............................................................................. 8
  4.2. Screening and selection of articles ............................................................................... 8
  4.3. Data extraction and analysis ....................................................................................... 9
5. Review results ................................................................................................................... 10
  5.1. Individuals’ preferences for using social media platforms as a source of information on vaccination and social media’s influence on individuals’ perceptions of vaccination ................................................................. 11
  5.2. Social media monitoring .............................................................................................. 12
  5.3. Using social media monitoring to inform vaccination communication strategies .............................................................................................................................................. 29
  5.4. Uses, benefits and limitations of social media as an intervention tool in relation to vaccination .................................................................................................................................................. 33
6. Discussion ......................................................................................................................... 36
  6.1. Use of social media for vaccination information .............................................................. 36
  6.2. Methodologies to monitor social media in relation to vaccination .................................... 36
  6.3. Review how social media monitoring methods and information gathered from monitoring can be used to inform communication strategies ........................................................................................................... 41
  6.4. Understanding the uses, benefits and limitations of using social media as an intervention around vaccination ................................................................................................................................. 42
  6.5. Limitations of this systematic scoping literature review ................................................... 43
7. Conclusions and the way forward ..................................................................................... 44
References .................................................................................................................................. 45
Annexes ...................................................................................................................................... 52

Figures

Figure 1. Prisma flow diagram .............................................................................................. 10
Figure 2. Social media monitoring phases ............................................................................ 12
Figure 3. Number of articles published by type of social media and by year until 2018 .......... 15
Figure 4. Number of articles published by type of vaccine ..................................................... 15
Figure 5. Number of articles published by country monitored ................................................ 16
Figure 6. Number of studies by type of social media monitoring tools used ............................ 17
Figure 7. Keywords most commonly used across all studies (>4 use) .................................... 21
Figure 8. Sentiment codes used across all studies .................................................................. 25
Figure 9. Number of studies using manual or automated sentiment coding, by social media .................................................. 27

Tables

Table 1. Inclusion and exclusion criteria for screening of articles .......................................... 8
Table 2. Data extraction categories ....................................................................................... 9
Table 3. Description of social media platforms identified in the scoping review .................... 14
Table 4. Different manual browser searches and limitations mentioned by the studies using the tool ................................................................................................................................. 18
Table 5. Social media APIs and their limitations mentioned by the studies using the tool ........ 19
Table 6. List of codes, definitions and counts for sentiment analysis used in the identified studies ................................................................................................................................. 26
Table 7. Suggestions for increasing presence on social media identified in scoping review studies .................................................................................................................................................. 31
Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>AI</td>
<td>Artificial Intelligence</td>
</tr>
<tr>
<td>API</td>
<td>Application Programming Interface</td>
</tr>
<tr>
<td>CDC</td>
<td>United States Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>ECDC</td>
<td>European Centre for Disease Prevention and Control</td>
</tr>
<tr>
<td>HTML</td>
<td>Hyper Text Markup Language</td>
</tr>
<tr>
<td>HPV</td>
<td>Human Papillomavirus</td>
</tr>
<tr>
<td>GDPR</td>
<td>General Data Protection Regulation</td>
</tr>
<tr>
<td>GPS</td>
<td>Global Positioning System</td>
</tr>
<tr>
<td>LDA</td>
<td>Latent Dirichlet Allocation</td>
</tr>
<tr>
<td>MMR</td>
<td>Measles Mumps Rubella</td>
</tr>
<tr>
<td>PHP</td>
<td>Hypertext Preprocessor</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>URL</td>
<td>Uniform Resource Locator</td>
</tr>
<tr>
<td>US</td>
<td>United States</td>
</tr>
<tr>
<td>VCP</td>
<td>Vaccine Confidence Project™</td>
</tr>
</tbody>
</table>

Glossary

- **Application Programming Interface**: Software allowing two applications to talk to each other (e.g. smartphone software sending text/images to the Twitter database/platform).
- **Global Positioning System**: A system of satellites, computers, and receivers able to determine the geographical location of an object on Earth.
- **Latent Dirichlet Allocation**: A generative statistical model (in natural language processing) used for topic extraction, representation and analysis from large datasets.
- **Hypertext Preprocessor**: Refers to how dynamic web pages (php) are created and accessed with precompiled and pre-processed code linking to databases, so that accessing them is faster and easier via different browsers.
- **Uniform Resource Locator**: A uniform resource locator is the address of a resource on the Internet.
- **Sentiment analysis**: A process that uses natural language processing, text analysis and computational linguistics to identify positive, negative and neutral opinions from text and social media.
- **Reach analysis**: Defined in social media as the number of people that see content - the greater the reach, the higher number of people that have seen content.
- **Vanity metrics**: In social media vanity metrics are measured by engagement (comments, shares, likes, clicks, and saves), providing information on how many people are interacting with content on social media platforms.
Executive summary

Introduction and background

We are living in an interconnected world, where social media have become part of the everyday life of many individuals around the globe. People use social media to stay connected to friends and family, to share personal information, views or beliefs, or to seek information and gather other peoples’ advice about certain topics, including health. These new communication technologies have also facilitated the recent spread of unsubstantiated negative information about vaccination online, influencing individuals’ views about vaccination, their levels of confidence in different vaccines and their willingness to be vaccinated or to vaccinate their children. The online spread of rumours surrounding vaccination, including adverse events following vaccination, has contributed to the growth of vaccine hesitancy and in some cases may have contributed to disease outbreaks in unvaccinated populations. However, social media also constitute an opportunity to spread positive messages about the benefits of vaccination and to restore trust in vaccination. Listening, monitoring and analysing social media conversations concerning vaccination could help us to understand low vaccination acceptance and provide valuable information to counteract the spread of rumours and misinformation.

In this report, social media have been defined as not just a means of communication, but also a space in which people socialise. Social media are therefore seen as online environments or platforms that see ‘interaction’ as a main purpose. This study focusses on social networking sites and content communities, which can be seen as more relevant in the context of vaccination.

Aims

The aim of this research project is to map, analyse and summarise knowledge and research on social media and vaccination. The key objectives were to identify preferences for using different social media platforms as a source of information on vaccination and the influence that social media have on individuals’ perceptions of vaccination; to identify different social media monitoring methods or tools in the context of vaccination and their strengths and weaknesses; to review how social media monitoring methods and information gathered from monitoring can be used to inform communication strategies, and to identify the uses, benefits and limitations of social media as an intervention tool around vaccination (i.e. to determine how effective social media are as a tool for increasing vaccination uptake).

Methods

In order to address these objectives, a systematic scoping review was commissioned by ECDC and conducted by researchers at the Vaccine Confidence ProjectTM[1]. A comprehensive search strategy was developed, reviewed by librarians, and adapted to different databases to identify peer-reviewed and grey literature published since 2000. Two reviewers independently screened all articles by title and abstract and then by full text, based on a set of inclusion and exclusion criteria. All disagreements were resolved by discussion. The articles included were divided into three groups: a) preferences for using different social media platforms as a source of information on vaccination and the influence that social media have on individuals’ perceptions of vaccination, b) social media monitoring and c) social media interventions. Data extraction was performed by four reviewers and followed by a descriptive analysis and synthesis.

Results

The systematic scoping review identified 115 articles: 13 on individuals’ preferences for using social media as a source for vaccination information and any influence on perceptions of vaccination; 85 on social media monitoring, 15 on social media interventions, one on both social media monitoring and social media interventions, and one on both social media interventions and individuals’ preferences for using social media as a source for vaccination information and any influence on perceptions of vaccination.

Preferences for using different social media platforms as a source of information on vaccination and the influence that social media have on individuals’ perceptions of vaccination

The 14 studies included in this category found that social media platforms were commonly used as a source of information for vaccination but that most of the time consulting social media had a negative influence on vaccine uptake. Population groups in different countries were found to use social media in a variety of ways, with some groups experiencing more positive influences from social media.
Social media monitoring

The majority of the articles on social media monitoring were published between 2015 and 2018, and are based on Twitter, YouTube, and Facebook. Most of the studies were based on social media monitoring in relation to vaccination generally, while some studies monitored particular vaccinations, including human papillomavirus (HPV) and measles, mumps, rubella (MMR) vaccination. The majority of studies involved conducting a manual search to identify social media posts on vaccination, using the search tools available within the social media networks. The second most commonly used method for identifying posts was the Application Programming Interfaces (APIs – software allowing two applications to talk to each other), followed by automatic monitoring systems using commercial software. Most of the keywords used to search for social media posts related to vaccination or vaccine-preventable diseases, with some studies also including negative keywords, for example side effects. While many studies only used a small number of keywords, other studies also used hashtags or longer sentences or questions.

Only a very small number of studies analysed the locations of posts, meaning that most of the studies were not limited to one country only. In most cases, geo-localisation was performed manually, for instance by screening user profiles, since Global Positioning System (GPS) information is not often available. Furthermore, most of the studies looked at social media on a continuous basis, extracting data over a period of 1–3 hours and for up to 16 years. Studies that were conducted at one specific point in time were mostly studies where a manual search had been carried out for the data.

Sentiment analysis1 was performed in almost all studies included in this review, with most of them conducting manual coding of data into either positive vs. negative or pro-vaccination vs anti-vaccination sentiments. Those that used automated systems to code sentiments mostly analysed Twitter using different tools to establish sentiments. Some studies also included other types of content analysis, such as qualitative thematic analyses. Finally, around half of the studies also analysed reach to understand how social media information is shared. The studies visualised data in different ways.

Some studies provided recommendations for health authorities and health professionals on how to use social media monitoring, in particular to start communicating on social media platforms and to use social media monitoring findings to inform the development of intervention and communication strategies.

Social media interventions

Three types of interventions were identified: social media as a source of information about vaccination; online group discussions and interactive websites. Most of these interventions were developed and implemented by researchers in Canada, Germany, the Netherlands, Taiwan and the United States. Three studies evaluated existing interventions. The effects of the interventions varied and no strong impact was identified overall. This may be due to the methodological challenge of linking the specific effects and influence of social media to actual behaviour. Studies measured the effect of social media interventions on knowledge and attitudes concerning vaccination, risk perception and concerns, intentions of being vaccinated and vaccine uptake.

Discussion

While social media usage has been associated with a negative impact on public views and behaviour concerning vaccination, it also presents many opportunities. More evidence is needed on which interventions using social media to address vaccine hesitancy are effective in different contexts. Furthermore, while many studies have been conducted on social media monitoring around vaccination, they have used different methodologies (e.g. use of manual tools to retrieve data compared to APIs or automated software; manual versus automated sentiment analyses) to obtain and analyse data, and these have not been evaluated. There is a need to evaluate different methodological approaches to better understand what works best and to eventually provide standardised research approaches to monitor and analyse social media. Furthermore, while the general data protection regulation (GDPR) may limit social media monitoring to publicly available data, this also highlights the need for more control over what happens with data collected online. It would be helpful if a code of conduct for ethical use of social media information could be developed to ensure that those reporting on social media monitoring results adhere to fair and responsible values.

Social media monitoring is highly dependent on what platforms have to offer in terms of APIs, geo-location data, and sentiment analysis. To reduce the number of manual searches and analyses, and thereby improve the quality of social media monitoring, easier ways of accessing data should be developed, whether through APIs or through computational software. Health authorities and researchers should also reflect on the consequences for research of the constant fluidity of online information, particularly since several platforms have decided to remove anti-vaccination content.

---

1 The process of computationally identifying and categorising opinions expressed in a piece of text, especially in order to determine whether the writer’s attitude towards a particular topic, product, etc. is positive, negative, or neutral (Lexico Dictionary, Oxford University Press)
Finally, the purpose and value of social media monitoring should be clearly defined. While some health authorities and researchers may try to use social media as a proxy for what the public thinks about vaccination, the reality is often much more complex. It is unclear whether social media users are representative of the general public. Social media monitoring should therefore be seen as a way of capturing the essence and the movement of online discourse around vaccination in order to better understand how it can influence public perceptions and decision-making around vaccination. Such evidence could then inform the development of targeted interventions to restore public confidence in vaccination.
1 Introduction

Vaccine hesitancy is increasingly being recognised as a growing problem globally. In 2019, the World Health Organization (WHO) acknowledged that it constitutes one of the ten biggest threats to global health [2]. Confidence in vaccination is complex and influenced by an array of individual, social, and structural factors; it can also vary depending on the vaccines and the diseases they prevent. While highly context-dependent on the one hand, there are growing global networks promoting vaccine hesitancy, connecting across countries and languages—aided by online translation tools and social media [3]. Vaccine refusers are a loud minority and such clustering can interfere with the immunisation uptake required for herd protection, risking an increase in the burden of disease [4]. Recent measles outbreaks across Europe [5-8] demonstrate the consequences of non-vaccination and confirm recent findings that Europe is the region in the world with the least confidence in the safety and effectiveness of vaccination [9].

Continuous advancements in communication technologies such as social media have contributed to the unmediated spread of concerns about safety and adverse events following vaccination. New communication technologies allow sentiments, rumours and beliefs about vaccination to quickly diffuse among networks across the world, influencing individuals and groups online as they assess risks and benefits of vaccination [10-12]. A number of studies have reviewed websites and social media for information on vaccination and found that it is of variable quality, with a predominance of negative or incorrect content that influences perceptions about the risks and benefits of vaccines [13-16].

However, social media have great potential to contribute positively to health communication by allowing direct interactions with individuals; enhanced availability, accessibility, and customisation of information; and individual and policy advocacy opportunities. The monitoring and measuring of content posted and shared on social media also provides an opportunity to listen to online discourses and develop targeted, audience-focused communications. There are some limitations to using social media for health communication, relating to quality, confidentiality, reliability, transparency, sponsorship and privacy concerns [17,18]. Engaging on social media can also be resource- and time-intensive for institutions, requiring radical changes in communication strategies to focus on direct engagement with the public and provide fast and targeted responses. Social media and new communication technologies are also rapidly evolving, and require constant adaptations to new platforms, tools and interactions between individuals. Due to these limitations, and the important shift in communication strategies that social media require, public health communities focussed on vaccination uptake and confidence have been slow and inconsistent to proactively engage with and invest in social media for monitoring opinion, communicating evidence-based information and/or countering misinformation. In the absence of a savvy, strong and sustained public health presence, pseudoscience, confusing information and public rumour have fuelled strong anti-vaccine sentiment and influenced vaccination decision-making through social media in countries across the world [19,20].

There are growing efforts in the field of public health and academia to better understand what is happening on social media and how they can be used to increase vaccine confidence and mitigate concerns. ECDC commissioned the Vaccine Confidence Project™ (VCP) [1] to conduct a scoping review on social media monitoring methods and interventions around vaccination. This research project stems from the necessity to synthesise all quality research produced to inform how social media monitoring methods and analysis can be used to understand and respond to public discourse about vaccination on social media and to understand the uses, benefits and limitations of using social media as an intervention tool around vaccination.
2 Background

Social media have been defined as ‘a group of internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of user generated content’ [21]. Web 2.0 refers to the new way in which software developers and end-users started using the World Wide Web, where content and applications are continuously modified by all users [21]. However, when defining social media, any given description is simply one of many and each discipline contributes its own perspective on the nature of social media. For this scoping review, we understand social media as not just a means of communication, but also a space where people socialise.

Prior to social media, conversations were either private or public, through broadcasting media. Social media now allow the dissemination of conversations and opinions within a vast network without mediation, which has contributed to the positioning of social media as a key tool to support people’s freedom of speech and expression around the world. However, this unbounded freedom to create and share content with users around the world also comes with major hazards, as it also facilitates the spread of unverified misinformation. This has been framed as the ‘postmodern Pandora’s box’ of the internet; whereby data circulate unbounded, shared and re-shared regardless of quality [22]. Virtual and in-person social interactions are deeply entwined and any definition that tries to separate both risks inconsistency [23].

As social media are not merely a tool but a social environment in which people operate, much is said about the various social platforms and how they account for different social spaces. However, social media should not be seen primarily as the platforms upon which people post, but as the content posted on these platforms. Social media users directly influence what social media are and what they will become – as seen in the recent decisions by certain social media platforms to censor content and change algorithms to promote or reject certain content. This also explains why social media will always be a continuously evolving environment. Recent research on social lives online shows that it is the people using social media who create what social media mean and represent rather than developers or social media platforms themselves. At the same time, research indicates the inability to understand any one social media platform in isolation. The different digital platforms must be seen as relative to each other, as people use the range of available possibilities to select specific platforms or media for particular genres of social interaction [23].

Social media and vaccination

This new boundless information ecosystem has shaped the nature of conversations about vaccination and related concerns. Dominant and singular narratives such as ‘vaccines are good’ are rejected, and instead vaccine-decisions are considered ‘vaccine by vaccine, disease by disease, case by case’ [22]. In this context, facts from authorities and experts are suspect and non-linear dialogue (dialogue that can flow in multiple ways rather than only chronologically), is the norm [24-26]. Largescale analyses have highlighted the importance of these social networks and trust relationships in influencing vaccine decisions [27]. As Leask et al. highlight, ‘a patient’s trust in the source of information may be more important than what is in the information’ [28]. Rather than consulting a single, authoritative source of information, it is more common for participants to want a variety of opinions [29].

At the same time that information is important for risk assessment and decision-making, sentiments about vaccination can strongly affect individual and group vaccination decisions [30]. New digital media, social media in particular, have allowed new levels of transmission of sentiments concerning vaccines [31], with negative vaccine sentiment posts being the most liked and engaged with [32]. The rise of internet-mediated communication has also had a significant impact on how fast rumours and unsubstantiated concerns can spread, feeding into the abovementioned negative vaccine sentiments travelling transnationally [30].

The amplification of risk and risk perception through social media, has led some countries and health authorities to start using social media to counter misinformation, mitigate anxiety and rebuild public trust [33]. Ireland and Denmark have recently managed to rebuild public trust in human papillomavirus (HPV) vaccination by adopting a strategy that had social media at its core to engage parents via YouTube and Facebook. Both countries took into consideration how information about HPV vaccination was consumed online by parents and developed their strategies accordingly [33,34]. Another central advantage of using social media within the scope of public health policy is the possibility to listen, in real time, to the concerns of populations and pick up signals at a very early stage. At the same time, vaccination discourses on social media need to be understood within a digital ecosystem, as users tend to be influenced by and use a range of social media platforms to express their feelings and beliefs. This digital ecosystem relates to a virtual environment where a community of interacting platforms is continuously growing and evolving which speaks to the importance of conducting social media monitoring and the valuable insights it can bring.

As there are many ways of defining social media, for this scoping review we attempt to understand them within the environment of public health policy and the impacts that they can have within this field. With regard to vaccination, we understand that it is pivotal to look at the social interaction processes that may be weighing into decision-
making and risk assessment. Kaplan et al. classify social media into blogs, collaborative projects (e.g. Wikipedia), social networking sites (e.g. Facebook), content communities (e.g. YouTube), virtual social worlds (e.g. Second Life), and virtual game worlds (e.g. World of Warcraft) [21].

Since we define social media in this report as online environments with a strong interaction component as their main purpose, we have made the methodological decision to focus on social networking sites and content communities. We have chosen to exclude online platforms that did not have social interactions as their main purpose, even though they had some scope for user interaction (e.g. blogs and websites with comments sections).
3 Goals and objectives

The aim of this scoping review was to systematically map, analyse and summarise knowledge and research on social media and vaccination and to identify examples of how information collected can inform communication and interventions to address vaccine hesitancy. We provide an overview of how social media monitoring and analysis of vaccination can support those working in public health agencies and immunisation programmes by looking at the type of social media data to collect, how social media data can be analysed and interpreted, and what types of intervention can be developed based on data collected to increase vaccine confidence and increase vaccination.

The specific objectives of the systematic scoping review were to:

- identify individuals' preferences for using different social media platforms as a source of information on vaccination and the influence that social media has on individuals' perceptions of vaccination;
- identify different social media monitoring methods and tools in the context of vaccination and their strengths and weaknesses;
- review how social media monitoring methods and information gathered from the monitoring can be used to inform communication strategies;
- identify the uses, benefits and limitations of social media as an intervention tool in relation to vaccination (i.e. how effective social media is as an intervention tool for increasing vaccination).
4. Review methods

Systematic scoping reviews are a relatively new method for mapping existing literature in a given field. Systematic scoping reviews have been used to ‘clarify working definitions and conceptual boundaries of a topic or field’ and have been particularly useful as an exploration tool for large, complex and heterogeneous topics usually not suitable for systematic literature reviews [35,36]. While systematic literature reviews are often focused on establishing the effectiveness of interventions, systematic scoping reviews take a broader approach and aim to map international literature or to identify how research has been conducted [35]. For these reasons, it was decided to conduct a systematic scoping review to address the aims of this study and to summarise methodologies that have been used to monitor social media in relation to vaccination. The methodology used to conduct this study, as described below, was based on the work provided by Arksey et.al. and further developed by the Joanna Briggs Institute [35-37].

4.1. Search strategy and database search

Librarians at ECDC developed the search strategy, balancing feasibility and comprehensiveness and including a mix of social media and vaccine keywords. The search strategy was developed for use in Embase, and adapted for use in PubMed, and Scopus by ECDC and in Medline, PsycINFO, PubPsych, Open Grey (grey literature), and Web of Science (grey literature) by the VCP and is available in Annex 8.1. Librarians at ECDC peer-reviewed the final search strategies for all databases.

One researcher from the VCP conducted the search in all databases in December 2018 and exported all articles into Endnote. Duplicates were then removed in accordance with guidelines provided by ECDC.

4.2. Screening and selection of articles

Two reviewers independently screened articles included in the Endnote file by title and abstract, according to a set of inclusion and exclusion criteria:

Table 1. Inclusion and exclusion criteria for screening of articles

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Study settings: no restrictions</td>
<td>• Not about vaccines, or not about human vaccines (i.e. vaccines for animals)</td>
</tr>
</tbody>
</table>
| • Research topics: articles were included if they studied the following topics: methods of social media monitoring around vaccination, use of social media monitoring to address vaccine hesitancy, use of social media interventions to address vaccine hesitancy (knowledge, hesitancy, confidence, awareness or coverage) | • Articles with studies focusing on:  
  − Other types of media (not social media) or online resources  
  − Articles that only use social media to recruit study participants |
| • Publication years: From 2000 (incl.), to include all studies conducted on social media monitoring | • Publication types:  
  − Conference abstracts, editorials, commentaries, letters to the editors |
| • Location: global | • Types of studies  
  − Efficacy trials, pre-clinical trial research  
  − Safety research  
  − Serologic investigations, immunogenicity studies  
  − Health economic studies |
| • Languages: The VCP extracted data from and analysed articles in English, Spanish, and Italian. | • Vaccines: Human vaccines |
| • Study design: quantitative and qualitative studies, observational and interventional studies | • In this review, social media included: social networking sites and content communities (e.g. Facebook, Twitter, LinkedIn, Instagram, Snapchat, YouTube, Vimeo, Reddit, Quora, online discussion forums, or Pinterest). |

After articles were selected through title and abstract screening, the two reviewers proceeded to full text screening to confirm the final list of included studies. All disagreements between the reviewers were resolved by discussion.

A summary of the search and selection process are provided with a PRISMA chart (see Figure 1).
4.3. Data extraction and analysis

During the full text article selection, articles were divided into three categories corresponding to the various objectives described above: articles describing individuals’ preferences for using different social media platforms as a source of information on vaccination and the influence that social media have on individuals’ perceptions of vaccination, social media monitoring articles and articles describing social media interventions to address vaccine hesitancy.

Three researchers from the VCP extracted data into an Excel spreadsheet for these three categories of articles, as per the information presented in Table 1.

Table 2. Data extraction categories

<table>
<thead>
<tr>
<th>Social media monitoring articles</th>
<th>User preferences articles and interventions articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Author/reference</td>
<td>• Author/reference</td>
</tr>
<tr>
<td>• Year of publication and study</td>
<td>• Year of publication and study</td>
</tr>
<tr>
<td>• Country of study</td>
<td>• Country of study</td>
</tr>
<tr>
<td>• Aims/purpose of study</td>
<td>• Aims/purpose of study</td>
</tr>
<tr>
<td>• Study population and sample size</td>
<td>• Study population and sample size</td>
</tr>
<tr>
<td>• Setting</td>
<td>• Setting</td>
</tr>
<tr>
<td>• Vaccine</td>
<td>• Vaccine</td>
</tr>
<tr>
<td>• Type of social media</td>
<td>• Type of social media</td>
</tr>
<tr>
<td>• Tool for data collection and details</td>
<td>• Methodology</td>
</tr>
<tr>
<td>• Keywords selection and exclusion criteria</td>
<td>• Intervention type and details</td>
</tr>
<tr>
<td>• Sentiment coding and analysis</td>
<td>• Duration of intervention</td>
</tr>
<tr>
<td>• Geo-location of data</td>
<td>• Outcomes and details</td>
</tr>
<tr>
<td>• Reach, spread and interaction</td>
<td>• Key findings</td>
</tr>
<tr>
<td>• Visualisation of data</td>
<td>• Limitations</td>
</tr>
<tr>
<td>• Other types of analyses</td>
<td>•</td>
</tr>
<tr>
<td>• Number of posts and results</td>
<td>•</td>
</tr>
<tr>
<td>• Public health implications</td>
<td>•</td>
</tr>
<tr>
<td>• How to use social media monitoring, in particularly to start</td>
<td>•</td>
</tr>
<tr>
<td></td>
<td>communicating on social media platforms.</td>
</tr>
<tr>
<td>• Limitations</td>
<td>•</td>
</tr>
</tbody>
</table>

Four researchers then summarised, charted and analysed the data extracted. The analysis of the included articles was mainly descriptive (see more details on the analysis conducted for each of the three types of articles below), as articles were heterogeneous and presented highly diverse purposes, methodologies and study outcomes.

Preferences for use of social media platforms as a source of information on vaccination and the influence that social media have on individuals’ perceptions of vaccination

Articles about individual preferences regarding social media were analysed by looking at the use of social media to gain or share information on vaccines and the possible influence of social media on vaccine attitudes and/or uptake. Results were noted, and the proportion of participants either using social media or being influenced by social media were listed for each study and then described in the report.

Media monitoring analysis

When analysing the media monitoring articles the key focus was to describe methodologies used in different studies to monitor social media and their evaluation (if applicable). The researchers therefore provided a descriptive analysis of the type of data collection tools used to gather data from social media, the keywords and search strategies used (including duration of search), and the various analytical methods (sentiment or content analysis, analysis of spread, reach and interaction, and geo-location of data). Data was first extracted to an Excel spreadsheet in accordance with the categories in Table 1; this allowed reviewers to compare results across all studies, list and identify the frequency of different methods used for social media monitoring in different studies, and identify common themes. Two reviewers met to discuss the extraction spreadsheet, the themes identified and the findings of this review.

Suggestions from the studies on how social media monitoring can inform vaccination communication strategies were also included.

Intervention articles

For the intervention articles, the data were first categorised by type of intervention. The VCP then recorded results for various study outcomes to provide a clear overview of the effects of the various interventions. For qualitative studies, a list of key themes was compiled and analysed. Some descriptive information was also provided, such as the number of studies reporting different types of interventions or conducted with different population groups; the names of social media platforms used most frequently by different population groups; or the methods used for monitoring social media platforms around vaccination.

Some analyses were also common to all three categories, such as the types of social media described, the type of vaccines studied, and the number of articles published over time, to reflect how much attention the topic has received in recent years.
5. Review results

The search across all databases generated 15,435 articles, from which 7,539 duplicates were excluded (see Figure 1 for PRISMA chart). The remaining 7,896 unique articles were screened by title and abstract using the inclusion and exclusion criteria listed above. A total of 7,628 articles were excluded, leaving 268 articles for full text review. From these, 153 articles were excluded (see annexes detailing reasons for exclusion) for the following reasons: article on media but not social media monitoring (n=96), no data provided in the article (n=19), about websites or mobile apps but not social media (n=26), conference abstracts or editorials/letters to the editors (n=6), article containing data already published in another included article (n=1), article not looking at vaccination (n=1). Additionally, the full text of four articles on social media monitoring was not accessible, even after making enquiries with multiple libraries.

At the end of the screening process, a total of 115 articles was included for analysis:

- 13 articles looking at individuals' preferences for using social media as a source for vaccination information and the influence that social media have on individuals' perceptions of vaccination,
- 85 articles on social media monitoring,
- 15 articles on social media as an intervention tool around vaccination,
- one article that looked at both an intervention and individuals' preferences for using social media as a source for vaccination information,
- one article that combined social media monitoring and a social media intervention.

**Figure 1. PRISMA flow diagram**

Records identified through database searching  
(n = 15,435)

Duplicates excluded  
(n = 7,539)

Records screened  
(n = 7,896)

Records excluded by title and abstract  
(n = 7,628)

Full-text articles assessed for eligibility  
(n = 268)

Full-text articles excluded, with reasons  
(n = 153)

Studies included in synthesis  
(n = 115: 85 articles on media monitoring, 15 on interventions and 13 on public perceptions of social media, 1 study contained both a media monitoring element and a social media intervention and 1 study contained both an intervention and social media user preferences)
5.1 Individuals’ preferences for using social media platforms as a source of information on vaccination and social media’s influence on individuals’ perceptions of vaccination

Key messages

Preferences regarding the use of social media as a source of information on vaccination:
- Between 4 and 62% of various study populations in different countries use social media as a source of information on vaccination, with results varying by type of social media platform.
- Overall Facebook was the most common social media resource for information on vaccination.

Social media users’ perceptions of vaccination:
- Most studies suggest a negative relationship between social media use and vaccination uptake and attitudes, which could sometimes be explained by the important presence of negative content concerning vaccination online.

A total of 14 articles explored individuals’ preferences for receiving information via social media, which social media platforms are used and how information shared on social media influences the perceptions of vaccination. Annex 8.2 provides an overview of the studies relating to the use of social media to gain or share information about vaccines and the possible influence of social media on vaccine attitudes and/or uptake.

5.1.1 Preferences regarding the use of social media as a source of information on vaccination

Several studies pointed to social media as a source of health-related information:
- Five out of seven parents in one US study cited social media as a common resource for information [38].
- Another study in the US found that 62% of adults questioned used Facebook to find information on the influenza vaccine, compared to 15% for Twitter [39].
- In a survey of undergraduate students in Seoul, South Korea, 30% of the respondents cited social media as a source for information on HPV [40].
- In the UK, a study found that in a group of 626 parents who used the Internet to find information about vaccinations, 13% used Facebook or Twitter and 6% used discussion forums [41].
- Another study in the UK focused on pregnant women using social media and found that 21% of the participants used social media to find information on vaccinations during their pregnancy, with Facebook and WhatsApp being the most popular platforms [42].

Limited use of social media as a source of information
- A Canadian study found that 68% of participating medical students had never used social networking sites such as Facebook or MySpace to obtain health-related information [43].
- Similarly, university student participants in a study in Northern Ireland reported social media to be their least preferred source of information on awareness of meningitis and vaccines [44].
- A dissertation from the US reported that although 66% of parents had seen information about HPV vaccination on social media, only 4% had actively used social media as their main source of information about HPV vaccination (a lower percentage than those using information from friends and government health organisations) [45].
- A US study found that 11% of parents who had heard HPV vaccine stories found them on social media and these accounts were more likely to be negative ‘stories of harm’ than content through other information channels [46].
- Regarding overall use of social media, a study conducted among medical students in Canada found that while 66% of participants sometimes or often used YouTube, 24% reported sometimes looking for health-related information on the platform, and only 2% reported always doing so [43]. Furthermore, 42% reported using YouTube for health purposes, including educational purposes, but 17% were uncertain about the platform’s trustworthiness and 36% reported minimal trust in health content provided on YouTube [43].

Willingness to share information on social media
- None of the female students in one study on a university campus in the United States shared HPV information on Facebook, 71% of them were willing to do so in the future [47].
- One Spanish study also looked at the willingness of medical students to use/follow/participate in Facebook pages promoting influenza vaccination. They found that 63% of students would accept an invitation to follow a Facebook page with formal or technical content on the healthcare worker influenza vaccination campaign, while 65% would accept an invitation to follow a Facebook page that communicated the same information informally (such as animations or offbeat news) [48]. In all, 19% of the students would actively participate in a ‘technical’ Facebook page, compared to 28% of students who would actively participate in an ‘informal’ Facebook page [48].
5.1.2 Social media as an influence on perceptions of vaccination

Several studies considered not only individuals’ preferences for social media use but also how this usage influenced their perceptions of vaccination, such as their attitudes and/or uptake of vaccination. Most of these studies suggested a negative relationship between various social media use and vaccination uptake, while others suggested the potential for the positive influence of social media on vaccination uptake. Seven of these specifically referred to Facebook, four referred to Twitter and seven did not specify a social media network or platform.

**Negative relationship between social media and vaccination attitude and/or uptake:**
- A study in the UK that asked pregnant or recently pregnant women how they searched for information on vaccinations during pregnancy found that 12% of participants believed the information they found on social media influenced their vaccination decisions [42]. This influence manifested in a significantly negative relationship in relation to pertussis vaccination, with women who used social media to gather information being 58% less likely to receive this vaccination during pregnancy[42].
- Another study in the UK reported that parents who used social media, such as discussion forums and Facebook or Twitter, were more likely to report that they had come across some material that made them doubt vaccinations (31% of parents who used discussion rooms and 23% of parents who used Facebook or Twitter versus 8% of all participating parents) [41].
- Similarly, three studies in the US found social media had a negative influence on parents’ perceptions of vaccines [49] [45]. In one of these studies, 10% of the participating parents and guardians felt that social media increased their sentiments of fear around the HPV vaccination [45].
- In the UK, a study considered social media as one of the various intervention strategies used to increase influenza vaccine uptake in healthcare workers over the course of four years. The researchers in this study reported a significantly reduced vaccination uptake when using promotions on Facebook (22%) and Twitter (24%) as an intervention, although no reflection on the reason for these results was provided [50].
- In India, a study was conducted to assess the influence on trust of a large measles-rubella vaccination campaign in the southern state of Tamil Nadu. This study found that most parents who rejected the vaccine for their children also placed higher levels of trust in social media platforms, including WhatsApp[51].

**Positive relationship between social media and vaccination attitude and/or uptake**
- A study on vaccines during pregnancy in the UK found that women who used WhatsApp and LinkedIn were more likely to receive both the influenza and pertussis vaccines while pregnant [42].
- A study in the US found that participants who used Facebook or Twitter as sources of health information were more likely to be vaccinated [39].
- Participants from another study in the United States proposed using social media to circulate positive messaging about the HPV vaccine [38].

5.2 Social media monitoring

There is a growing body of literature describing social media monitoring methods. For this report the results of the social media monitoring are organised into three major phases (see Figure 2): 1- preparation, 2- data extraction and 3- data analysis.

**Figure 2. Social media monitoring phases**
Articles on social media monitoring in this review were therefore reviewed in accordance with the following three phases:

1. Preparation:
   - Characteristics of the studies in this report - purpose of social media monitoring and platforms monitored
   - Ethics approval

2. Data extraction:
   - Data extraction tools
   - Period of monitoring
   - Search strategies
   - Visualisation of data

3. Data analysis:
   - Geo-localisation
   - Reach
   - Trends, content and sentiments

### 5.2.1 Preparation

#### Key messages
- In 2015, the number of articles published on social media monitoring increased substantially, with 83% of all articles identified in this review published since 2015.
- The large increase in the number of articles from 2015 was mostly attributed to an increase in studies conducted on Twitter.

#### Purpose
- The purpose of analysing information about vaccination online will influence how and which data are collected. Different purposes were identified:
  - increasing understanding of how vaccination is portrayed on social media through online discourse, sentiment or how information is produced, shared and engaged with;
  - monitoring the reaction after an outbreak;
  - monitoring the impact of a campaign or intervention or a vaccination programme;
  - monitoring misinformation;
  - monitoring public concerns and questions in general or over time.

#### Types of social media
- A large majority of studies focused on Twitter, followed by YouTube, Facebook and various online forums.

#### Ethics
- The questions relating to ethics approval to perform social media monitoring research are growing. In addition, a number of studies raised the issue of posts not being publically available.
- Out of the 86 articles on social media monitoring, only 13 (15%) explicitly mentioned having received approval from an institutional ethics review board. Some of the other studies considered that they were exempt from institutional/ethical review as their studies did not directly involve human subjects or because social media analysis only included publically available data.
- Other researchers believe that anonymization is not enough and they urge that other solutions should be found due to the fact that private data can easily be revealed.

#### Study characteristics
A total of 86 articles monitored and analysed social media in relation to vaccination (see Annex 8.3 for a table summarising the characteristics and methods used in these articles). While the first study was published in 2006, only a very small number of studies were published between 2006 and 2014. In 2015, the number of published articles about social media monitoring increased substantially, with 83% of all articles identified in this review published since 2015. Nine studies were published in 2015 (11%), 14 in 2016 (16%), 25 in 2017 (29%) and 21 in 2018 (24%). As the search was conducted in December 2018, only two articles, available ahead of print, were identified for 2019.

#### Purpose of social media monitoring
It is important to establish the purpose of analysing social media information on vaccination as this will influence how and which data are collected. For the majority of studies (55/86, 64%) the goal was to increase understanding of how vaccination is portrayed on social media, through online discourse, sentiment or the way in which information is produced, engaged with and shared. Other aims included monitoring the reaction after an outbreak, monitoring the impact of a campaign or intervention or a vaccination programme, monitoring misinformation or monitoring public concerns and questions.
Type of social media monitored
A large majority of studies focused on Twitter (n=42) [30,52-92], followed by YouTube (n=12) [32,93-103], Facebook (n=11) [45,104-113], and various online forums (n=9) [114-122]. The forums included in the studies reviewed in this report were babytet (China), Iltalehti and KaksPlus (Finland), Mothering.com (UK), and Mumsnet (UK). Additionally, five studies either used multiple forums from the same country identified by a Google search, forums specifically designed for a particular event or study, or failed to name the forum analysed. Other types of social media monitored included Yahoo! Answers (n=2) [123,124], Pinterest (n=1) [125], Reddit (n=1) [126], and Weibo (n=1) [127]. An additional seven studies monitored a mix of social media networks, including Digg, Hyves, Facebook, unspecified forums, LinkedIn, Reddit, Twitter, and YouTube [128-134]. A description of all the different social media platforms monitored across the 86 studies is provided in Table 3.

Table 3. Description of the social media platforms identified in the scoping review

<table>
<thead>
<tr>
<th>Platform</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Digg</td>
<td>Platform allowing users to post, save and share news stories and to vote content up or down.</td>
</tr>
<tr>
<td>Facebook</td>
<td>Platform used for social networking, allowing users to create profiles with personal information about themselves, and to post, interact, comment or share messages, photos, videos and other media content with other members (friends or followers). The platform also allows groups and professional pages to be created, with comments, likes and shares of these posts across both personal profiles and group/pages (depending on privacy settings).</td>
</tr>
<tr>
<td>Forums</td>
<td>Type of social media platforms allowing users to write content in message boards or online discussion sites/threads. The forums included in the studies reviewed in this report were babytet (China), Iltalehti and KaksPlus (Finland), Mothering.com (UK), and Mumsnet (UK).</td>
</tr>
<tr>
<td>Hyves</td>
<td>Platform used for social networking, allowing users to interact with other members (Dutch equivalent of Facebook, discontinued in 2013).</td>
</tr>
<tr>
<td>LinkedIn</td>
<td>Platform used for professional networking and for posting jobs and/or curriculum vitae or sharing content in the form of short messages, images, videos or links.</td>
</tr>
<tr>
<td>Pinterest</td>
<td>Platform for posting, interacting with and sharing images/articles, referred to as pins, as well as videos and other media content.</td>
</tr>
<tr>
<td>Reddit</td>
<td>Platform for posting links, text messages, videos and images. These are then voted up or down and discussed by other members.</td>
</tr>
<tr>
<td>Twitter</td>
<td>Platform for posting, interacting with and sharing short messages (tweets) of maximum 280 characters, video and/or links.</td>
</tr>
<tr>
<td>Weibo</td>
<td>Platform for posting, interacting with and sharing short messages (Chinese equivalent of Twitter).</td>
</tr>
<tr>
<td>YouTube</td>
<td>Platform for posting, interacting with and sharing videos and blog posts.</td>
</tr>
</tbody>
</table>

Figure 3 shows the number of articles identified by year and by type of social media (excluding the two 2019 articles). It indicates that the large increase in the number of articles from 2015 was mostly attributed to an increase in studies conducted on Twitter (n=37, 54% of all articles published between 2015 and 2018), and to a smaller extent Facebook (n=10, 15%). Articles about less commonly studied types of social media (Pinterest, Weibo, Reddit, and Yahoo! Answers) were all published after 2015.
Figure 3. Number of articles published by type of social media and by year until 2018

Note: Forum refers to the different forums included in the articles covered by this report: babytree (China), Iltalehti and KaksPlus (Finland), Mothering.com (UK), and Mumsnet (UK)

Type of vaccine monitored
Most of the articles identified in this review looked at vaccines in general (40%, n=34) [32,55-57,59-61,68,72,78,81,83,87,89,90,95,97,98,101,103-107,110-113,118,121,122,125,126,132], HPV vaccination (27%, n=23) [45,58,63-66,69,70,73-75,82,84,86,92-94,96,99,102,117,123,130] or measles vaccination (14%, n=12) [52,62,77,80,85,91,116,119,129,131,133] (Figure 4). Additionally, five studies monitored social media in relation to the 2009 A(H1N1) influenza pandemic [30,76,114,120,128] and four studies looked at seasonal influenza [67,71,124,134]. Other vaccines monitored on social media included polio (n=2) [108,109], diphtheria (n=1) [79], hepatitis B (n=1) [127], meningococcal B (n=1) [100], pentavalent DTP-HepB-Hib (n=1) [54], and rotavirus (n=1) [115]. One study also looked both at polio and HPV vaccination [53].

Figure 4. Number of articles published by type of vaccine

Countries monitored
A large proportion of studies did not restrict monitoring to one specific country and therefore contained global results (n=41) [52-57,59,62-65,67-70-75,77-78,80,81,84,86,90,92-95,97,99-105,110,125,126] (Figure 5). However, some of these studies have restricted their search to specific languages such as English or Spanish, which may therefore provide skewed results towards particular regions of the world. Fifteen studies were conducted specifically with data coming from the United States (US) [30,45,58,61,66,69,70,77,78,80,81,84,86,90,92-95,97,99-105,110,125,126], seven from Italy [32,60,89,98,106,118,133], three from the Netherlands [69,131,134] and three from the United Kingdom (UK) [76,116,122]. Other countries specifically monitored included Canada (n=2) [113,128], China (n=2) [115,127], Israel (n=2) [108,109], Spain (n=2) [79,114], Australia (n=1) [119], Chile (n=1) [123], Finland (n=1) [120], Japan (n=1) [124], and Romania (n=1) [117]. Four studies looked at data from multiple countries, including Australia, the US, Canada, and the UK [82,111,121,132].
Figure 5. Number of articles published by country monitored

<table>
<thead>
<tr>
<th>Country</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Global/not specified</td>
<td>41</td>
</tr>
<tr>
<td>United States</td>
<td>15</td>
</tr>
<tr>
<td>Italy</td>
<td>7</td>
</tr>
<tr>
<td>Mix of countries</td>
<td>4</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>3</td>
</tr>
<tr>
<td>Netherlands</td>
<td>3</td>
</tr>
<tr>
<td>Spain</td>
<td>2</td>
</tr>
<tr>
<td>Israel</td>
<td>2</td>
</tr>
<tr>
<td>China</td>
<td>2</td>
</tr>
<tr>
<td>Canada</td>
<td>2</td>
</tr>
<tr>
<td>Romania</td>
<td>1</td>
</tr>
<tr>
<td>Japan</td>
<td>1</td>
</tr>
<tr>
<td>Finland</td>
<td>1</td>
</tr>
<tr>
<td>Chile</td>
<td>1</td>
</tr>
<tr>
<td>Australia</td>
<td>1</td>
</tr>
</tbody>
</table>

Ethics approval - public versus private data

The issue of posts not being publically available was raised in nine studies, either as a pre-defined exclusion criterion or as a limitation [45,53,69,80,87,108,111,121,133]. This could be linked to certain ethical issues.

- Out of the 86 articles on social media monitoring, only 13 (15%) explicitly mentioned having received approval from an institutional ethics review board in Australia, Canada, Israel, Romania, the UK and the US [45,58,62-64,76,82,92,105,108,109,113,117].
- Additionally, one study did not mention whether they had received ethics approval, but stated ‘guidelines from the Institutional Review Board have been considered and applied to protect the identity of forum users’ [115].
- Nine studies also specifically stated that they were exempt from institutional/ethical review as their studies did not directly involve human subjects or because social media analysis only included publically available data [56,57,70,74,86,95,99,104].
- The authors of a study that obtained ethical approval, conducted on Facebook in Israel, further explained that as they anonymised their data, participant consent was not required as conversations on the Internet happen in public fora, where ‘subjects would expect to be observed by strangers’ [108].
- However, anonymisation was not enough for the authors of a global study conducted on Twitter, who were keen for other solutions to be found. They explained that private data could easily be revealed ‘through the integrative analysis of multiple datasets’ and that revealing the identity of social network contributors who may have wished for it to be kept secret was feasible (the study did not mention seeking ethical approval) [80].
- Finally, Tangherlini et al, who analysed comments on forums in the US and Canada (but did not mention seeking ethical approval) raised the growing challenge of accessing data on social media, as corporations are constantly reducing access to data [121].
5.2.2 Data extraction

Data extraction tools

Key messages

- Studies that used manual browser search functions within social media platforms tended to collect less data than those accessing the automatic Application Programming Interfaces (APIs) or other software.
- A large number of studies used the Twitter API to collect data due to the ease of access given by the Twitter platform to its data stream compared to other platforms.
- Studies used a range of commercial software, with the majority accessing paid-for periodical and historical Twitter data.

In order to collect data from social media on the subject of vaccination, the studies in this review used:

- Manual browser searches on web browsers such as Firefox, and Google Chrome. Browser searches are performed from within social media platforms – e.g. the basic or advanced search bar usually found at the top of the page on Twitter, YouTube or Facebook.
- Social media APIs (Application Programming Interfaces). The term 'API' refers to a software intermediary that allows two applications to talk to each other. When Twitter is used, the Twitter application connects to the Internet and sends data (e.g. the text or images posted with a tweet) to a server. The server then retrieves the data, interprets it, performs the necessary actions and sends it back to the Twitter application on a user's phone, web browser or a researcher's database, which is then interpreted and shown to the user in a readable format. APIs work across all social media platforms to pull and interpret data from servers storing information for Facebook, Twitter, YouTube, Reddit and many more.
- Automatic monitoring (commercial software). These can be automated web platforms that are free, open source (open to development from other developers), or commercial (where access is allowed via a subscription pricing structure);
- Use of both manual searches and APIs.
- Use of both automatic software and APIs.

Figure 6 shows the number of software tools used within each category.

Figure 6. Number of studies by type of social media monitoring tools used

![Bar chart showing the number of studies by type of social media monitoring tools used.]

Notes to the figure:
API – Social media Application Programming Interfaces
Manual - Manual browser searches on web browsers
Automatic or commercial tool - Automated web platforms.

Manual browser searches
A total of 36 studies used web-based manual tools. Studies that used manual browser search functions within social media platforms tended to collect less data than those accessing the automatic Application Programming Interfaces (APIs) or software. Some of the limitations of manual browser searches are described in Table 4.
Table 4. Different manual browser searches and their limitations mentioned by the studies using the tool

<table>
<thead>
<tr>
<th>Social media tool</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>YouTube search browser</td>
<td>• Despite the use of a variety of search terms being seen as a strength of the study, only the top 50 hits according to relevance were chosen to be analysed (this is in the context of the three million videos posted on the topic of vaccines currently on YouTube at the time of the project) [96]</td>
</tr>
</tbody>
</table>
| Facebook search tool            | • Due to the time intensity that assessing each Facebook site required, it was impractical to analyse each site in detail. Another limitation mentioned was that the focus of the assessment was on the most recent posts. The nature of posts on Facebook sites may change as new information regarding vaccines reaches the general public, such as during flu season or when school starts, and parents must turn in their child's vaccination records. During the short time for the data collection, there was no major news related to vaccines that had recently been reaching the general public. Finally, the authors did not gather data regarding individual users and cannot determine whether activity on the site centred on several engaged users or was spread among site membership [104]  
  • A small limitation to using a Hypertext PreProcessor (PHP) script supplied by Facebook as an add-on to the basic Facebook search tool as the script served to only collect each post's first 25 comments - this meant that not all comments for every post were analysed. However, it was not considered a strong limitation since each post or comment was analysed as an individual unit. From the sampling frame, a sample of 2,289 items were randomly selected using a 'randomise numbers' command. This was considered a representative sample of the initial sampling frame. This study was made before the data protection ethics and protocols linked to the 2018 General Data Protection Regulation (GDPR) rules came into place [135], although all the data were anonymised and available for scientific use, the authors acknowledged that this methodology may give rise to ethical concerns, given that identifiable comments made by people on public Facebook pages are scrutinised. Nevertheless, at the time of the study (2016), according to the Codes of Ethics and Conduct of Internet Research [136], if an observation of public behaviour takes place in public fora where subjects would expect to be observed by strangers (such as an open Facebook discussion), explicit individual consent is not required. If this search was made today, however, the analysis of potential identifiable user posts on Facebook would be limited [109].  
  • Luisi (2018) [45], found that the Facebook search feature does not allow users to organise results by date or engagement (e.g. likes/comments). This limits flexibility in data collection. Technology also limited the ability to archive Facebook posts. When loading the search results, one would have to scroll down to make the area printable. Scrolling down too far would cause internet browsers to crash. Moreover, this study only collected public Facebook content in an effort to only analyse content that would be available to any Facebook user, because access to private social media feeds is not possible without specific participant consent.  
  • Suragh et al. (2018) [112], found that a limitation of just using the Facebook browser search tool was the inability to examine entire social networks, which means that the fraction represented by the study data of what actually exists is unknown. The study was also limited to the information included in the online reports, with potential biases and errors in reporting. Lastly, there was the challenge of conducting searches in different countries. The findings from the Google and Facebook searches were dependent upon the geographic location of the reviewer and this reflected on targeting 'popular' findings according to the search location and specific algorithms used by these companies. This limitation could have also been a result of the study methodology, which only included reports found in the first three pages for Google and top 20 posts for Facebook. It is possible that if larger search samples (Google produced hundreds of thousands of URL (Uniform Resource Locator) links per search term) were analysed, both reviewers would have found exactly the same results. Facebook results were dependent on the date and time of the search (e.g. the highest placed posts found on one day were not the same as those found the next day) therefore searches had to be completed in one sitting and some of the URL links identified in Facebook did not work. The study used standardised search terms but other reports of cluster immunisation may probably have been found by including additional search terms and expanding to different languages, countries and regions. |
In one study by Skea (2006) relating to internet forum discussion on the measles-mumps-rubella (MMR) vaccine, one limitation found was that the 617 messages analysed were those posted to only one website, which meant that participants were probably not demographically representative of the wider population. In addition, a higher proportion of participants in the fora had refused MMR vaccine than in the general population. All these factors raised legitimate questions whether it is appropriate to generalise from the study’s findings to the wider parent population, and whether and how insights from this study should inform future communications on MMR vaccine or vaccination more generally.

A study by Guidry et al. (2015) found that a limitation of using the manual browser search was that Pinterest does not list its pins chronologically and does not list an exact time stamp for each pin. The authors found that this made using a more conventional content analysis sampling method, such as a constructed two-week time period, virtually impossible.

In addition to the various web-based manual tools mentioned in the table above, three other studies used the Google Search tool, three used a combination of the Twitter and Facebook search tools, two studies used manual HTML (Hyper Text Markup) extraction, one study used the Yahoo! Answers search engine, and one study used the basic Twitter search tool.

### Social media APIs

Thirty-one studies sampled their data directly from their target social media platform’s API. There was a strong focus on the Twitter API, which pushes focus on Twitter and neglects data on other social media platforms. The results of the scoping review found that Twitter does not provide a full reflection of all social media discussion, or indeed general discussion of vaccines overall. There is a need for a broader understanding of discussions on other platforms, and how they may influence vaccine uptake. Some of the limitations of social media APIs are described below.

#### Table 5. Social media APIs and their limitations mentioned by the studies using the tool

<table>
<thead>
<tr>
<th>Social media APIs</th>
<th>Limitations</th>
</tr>
</thead>
</table>
| Twitter API       | • One study used a combination of two Twitter APIs. This was because they found that general Streaming Twitter API did not provide an easy way to retrieve complete conversations (many of which were partially truncated/cut-off, due to some accounts being protected/private). Multiple replies to the same tweet can also occur, which the study’s data retrieval method may not have detected. To retrieve a more complete sample of conversations on Twitter they used a combination of checking for replies to tweets within their user group and screen scraping from the Twitter browser page itself. It was found that data collected through the relevant keywords and accessed via the basic API stream accounted for only a quarter of the total number of results. This is, in itself, a highly interesting result: a search using keywords would miss 75% of the relevant tweets. One possible way to avoid this would be to gain access to the Twitter Firehose or all tweets via a subscription-based and automated service – however, this may be cost-prohibitive to some studies.  
• In one study, one of the limitations of using the Twitter API was determined by looking at the scope of open debate on social media analysis, and whether social media discussions are a valid and accurate proxy for the rationales of the population at large. This applies both in terms of users’ demographics and the potential for fake users (or automated bots) to spam social networks or post fake and polarising content. There was also a need to be aware of the (limited, but needed) amount of technical supervision required when analysing the sentiment and geolocation of tweets - the system requires computational capacity and server administration, as well as the creation of machine learning classifiers to annotate large amounts of social media data (i.e. tweets, images, posts, or comments).  
| Facebook API      | • In one study, one of the limitations acknowledged was that the research conducted was limited by the combined public/private nature of Facebook. While public Facebook pages do provide a wealth of network information, the authors were unable to gather information about how information shared from anti-vaccination pages disseminates through private Facebook pages or personal social media networks.  |
Automatic monitoring or commercial software
Twenty-six studies used automatic, commercial software to monitor social media with the majority accessing paid-for periodical and historical Twitter data (see Appendix 8.4 for a list and details of the automated tools and commercial software used in the studies in this review). Automatic monitoring or commercial software extract large amounts of data at one time. Costs can be high and there is a need for sufficient human resources to analyse the data captured.

Period of monitoring

Key messages
- The aim and resources available dictate the time period chosen for monitoring, whether in retrospect at a single point in time or over a continuous period.
- Regardless of the data collection period, studies with the highest number of results consistently came from the use of social media APIs or automatic data sampling.
- Yahoo! Answers API provided the largest sample size from a single platform over a sampling period of five years (16 million messages).
- Crimson Hexagon was the automatic platform that provided the largest mixed sample size, with a mixture of 58 078 Facebook posts and 82 993 tweets.

All studies sampled data from different social media platforms over varying periods of time. Below is a summary of the different types of timed data collection in relation to the monitoring tools used and the amount of data collected.

Single point in time
Nine studies sampled data over a single point in time. It was found that these specific studies used a manual form of data collection. Three studies used the YouTube browser search tool [95,102,137]. Three studies used the search tools within forums that they drew data from [114,115,119]. Two studies used the basic Facebook search function [104,105]. One study sampled data using the Pinterest browser search tool [125].

Continuous period of time
Seventy-five studies were carried out over a continuous period of time.

Months
Thirty studies were conducted over a period of 1−20 months [30,52,62-65,68,69,73,74,76,78-80,85,88-90,93,107-109,113,120,123,127,128,131,132,134]. The studies were performed using a combination of API and automatic searches.

Years
Thirty-five studies were carried out within a one year and 16-year time-span [32,53-57,59,61,66,67,71,75,77,82-84,86,87,91,96,98,99,106,110,111,116-118,122,124,126,129,130,133].

The longest period of data collection was by a study that covered 237 112 Italian Facebook posts in Facebook groups during a 16-year period, with the aim of understanding the linguistic and psychological features of the language used to talk about vaccinations on social media [106].

Overall, studies that were conducted over a period of years were done with a combination of API and automatic searches.

- Two more studies with large datasets retrieved 6 288,653 vaccine images on Twitter directly from the Twitter API over one year and eight months [59], and 1 448 010 tweets and data over seven years via the Twitter API [55].
- Two studies collected data covering a period of ten years, using Facebook [45] and YouTube [98]. In the first study, 6 537 posts were collected using the Facebook browser search tool, with the aim of studying likes and parent/guardian perceptions, as well as social media representations of the HPV vaccine [45].
- In the second study, the YouTube browser search tool was used to sample 560 Italian videos over a period of ten years, with the aim of analysing any connections with discussions on the reputed vaccine/autism link or links between vaccines and other serious medical conditions in children [98].
- The largest collection of posts from a mixed study, using an automatic tool, was a study on Crimson Hexagon looking at a mixture of 58 078 Facebook posts and 82 993 tweets - to examine Facebook and Twitter discussions of vaccination in relation to measles during a period of several widely publicised outbreaks over a 7.5 year period [129].
Search strategies

Key messages

- Social media monitoring studies often used a small number of keywords related to vaccination and/or vaccine-preventable diseases.
- Studies looking specifically for negative content around vaccination included keywords related to safety or risk, specific side effects, or certain conspiracy theories or celebrities.
- Questions, phrases and/or hashtags (e.g. #vaccine) were used in different searches.
- The use of three categories of keywords - relevant, semi-relevant and non-relevant - was found to increase precision in a search.

List of keywords used for social media monitoring

Seventy-one articles provided a list of keywords used to monitor social media (see Annex 8.5 for the full list). From these 71, only 10 specifically mentioned an extensive search strategy, with Boolean operators to link keywords (e.g. and, or) or truncations to identify words with different endings (e.g. vaccin*). Many studies only used a small number of keywords to monitor social media: 13 studies used only one keyword (e.g. vaccination, measles, MMR) [32,57,62,73,81,85,103,104,116,120,124,127,131], eight studies used two keywords (e.g. HPV and vaccination, vaccination and immunisation) [56,69,70,86,94,95,101,115] and five studies used three keywords (e.g. vaccine, vaccines or vaccination) [54,93,110,118,132]. Studies looking specifically for negative content in relation to vaccination included keywords related to safety or risk, specific side effects, or certain conspiracy theories or celebrities. Most of the 71 studies were conducted on Twitter (n=10), YouTube (n=6) and forums (n=4). Three of these studies mentioned the small number of keywords as a limitation [32,56,96].

Most keywords can be classified as:

- words related to vaccines or vaccination (including the generic names and brand names of specific vaccines)
- vaccine-preventable diseases
- types of side effects
- anti-vaccination related keywords
- references to certain controversies and names.

The keywords most commonly used across all studies are shown in Figure 7.

Figure 7. Keywords most commonly used across all studies (>4 use)

Use of hashtags

Ten studies also included hashtags in their keywords when searching Twitter [55,56,60,70,74,75,81,86,87,129]. While some of these studies used generic vaccination keywords (#hpv, #vaccine, #vaccination), others searched for more specific hashtags used in social media discussions (#cdcwhistleblower, #b1less, #hearsus, #iovaccine, #vaccineswork). One study, conducted in the United States, explained that those specific hashtags were chosen because they were used by journalists in articles covering anti-vaccination beliefs on Twitter [87].

Use of questions

While some studies used simple keywords or hashtags to conduct searches, others used questions. For example, a study conducted on YouTube concerning HPV used the keywords 'should I get the HPV vaccine' or 'what can go wrong with the HPV vaccine' [99]. These keywords were selected based on a modified Delphi procedure, where investigators asked for and reviewed terms provided by non-medical and medical colleagues as well as patient representatives and practitioners. One of the two studies conducted on Yahoo! Answers typed in questions such as 'what is papillomavirus' and 'what is the effectiveness and safety of HPV vaccines' to collect results [123].
**Use of phrases**
A search on Facebook looked for various phrases about mass psychogenic illnesses related to vaccination, including 'mass hysteria after vaccine' and 'fainting in school children after vaccine' [112]. These terms were developed after consultations with safety experts at WHO and the US Centers for Disease Control and Prevention (CDC) and then pilot tested.

**Exclude data**
Two studies also used keywords to exclude data. A study conducted on Twitter in the US used words such as 'malware, caffeine, heroin and needle exchange' to exclude irrelevant results [68]. A Dutch study, also conducted on Twitter, used words such as 'blood tests or travel vaccinations' [69].

**Use of languages**
Twenty-four studies specified using English keywords or excluding results not published in English [30,45,52,56,64,65,70,71,74,82,84-86,90,93-96,99,101,104,110,112,128]. Seven of those discussed the decision as a limitation in their discussion [56,71,86,90,99,112,128]. Another seven studies focused on social media posts in other languages, without necessarily using keywords in other languages. Four studies, conducted in Italy [106], Israel [109], Canada [113] and Spain [114] did not provide the keywords but directly extracted data from Facebook groups in Italian, Hebrew and Canadian French/English, and from YouTube videos in Spanish or Catalan. A Romanian study analysing online forums did not specify the language of the keywords used, but explained that only Romanian discussion forums were included [117]. Another study used keywords in English but also included in their analysis tweets identified in other languages [67]. Finally, one study developed a keyword strategy ('pentavalent OR pentavac OR quinvaxem') with the purpose of retrieving messages from multiple national discussions [54]. However, the authors acknowledged that their search terms did not include all brand names, which could have limited results from a number of countries.

**Evaluation of keywords**
Only two studies evaluated their keywords: one conducted on Twitter in the Netherlands [69], and the other on Twitter and Reddit in Canada, the UK and the US [132].

- The Dutch study used three lists of keywords (in Dutch): relevant (HPV AND vaccination), semi-relevant (HPV OR vaccination), and non-relevant keywords (words related to other types of injections and other meanings of the search keywords). These keywords were generated manually by the authors and by using a quick scan of initial search results. They found that using such a system allows good precision. Semi-relevant keywords were particularly useful, as 66% of tweets by users from the target group were found to be relevant. On average, 59% of tweets occurring before and later in the conversations were relevant [69].
- The study conducted on Twitter and Reddit used two sets of keywords: one for vaccines (vaccine OR vaccines or MMR) and the other one to look for discussions around the vaccine-autism link ((vaccine OR vaccines OR MMR) and autism). The average precision and recall estimates were 95% and 92%, respectively [132]. However, the authors mentioned that their keywords might not have sufficiently considered differences in cultures and norms.

**Visualisation of data**

**Key messages**
- Various formats were used to visualise data. The most commonly used form of data visualisation was created with Microsoft Office Software (e.g. Excel or Word), with the table being the most frequently used format.
- Visualisation of social media monitoring results is a developing field. There is a great deal of variation in interpreting and presenting the results in order to communicate clearly and to have an impact on policy.

The most commonly used form of data visualisation was created with Microsoft Office Software (e.g. Excel or Word), with the table being the most frequently used format; 75 studies used this format to represent their findings [32,45,52,54,56-70,72-84,86-90,92-107,110-117,119,121-124,126-128,130-134,137].
Other visual representations of data identified were:

- line charts (27 studies) [30,32,60-65,67,74-76,85,87,89,91,92,106,109,110,124,126-129,131,133]
- flow charts (11 studies) [60,62-64,75,77,78,88,89,92,121]
- diagrams (seven studies) [60,74,77,78,89,92,121]
- scatter charts (six studies) [30,84,88,110,121,126]
- calculus diagrams (six studies) [30,60,89,91,121,126]
- pie charts (five studies) [60,63,64,90,120]
- area charts (two studies) [60,126]
- dendrograms (diagrams representing a tree) (two studies) [84,126]
- proportional boxes (one study) [54]
- treemap (one study) [126]
- bubble chart (one study) [68]
- whisker graph (one study) [66]
- box graph (one study) [66].

Six studies used screenshots to visualise their findings [45,73,78,111,113,125]. Two were screenshots from the basic Facebook search browser [45,113]. One was from the automated Topsy tool [73], one was from Facebook data taken from the automated Social-Media Lab [111], while one was from the automated VaccineWatch software [78]. One study used screenshots from Pinterest [125] and one study used a story gram (creation software unknown) [121].

Thirteen studies used social network charts [52,62,68,76,81,82,84,85,88,110,111,121,126] – these were created using the Gephi software package [138].

Visualisation of social media monitoring results is a developing field. There is a great deal of variation in the interpretation and presentation of the results in order to communicate clearly and have an impact on policy.

5.2.3 Data analysis

Once extracted the data were analysed in different ways (see Appendix 8.3 for more information on each of the studies aims). This included:

- calculating the number of posts available over a period of time;
- detailed content analysis to identify the frequency of particular concerns or conspiracies relating to vaccination;
- qualitative thematic analysis;
- language and discourse analysis;
- comparing social media posts to disease incidence or outbreak cases.

The most common type of analysis looked at sentiments expressed towards vaccination (70% of studies, 60/86).

Geo-localisation

**Key messages**

- Only a small number of studies extracted and analysed location data from social media.
- Country-specific social media monitoring was difficult due to the very small proportion of tweets, posts, videos or profile pages with geo-location tags enabled or with public information on location.
- Dictionary of terms for geographical entities may be used to automatically identify mentions of countries or cities.

**Manually extracting location information**

- Some studies collected meta-data on location information (if available) or by manually screening for locations within posts [65,82,132].
- McNeil et al. filtered their data using location-specific search terms (United Kingdom, Scotland, Wales, Northern Ireland, etc.) to screen Twitter users’ profile pages [76].

Manual methods do not always provide enough information, as Dunn et al. explain in their study: ‘accurate location information can be found in only a small proportion of tweets that have coordinates stored in the metadata of the tweet (geo-tags)’, which corresponds to only 1% of tweets [66].

**Automated mechanisms to retrieve location information**

All the studies that used automated mechanisms to retrieve location information were conducted on Twitter and were either global studies [53,54,67,80] or studies focusing on the US [66,87,91]. Four of these studies used various types of software (Carmen, Geodict, Nominatim, GeoSocial Gauge) to extract location information from tweets or user profile pages but did not provide detailed information about the software [66,67,80,91].
In their study, Bahk et al. described the 'Vaccine Sentimeter', a tool that facilitates media monitoring for vaccination. Their tool allows results to be filtered by location and to display articles geographically. Posts are automatically tagged for location (if available) using HealthMap technology, followed by human curation to validate and correct the automated tags [53].

Becker et al. used a dictionary of terms for geographical entities of countries, GeoNames, to automatically identify mentions of countries (or cities) in tweets. For countries and cities with the same names (e.g. Bali is both a city in India and an island in Indonesia), the result with the largest population was selected, which may have led to some misallocations. However, the authors explain that this mechanism does not distinguish between country mentions that are related to the vaccines being discussed and those that are not [54].

Tomeny et al. used a tool to define geographical entities [87]. As their study was focused on the US, they used the Office of Management and Budget's Metropolitan and Micropolitan Statistical areas. The tool categorises areas into metro (>50 000) and micro areas and a list of counties. Tweets were geo-located based on these entities by using the Twitter Global Positioning Systems (GPS) coordinates (if available) or the user's self-disclosed location in their profile page. While only 1% of tweets identified had GPS coordinates, 63% provided self-disclosed locations on users' profiles. The authors then used the Census Reporter's API to resolve city names to the correct micro or metro areas. An external validity check was also performed by manually locating 560 random user profiles and found that 531 profiles (95%) of locations had been correctly identified [87].

Trends, content and sentiment

Key messages

- The sentiments most commonly used by researchers to categorise content relating to vaccination in social media were 'neutral', 'negative', and 'positive'. Only a small number of studies used more complex sentiments (e.g. sarcasm, humour or hesitancy).

  Manual sentiment analysis:
  - The majority of studies manually coded sentiments based on a thematic analysis.
  - Limitations of manual sentiment analysis: time-consuming, requires 2-4 trained coders and codebooks, highly subjective, difficult to code sarcasm, slang or hyperbole.
  - Advantages of manual sentiment analysis: no computational skills needed, easy to conduct.

  Automated sentiment analysis:
  - The studies using automated systems were mostly conducted on Twitter. They used machine learning, based on a sample of manually-coded data.
  - Lightside was identified as an accurate and valid algorithm to code sentiments. Other non-evaluated algorithms included Latent Dirichlet Allocation, Naïve Bayes, Brightview Classifier and Topsy.
  - Limitations of automated sentiment analysis: prone to bias as relying on manual coding to train algorithms requires strong computational skills, and it is difficult to code sarcasm or irony.
  - Advantages of automated sentiment analysis: more accurate and less time-intensive than manual coding.

Categories of sentiments used and definitions

Sixty studies (70%) provided some type of sentiment coding and analysis, two of which did not specify the categories used to code sentiments [119,120] (Figure 8).
With the exception of a few studies that only searched for negative or anti-vaccination sentiments [61,65,92], studies generally used a set of codes to characterise different types of sentiments in their data. The most commonly used set of sentiments across all studies was ‘positive, negative or neutral’, or similar (e.g. positive or negative). Thirty-two studies used these exact three sentiments to classify their data, 21 manually coding the data [32,45,54,58,68,69,72,73,79,86,93,96,98-102,112,113,116,127], and 10 using automated coding [30,53,63,64,66,74,75,83,89,106]. One study also used a combination of manual and automated coding, using a sentiment score for the automated coding (from 0-100)[70].

The other most commonly used types of sentiments were ‘pro-vaccine, anti-vaccine, neutral’, which were used in 20 studies. Other combinations of these sentiments included ‘pro-vaccination and anti-vaccination’, or simply ‘pro and anti’. Thirteen of these studies used manual coding [52,56,57,61,69,90,103-105,110,114,125,133] and seven automated coding [62,77,87,88,91,92,129].

Some studies used different types of sentiment categorisations. Two studies conducted on YouTube used the words ‘encouraging, discouraging or neutral’ [94,95]. Two studies, one on YouTube[97] and one on Twitter[60] used the terms for/in favour of vaccination, against/not in favour of vaccination, or neutral. A study conducted on Reddit used the terms affirmative and negative [126]. Huang et al., used the question ‘does this message indicate that someone received or intended to receive a flu vaccine?’ (yes/no) to code sentiments on Twitter using an automated system [67].

Only two studies used a more comprehensive and thorough list of sentiments, including humour/sarcasm, concern, relief, and minimised risk. One of these was conducted in Dutch on Twitter, Facebook and fora [131] and the other was conducted on Twitter in Spain [79].

One study, used WHO’s SAGE determinants of vaccine hesitancy framework to design a list of initial codes and sentiments that was then reviewed after testing it on a few posts [113].

Two studies coded sentiments as binary variables (positive vs. negative), while another two studies combined positive and neutral sentiments in the analysis [54,127].

One study conducted on Twitter explained that 0.1% of the 1,154,156 tweets identified were coded (1,151), by selecting the first tweet with a random number generator and then coding every 1000th tweet [62].

In summary, the codes most commonly used to characterise sentiments were neutral (n=37), negative (n=33), positive (n=31), anti-vaccine or anti-vaccination (n=20) and pro-vaccine, or pro-vaccination (n=20).

Twenty-six studies (43%) provided definitions of the different codes used for the sentiment analysis (Table 6).
### Table 6. List of codes, definitions and counts for sentiment analysis used in the identified studies

<table>
<thead>
<tr>
<th>Category</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Negative</strong></td>
<td>Negative sentiments, attitudes or arguments against vaccination [32,65,68,74,91,99-101,113,125,127]</td>
</tr>
<tr>
<td></td>
<td>Concerns about safety, efficacy, cost, resistance due to cultural or emotional issues, programme suspension or other types of concerns [54,63,65,96,99,112,113]</td>
</tr>
<tr>
<td></td>
<td>Posts that would lead readers to be less inclined toward vaccination [53]</td>
</tr>
<tr>
<td>Anti, anti-vaccine, anti-vaccination</td>
<td>Posts expressing scepticism or denial of vaccines as a safe and effective way of preventing diseases, or discussing alleged side effects such as autism [56,87,90,103]</td>
</tr>
<tr>
<td></td>
<td>Source of the post judged unreliable [116].</td>
</tr>
<tr>
<td></td>
<td>Discouraging people from vaccinating, advocating for the right to choose not to vaccinate [90]</td>
</tr>
<tr>
<td><strong>Discouraging</strong></td>
<td>Uncertainty of effectiveness, possibility of adverse reactions, links/suspected links to autism, and statistics stating the current absence of childhood diseases therefore eliminating the need for future immunisations [95]</td>
</tr>
<tr>
<td><strong>Positive</strong></td>
<td>Posts communicating public health benefits or safety of vaccination, or encouraging vaccination [32,53,63,68,74,96,99-101,112,113]</td>
</tr>
<tr>
<td></td>
<td>Positive tones, optimistic sentiments, supportive attitudes towards vaccination [63,91,99,125,127]</td>
</tr>
<tr>
<td></td>
<td>Education on a vaccine [99]</td>
</tr>
<tr>
<td></td>
<td>Refuting claims the vaccine is dangerous [99]</td>
</tr>
<tr>
<td></td>
<td>Describes risk of not vaccinating [113]</td>
</tr>
<tr>
<td></td>
<td>Source of the post judged credible [116]</td>
</tr>
<tr>
<td>Pro, pro-vaccine, pro-vaccination</td>
<td>Posts communicating that a vaccine is a safe and effective way of preventing diseases [56,103]</td>
</tr>
<tr>
<td></td>
<td>Positive opinion about vaccination or current policies [89,129]</td>
</tr>
<tr>
<td></td>
<td>Expressing opposition to vaccine hesitancy or refuting claims made by anti-vaccination groups [90,129]</td>
</tr>
<tr>
<td></td>
<td>Encouraging people to vaccinate, spreading scientific information about vaccinations [90]</td>
</tr>
<tr>
<td><strong>Encouraging</strong></td>
<td>Positive messaging, such as stating that vaccines are safe and effective, benefit society as a whole, have not been linked to autism and save thousands of children’s lives each year [95]</td>
</tr>
<tr>
<td><strong>Positive/neutral</strong></td>
<td>No indication of public concern about a vaccine or vaccination programme [54]</td>
</tr>
<tr>
<td><strong>Neutral</strong></td>
<td>Posts that do not convey pro- or anti-vaccine messages, approve or disapprove of vaccination; no sentiment or opinion [32,56,63,74,89,90,95,96,99,100]</td>
</tr>
<tr>
<td></td>
<td>Sentiments or attitudes ambivalent (containing both positive and negative sentiments) or unable to be determined [63,68,98,127]</td>
</tr>
<tr>
<td></td>
<td>Reports of research findings, facts [53,74]</td>
</tr>
<tr>
<td></td>
<td>Individuals sharing information that they have been vaccinated, without any associated sentiment [53]</td>
</tr>
<tr>
<td></td>
<td>Source of the post neutral [116]</td>
</tr>
<tr>
<td><strong>Ambiguous</strong></td>
<td>Contains both disapproving and approving information [32,96,100,101]</td>
</tr>
<tr>
<td></td>
<td>Unclear [113]</td>
</tr>
<tr>
<td><strong>Hesitant</strong></td>
<td>Universal opposition, opposition to content of selected vaccines or vaccination schedules, conviction that vaccine-related injuries occur at higher rates than commonly believed [129]</td>
</tr>
<tr>
<td></td>
<td>Indecision or uncertainty on the risks or benefits of vaccination [113]</td>
</tr>
<tr>
<td><strong>Frustration</strong></td>
<td>Message contains anger, irritation, contempt, criticism, or source is flabbergasted [131]</td>
</tr>
<tr>
<td><strong>Humour/sarcasm</strong></td>
<td>Message is funny or expresses sarcasm [131]</td>
</tr>
<tr>
<td><strong>Concern</strong></td>
<td>Message contains fear, concern, anxiety, worry, or grief [131]</td>
</tr>
<tr>
<td><strong>Relief</strong></td>
<td>Message contains joy, happiness, relief [131]</td>
</tr>
<tr>
<td><strong>Minimised risk</strong></td>
<td>Message minimises risk of vaccine-preventable diseases or complications [131]</td>
</tr>
</tbody>
</table>

**Other types of content analyses**

In addition to sentiment analyses, some articles provided a more detailed content analysis (for example by looking at the topics discussed on social media, the prevalence of conspiracy theories, or the type of concerns raised by social media users).
Four studies used the Health Belief Model to facilitate content analysis, whether qualitative or quantitative [45,82,96,125].

Five studies described a qualitative thematic analysis of the content of social media, with an inductive or deductive identification of codes and themes [71,108,109,119,134].

An additional seven studies focused their qualitative analysis on language and discourse analysis [76,78,107,115-117,130].

Twenty-one studies coded the content in a quantitative manner, with a pre-defined codebook used to ascertain the absence or presence of themes in the data [45,52,56,72-74,79,85,86,93-96,99-101,103,106,113,118,125].

Four studies used supervised machine learning to code content on social media, including: analysis of image sharing; measuring proportion of vaccine concerns; text-based analysis by comparing percentage of words within different categories; and developing a method for story aggregation [59,82,105,121].

Four studies compared social media posts to disease incidence or outbreaks [66,124,129,131].

One study analysed content differences between 'human' tweets and those coming from bots [57].

**Methods used for coding and analysing sentiments**

From the 60 studies that coded sentiments in social media, 40 (67%) used a manual coding system and 19 (32%) used an automated system. One study used both a manual and automated system [54]. Almost all of the studies that used an automated system were conducted on Twitter (n=16, 84%). Studies where sentiments were coded manually most commonly analysed Twitter (n=14, 35%) as well as YouTube (n=12, 30%), Facebook (n=6, 15%) and fora (n=4, 10%) (Figure 9).

**Figure 9. Number of studies using manual or automated sentiment coding, by social media**

![Number of studies using manual or automated sentiment coding, by social media](image)

**Manual sentiment coding**

Many studies explained that manual coding was conducted based on a thematic or content analysis of sentiments [32,45,56-58,72,73,79,86,96,113,116,131,133]. Reviewers were provided with training, definitions of codes, and codebooks to code the data.

While most articles simply coded the social media posts (tweets on Twitter, pages/posts on Facebook, videos on YouTube, etc.), a small number of articles coded specific parts of the data:

- YouTube: in addition to coding videos on YouTube, two studies also coded comments related to those videos [93,98].
- Facebook: while one study mentioned focusing on comments related to a specific post [105], another study looked for sentiments on pages, groups and places [104], and another one obtained sentiments from main objectives of the pages or groups, the title, content of the introductory description, and messages posted by the group creator [133].
- Twitter: Three articles also discussed how they coded sentiments on Twitter: one looked at the title, headline and source or domain of tweets [68], another one used the verbs, adverbs and adjectives within Tweets [72] and the last one used both Inlink sites and Twitter profile pages [90].
- Three studies also coded the sentiments of hashtags used on Twitter, for example coding #vaccineswork as positive and #killingusslowly, #cdcfraud or #vaxxedthemovie as negative [52,61,86].
- One study also explained coding the hashtag #antivaxxers as positive and #provaxxers as negative, to reflect the fact that social media users against vaccination do not usually talk about themselves as antivaxxers or vice-versa [52].
- Pinterest: the only study conducted on Pinterest coded sentiments from images, captions and links [125].
Reviewers to code the data
- Fourteen studies used two reviewers to independently code the data [45,56,62,69,70,73,79,96,97,99,104,110,125,131], with one study specifying that the two reviewers were blinded to the research question [96].
- Ten studies used three reviewers to code the data [32,72,86,101,105,112,113,127] [68,102], with one study mentioning that the third reviewer was unaware of the study hypothesis [105]. In some of studies that used two or three reviewers, the second or third reviewer sometimes just analysed a small sample of the dataset to establish the reliability of the coding frame. Some studies explained disagreements were resolved by discussion and consensus instead [45,57,69,104,105,113,131].
- One study used four reviewers (with the fourth one consulted only for discrepancies) [57].
- One PhD dissertation used only one reviewer [116].
- Fourteen studies did not specify how many reviewers manually coded the data.

Interrater reliability of the coding
Twenty-three of the 40 articles that manually coded sentiments in social media tested interrater reliability to identify the extent to which the codes correctly represented the sentiments measured.
- Twelve studies used Cohen’s Kappa score to test interrater reliability, and obtained resulted between 0.31-1.0 [56,62,69,73,79,93,94,102,105,110,127,131].
- Two studies used Krippendorff’s alpha and obtained scores of 0.65 and 0.67 [45,96].
- One study used Scott’s Pi, and obtained a measure of 0.84 [125].
- Eight studies did not specify which methods were used to calculate interrater reliability, but stated researchers reached 80–100% agreement on coding [32,68,70,95,97,99,101,113].

Limitations of manual sentiment coding
Studies that used manual coding of sentiment described limitations such as the analysis resulting from a subjective coding and the difficulties of manually ascribing sentiments to posts or tweets [69,93,131]. The difficulty of coding sarcasm, slang and hyperboles was also discussed [52,58,68]. Manual coding was also described as labour intensive, which could reduce the number of posts analysed [56].

Automated sentiment coding
Fifteen studies, all of them conducted on Twitter, discussed the use of leverage or supervised machine learning to code sentiments in their datasets [53,60,63-65,67,74,75,77,83,88,89,91,92,106].
- Five studies described how they trained the machine to learn how to code different sentiments, by first manually coding a range of tweets (between 693 and 8,261 tweets) [65,74,75,89,92].
- Four other studies used Amazon Mechanical Turk to train the machine in sentiment coding [67,77,83,91]. In one study, in which Amazon Mechanical Turk was used to code a random sample of 10,000 tweets, the authors rejected coding from three annotators as their agreement was below 60% [67].
- One study also manually coded tweets after the computer-assisted coding to refine the classification results and randomly selected tweets to validate model classifications after each round of coding [75].
- Two studies used topic modelling to code Tweets and Reddit posts [83,126]. The studies used Latent Dirichlet Allocation (LDA), an unsupervised machine-learning algorithm that automatically determines topics in a text. One of the two studies explains that LDA ‘assumes words in documents co-locate near other words (possibly across documents) because they are related, and the algorithm collects and reports groups of such related words, with the groups representing topics’ [83].
- One study evaluated on Twitter three standard classification algorithms to automatically predict sentiments based on manually rated tweets: Naive Bayes, Maximum Entropy and a Dynamic Language Model classifier [30]. In the end, the authors selected Naive Bayes for their study, using the Natural Language Toolkit.
- One study conducted on Twitter used Lightside, an open-source platform that performs feature-extraction [87]. This study first trained the algorithm on 2,000 manually coded tweets, coded independently by two reviewers, before using Lightside to automatically code the rest of the tweets. The model was evaluated and judged as accurate and valid by the authors [87].
- A study conducted on Facebook and Twitter used BrightView classifier, provided by Crimson Hexagon to code sentiments [129]. BrightView is a ‘supervised learning algorithm based on stacked regression analysis of simplified numerical representation of text’ [129]. To train the algorithm, some of the investigators manually coded a random sample of tweets and posts before and after the automated coding.
- Finally, one study used Topsy to analyse sentiments in tweets. Topsy was software (bought by Apple in 2015) that used natural language processing to establish a sentiment score ranging from 0 (negative) to 100 (positive) [70].

Limitations of automated sentiment coding
Some studies discussed the limitations of automated machine learning systems for sentiment analysis of social media. Three studies discussed the difficulties for models to handle sarcasm and irony [60,89,126] and one explained that slang and abbreviations may make it more difficult for machine learning systems to correctly identify sentiments [70]. This study also mentioned that when URL are shared in tweets they are not coded, however they include important contextual information that may help the sentiment analysis [70]. Three studies also mentioned that automated systems still rely on manual annotation of some part of the data to train the system, which is prone to biases [53,70,126].
**Reach analysis**

### Key messages

- Studies examined the interactions of different social network communities to try to understand how information can spread and be shared on social media and how it can impact overall sentiment towards vaccination.
- The majority of studies measured:
  - the conversational discourse and sentiment in comments
  - the number of followers that posters had on different social media platforms
  - the amount of retweets that key posts received.

Forty-nine studies measured potential social media reach by examining interactions of different social network communities in order to understand how information can spread and be shared on social media.

- Twenty-five studies measured the conversational discourse and sentiment in comments to posts on vaccines [32,45,55,71,72,93,96,98-100,103-105,107-113,117,120,121,125,126].
- Five studies included the number of followers that posters had on different social media platforms, while two of these specifically looked at how the number of followers a user had affected the amount of retweets, and tone of sentiment in relation to those retweets [30,65,82,86,92].
- Nineteen studies mentioned the amount of retweets that key posts received [56,59,65,69-71,73,74,76,79,80,82,84,87,88,129,131,132], with seven of these studies analysing the effect of retweets on reach and influence in more detail [56,59,65,69,70,74,76,79,80,88,129,131].

The following is a brief overview of some of the studies that assessed the impact of followers and retweets on vaccine discussion across different types of social network communities, and the effect this had on overall sentiment towards vaccination.

- One study investigated how two types of communities interacted with each other within conversations on health and its relation to vaccines [88]. From a retweet network, of 660 892 tweets published by 269 623 users – the study compared 'structural community' with another ‘opinion group’ and used community detection algorithms and auto-tagging to measure the interaction, sentiment and influence that retweets had in conversations between the two communities.
- Another study focussed on shared concerns relating to the HPV vaccine [82].
- One study looked at communication patterns revealed through retweeting [80]. They assessed the impact of various sources of information, contrasting diverse types of authoritative content (e.g. health organisations and official news organisations) and grassroots campaign arguments (with the anti-vaccination community views serving as a prototypical example).
- One study analysed the content and source of the most popular tweets relating to the controversial death of a child in Spain - an unvaccinated child who contracted and later died from diphtheria [79].
- Another study analysed both tweets and retweets together to compare the weekly number of online social media messages with the weekly number of reported measles cases in a Dutch measles outbreak [131].
- One study looked at a combination of 83 551 tweets or retweets from 30 621 users [65]. The study defined social connections as the sets of users that followed, or were followed by the users that tweeted about HPV vaccines.
- One study specifically looked at the content of two vaccine-related Twitter datasets, with a focus on retweets and their frequency, and possible influence of retweet frequency on sentiment [56].

### 5.3 Using social media monitoring to inform vaccination communication strategies

#### Key messages

- Some studies recommended that health authorities, governments and/or healthcare professionals start monitoring social media to detect increases in online activity, shifts in sentiments, or other signals that may influence vaccination uptake or confidence in real time.
- Some studies also acknowledged that social media monitoring could help health authorities anticipate, understand and respond to public questions and concerns.
- Results from the monitoring also led some studies to discuss the need for health authorities to increase their presence, and their popularity on social media.
None of the studies formally evaluated how social media monitoring methods and information gathered from monitoring can be used to inform communication strategies. However, some studies provided recommendations and suggestions as part of their discussions and data interpretation.

**Detect increases in online activity, shifts in sentiments, or other signals**
A first set of studies recommended that health authorities, governments and/or healthcare professionals start monitoring social media to detect increases in online activity, shifts in sentiments, or other signals that may have an influence on vaccination uptake or confidence in real time [53, 64, 75, 87, 88, 112, 118, 128].

- A specific recommendation from Kang et al. is that social media monitoring should also incorporate a semantic network analysis of sentiments to improve understanding of the scope and the variability of public attitudes and beliefs [68].
- Two studies recommended identifying the platforms people use to gather information on vaccines or those where misinformation or low-quality evidence is shared [56, 66].
- Seeman et al. also explained that social media monitoring is not only about identifying content and that health authorities should also measure engagement ² to detect more popular content and better understand how it is shared [128].
- Two studies explained that social media monitoring can be used to examine the effectiveness of vaccine promotion strategies and the impact of positive information on vaccination [64, 88].
- Another study also stressed the importance of flagging anti-vaccine websites [128].
- One study also described social media monitoring as an important source of information for adverse-events following immunisation surveillance, particularly anxiety-related reactions [112].

**Anticipate, understand and respond to public questions and concerns**
Some studies also acknowledged that social media monitoring could help health authorities anticipate, understand and respond to public questions and concerns [32, 53, 68, 82, 109, 112, 113, 120, 125, 131].

- Seven studies concluded that real-time information about which topics or issues the public is discussing on social media would enable health authorities to develop tailored, targeted, cost-effective and responsive public engagement or communication strategies, for example by informing press releases and vaccination campaigns, or by directing responses to online content more effectively [53, 66, 96, 117, 118, 130, 133]. More specifically, health authorities should seek inspiration from highly shared information to guide the development of improved messaging using visual designs, features and language formatting [128].
- Two studies raised the possibility of producing spatio-temporal indicators from social media monitoring which could allow public health organisations to better target their health information campaigns to reach those who have concerns about vaccination, for example using an interactive map that would produce notifications when there is an increase in concern about vaccination in certain areas [84, 87].
- Two studies also discussed the usefulness of social media monitoring during infectious disease outbreaks as it may allow health authorities to create adaptive messages during different stages of the crisis, respond to specific concerns on social media and provide rapid responses carefully planned in advance [85, 120].
- Finally Seeman et al. referred to the use of counter-marketing strategies, which they defined as a way to 'proactively identify and expose misinformation and anecdotal evidence' and engage 'in publicly viewable web discussions with authors of anti-vaccine postings' [128]. They argue this type of communication shows constructive and transparent engagement and provokes dialogue rather than shutting down dissent [128].

**Increase presence, and popularity on social media**
Results from the social media monitoring studies also led some authors to discuss the need for health authorities to increase their presence, and their popularity on social media [32, 66, 90, 94, 106, 109, 125, 127], with one study discussing the ethical implications of non-engagement [113]. A few suggestions were made for health authorities wishing to increase their presence on social media and these are summarised in Table 7.

---

² Engagement of users in social media can be measured by analysing comments, shares, likes, retweets, mentions, clicks and saves.
Table 7. Suggestions for increasing presence on social media identified in scoping review studies

### Messages
- Address issues related to vaccine hesitancy (safety of vaccines, effectiveness, benefits, etc.) as well as enhancing public trust in relevant scientific institutions in order to lower institutional distrust [68]
- Provide precise information without too much detail [106]
- Use lay terms and appropriate language [112]
- Use more narrative styles of communication, discuss the protective effects of vaccines, describe the lives saved through vaccines [74,125]
- Share messages of empowerment [130], be respectful [119]
- Communicate evidence-based information [112]
- Aim to enhance public understanding of science and the scientific methods and emphasise the importance of scientific information [90,105]
- Immunise users against the critical arguments they are likely to encounter in the online platform they are entering [118]
- Share new research by sharing media articles rather than publications to engage the general public [74]
- Avoid using the name of brands in messaging which could lead to more negative reactions [75]
- Avoid downplaying negative sentiments, for example by saying side effects are minimal [75]

### Use of emotions
- The use of emotions is controversial. While some authors advise that communication should be emotional and cognitive [94] and that it should elicit emotions such as anxiety, fear, regret and blame [117], others recommend not to use anxiety or anger and avoid fear [106]. One study also explains that fear can be used if balanced properly but should be avoided with certain audiences [130].
- Emotion-filled arenas call for new rhetorical strategies to complement logical arguments [120]
- Be careful with unclear, hostile, inaccurate messages from pro-vaccination sources [105]
- Be non-judgemental and transparent [113].

### Mechanisms
- Provide online dialogues including hosting real-time Q&A sessions [127]
- Create twitter chats [74]
- Adapt messages – deliver more persuasive messages on weekends instead of the middle of the week as negative opinions are more prevalent on these days [64]
- Ensure sufficient resources are available for regular communication [120].

### Reach and engagement
- Enable public health institutions to become skilled influencers [32]
- Decide whether using individuals or organisations will have a higher impact [120]
- Use key opinion leaders on social media to disseminate messages which could reach users who would not normally follow the social media accounts of health agencies [56,75]
- Use hashtags, mentions and links to increase dissemination and reach and to appear in searches and avoid echo-chamber effects where people only hear from their own circles [74,75]
- Non expert sources may be more important than expert sources when reaching parents in online fora [115]
- Prioritise parents with children aged two years and under, as they are highly motivated to participate in discussions, eager and responsive [115]
- Capitalise on awareness days to raise engagement and interest [74]
- If possible use consistent, long-term activity of communications, rather than only media or event-driven episodic messaging [124].

### Responding to social media posts
- Correct misinformation on platforms (advocates and medical professionals) [58] [82,109,112,113]
- Develop systems to instantly detect anti-vaccine tweets and directly reply with counter messages [87]
- Answer questions using the same social media platform where the question was asked [124]
- If faced with bots or trolls, emphasise that the credibility of the source is dubious and that users exposed to such content may be more likely to encounter malware [57].

In addition to these suggestions and tips, Nicholson et al. provided seven key recommendations as to how advocates of immunisation, such as vaccination programme managers, public health institutions, or healthcare professionals may engage in social media, particularly fora with a large group of fence-sitters seeking information [119] (see Box 1 below).
Box 1. Recommendations for health professionals and other advocates of immunisation on how to best participate in online discussion forums about immunisation [119]

- **Resolve questions of whether to actively engage.** There is often a dilemma about whether to respond to posts on forums, which are often monopolised by vocal opponents of immunisation. Here the concern is that participation in the discussion legitimises and even amplifies anti-vaccine arguments. The absence of vaccine advocates may create a void into which misinformation could reign uncontested.

- **Prepare.** Engage a group of vaccine advocates; agree on the most important messages; and who will advance them. Ensure sufficient numbers of designated experts and advocates who are able to type quickly and are available to respond for the duration of the discussion, or arrange 'shifts'.

- **Diversify the support base.** Ensure that each participating advocate is able to address various issues including vaccinology, disease outcomes, primary care practice, and consumers and professionals who can identify with people experiencing specific outcomes, but who support immunisation.

- **Set the agenda.** Vaccine advocates should lead the discussion and avoid the traditionally defensive mode in which debates operate.

- **Introduce messages known to positively influence behaviour.** Promote messages that appeal to the core parental values of protecting children from diseases and facilitating the telling of stories around disease impact. Messages known to increase intention to immunise include emphasising potential regret of not vaccinating in a non-confrontational way; appealing to altruism in terms of protecting the vulnerable; and the ‘band-wagon’ phenomenon where learning that others are vaccinating makes a parent more likely to want to do so. Social media’s advantages include the capacity to role model positive health behaviour. Those who have immunised could be asked what factors influenced their decision, which allows wavering parents to see potential advantages of immunisation that they may not have considered.

- **Do not oversell the product.** It is important to acknowledge that vaccines can produce common minor side effects and rare but serious reactions. Promotional messages that also acknowledge the side effects of immunisation paradoxically lead to lower risk perceptions. Giving information on what is known about vaccine risk defines the boundaries between fact and fiction and signals that the person conveying the information is knowledgeable and balanced, increasing their trustworthiness.

- **Do not attack the opposition.** Compassion and respect should underscore vaccine advocacy. Direct attacks of the opposition often result in vitriolic debates played out before ambivalent audiences who will often make their decisions via an assessment of source credibility.
5.4 Uses, benefits and limitations of social media as an intervention tool in relation to vaccination

Key messages

Information on social media
- None of the quantitative studies found that providing information on social media regarding vaccination significantly increased uptake or willingness to get vaccinated, which may reflect the methodological challenges of establishing a causal link between vaccine behaviour and social media exposure.
- Information supporting vaccination on Facebook in the US was found to significantly decrease perceived barriers to HPV vaccination, decrease perceptions of risk, and increase knowledge about the HPV vaccine.
- The content matters: loss-framed messages on Facebook were associated with a significantly higher intention of getting vaccinated than gain-framed messages.
- Narratives containing information about vaccine adverse events corresponded to decreasing intention of getting vaccinated.

Online group discussions
- A Facebook-assisted teaching method increased knowledge and intention of getting vaccinated.
- Parents and friends were found to have a strong influence on vaccination decision-making, whether they shared their views online or in person.
- When comparing factual information to personal experiences in fora, no difference was found in the number of responses to each type of post, but responses to personal experiences were more emotional.

Interactive websites
- Interactive websites with a space for parents to contribute with content and discuss concerns were found to significantly reduce parental concerns around vaccination but no impact was found on vaccine-related attitudes or vaccine uptake.
- A survey in the US found that 50% of parents who accepted, delayed or refused vaccines would use interactive websites if available.

A total of 17 articles describing social media as an intervention tool in relation to vaccination were identified in this review. The articles were divided into three categories of intervention, as described below.

- Interventions using social media as a source of information
- The use of online group discussions to engage the public
- The development of websites with an interactive component.

Annex 8.6 provides an overview of the studies on social media as an intervention tool in relation to vaccination, including a short description of the intervention and outcomes/results.

5.4.1 Interventions using social media as a source of information

Ten articles, published between 2012 and 2019, described how social media could be used to provide information about vaccination to the public, thereby aiming to address vaccine hesitancy [43,139-147]. Of these, five interventions used Facebook, one used an online forum, one used YouTube and three used a mix of social media tools (Twitter, Facebook and Vine; Instagram, Facebook, Twitter and YouTube and Facebook and Instagram). Most of the studies were conducted in the United States (n=4), with other studies conducted in Germany (n=2), Canada (n=2), Italy (n=1), and globally (n=1). Three interventions addressed vaccination in general, five focused on HPV vaccination and two on influenza vaccination.

Exposure to messages and video contests
- A qualitative study found that exposure to messages and video contests (participants submitted videos where they were asked to finish the sentence ‘I received the HPV vaccine so that I have time to...’) about HPV vaccination on Facebook, Twitter, and Vine seem to increase uptake of HPV vaccination among some participants[147]. None of the quantitative studies assessing the impact of social media information in relation to vaccination, vaccination uptake or willingness to get vaccinated found a significant effect [144,145].

Impact of advertisements
- One study, looking at the impact of advertisements relating to HPV vaccination posted on Facebook (including cues for action to motivate adolescents to seek vaccination), found that out of 155 110 adolescents reached and 2 106 engaged with the messages (e.g. liked or shared posts), only 152 had received at least one dose of HPV vaccine (significance not measured) [143].
Differences between gain-framing (i.e. health benefits from getting the HPV vaccine) and loss-framing (i.e. negative consequences of not getting the HPV vaccine) messages[142].

- One study found that participants exposed to a loss-framed message on Facebook had a significantly higher intention of getting vaccinated than those in the gain-framing condition (p<0.05). This same study also found that participants exposed to Facebook messages perceived lower barriers to getting vaccinated against HPV than those exposed to a newspaper message (p<0.05), but also perceived the severity of HPV to be lower (p<0.05). No significant effect was found on the perception of benefits of vaccination [142].

Impact of pro-vaccination or anti-vaccination comments on risk perception

- One study conducted in Germany on Facebook found that readers exposed to the post and comments supporting vaccination had a lower perception of risk than readers exposed to comments opposing vaccination. The study also found that participants who read the post with likes had more positive attitudes towards influenza vaccination than those who read the version of the post without any likes [145].

Source credibility

- Another study conducted in Germany attempted to discern the impact of source credibility on resulting vaccination perception [140]. These researchers found that, irrespective of the source, narratives containing information about vaccine adverse events corresponded with decreased intentions of getting vaccinated [140].

Impact of social media on knowledge of the HPV vaccine

- A study conducted in the United States found that participants with greater exposure to Facebook post notifications were more likely to have a higher level of knowledge about HPV and the vaccine, but were no more likely to be vaccinated [144].
- A Canadian study that used social media as one tool in an education campaign on HPV vaccination and cervical cancer concluded that social media did not have a significant impact on HPV vaccination uptake in university students [146].
- Another study in Canada found that the rhetoric-style of a video (whether evidence-based or anecdotal) did not have an impact on medical students’ responses to informational questions about seasonal influenza and vaccines [43].
- A qualitative study in the United States found that a large majority of the 18 university students in their study exposed to messages on Facebook, Twitter and Vine had heard of HPV vaccination following the campaign and most of them believed the vaccine was successful at preventing cervical cancer [147].

Use of existing national or international social media platforms developed to respond to vaccine hesitancy

- One study looked at Vaccines Today, a website with various associated social media channels (Instagram, Facebook, Twitter, YouTube) developed to provide factual information about vaccination [139]. The study found that their most popular content was a post on their Facebook account ‘how measles can change a life’ (average reading time: 7 minutes 16 seconds, views: 233 996) and an animation video on YouTube showing how herd protection works (53 000 views).
- The second study described an Italian Facebook campaign by the Italian Alliance of Vaccination Strategies, designed to share information about vaccination three times a week using short messages (with images) selected by health professionals and scientific communication experts [141]. The study looked at the number of likes on each of the posts, and found that Facebook event pages were the most popular type of communications, followed by press releases and scientific publications. Press releases were the most shared types of posts, followed by scientific publications and institutional documents. Facebook users were found to like and share more posts on Fridays.

5.4.2 Use of online group discussions to engage the public

The impact of engaging the public in online group discussions on vaccine uptake and confidence was analysed in three articles - one study was conducted in Taiwan [148], one in the Netherlands [149], and one in Germany [150]. The three studies aimed to observe effects of online group discussion on behaviour and attitudes about vaccination.

- The Taiwanese study found that participants receiving a Facebook-assisted teaching method were more likely to have the intention to be vaccinated than others who received traditional teaching instructions [148]. Knowledge concerning vaccination was significantly higher in the intervention group than the control group.
- The Dutch study asked parents to share opinions in an online group discussion about vaccinating their daughters [149]. The results show that parents online had a similar influence to that of friends and offline peers. Nonetheless, family members appear to have the strongest influence, suggesting that social media interventions might need to concentrate on family members rather than individual decision-makers.
The German study compared the use of factual information and personal experience in an Internet forum post on the subsequent nature and volume of responses [150]. The researchers found that while personal experience posts did not result in significantly more responses, the responses were more emotional in nature [150].

5.4.3 Development of websites with an interactive component

Four articles reported on websites with built-in interactive, social-media like components and its effects on vaccine attitudes and beliefs, detailed below.

- Two articles report on the same study, conducted in the United States between September 2013 and 2016 [151,152]. Both studies are based on a single site randomised controlled trial testing the effects of interactive websites. Despite reporting on the same study, both articles had different outcomes: in one study, interventions were associated with significant reductions in parental concerns surrounding vaccination - nonetheless no change was observed in vaccine-related attitudes. In the second article, infants with parents who had received the intervention were twice as likely to have received MMR vaccination than infants with parents in the control group, although this was not significant.

- A third article reports on an interactive website developed by the Italian health authority to inform the population in relation to vaccination safety and benefits [153]. The website was intended for the Italian population in general and for healthcare workers. It used Twitter to advertise its use and drive traffic to the website. Most visits to the website were from populations in Rome and Milan. The website remained one of the top results in Google after only one month of intervention, indicating a high number of visits and the potential of such initiatives.

- One article aimed to create a web-based tool to provide evidence-based information where parents can contribute with content and discuss concerns with other parents and vaccine experts [154]. Based on a manual medical record review, a set of surveys was sent randomly to parents in the US who accepted vaccines, parents who delayed vaccination and parents who refused vaccination. Fifty percent of parents in all three vaccine groups reported they would use the web-based tool more often. The overall results from this study suggest that the web tool may represent an effective intervention tool to help parents make informed vaccination decisions for their children.
6. Discussion

This report provides the results from a systematic scoping review, conducted with the following objectives:

- to identify preferences for using social media as a source for vaccination information and the influence that social media have on individuals’ perceptions of vaccination;
- to identify different social media monitoring methods and tools in monitoring vaccination and assess their strengths and weaknesses;
- to review how social media monitoring methods and information gathered from the monitoring can be used to inform communication strategies;
- to identify the uses, benefits and limitations of using social media as an intervention tool in relation to vaccination (i.e. how effective social media are as an intervention tool for increasing vaccination).

An extensive database search led to the inclusion of 115 articles: 13 on the use of social media, 85 on social media monitoring, 15 on interventions, one with both social media monitoring and a social media intervention, and one with both an intervention and an analysis of social media users’ opinions about social media. The results from these three categories are summarised and discussed in detail below.

6.1 Use of social media for vaccination information

In this systematic scoping review, social media were identified as a common source of information on vaccination. However, the way in which this information is conveyed and consumed was found to vary according to the social media platform used, countries and specific populations. This finding resonates with a global study on social media usage, which found that social media dynamics were dependent on the local social dynamics. This study concluded that, in fact, users shape social media platform dynamics rather than the other way around [23]. Individuals commonly use social media to look for health information, and more importantly, are often exposed to information about vaccination online without necessarily looking for it.

Summary of the key findings on the use of social media for vaccination information and the influence on perceptions

- The types of social media platforms and their use vary by country and by population group (e.g. pregnant women’s consumption of vaccine information on social media was found to be different from the general population).
- There is a need to have an understanding of who may influence decision making, for example one study included in this review found that family members often have the strongest influence on vaccination decision making, highlighting the importance of communication and interventions targeting entire families and possible influencers rather than solely at the main decision-makers [149].
- Social media interventions to address vaccine hesitancy should target specific populations. Public health authorities should first seek to understand what platforms their local populations use (e.g. parents, versus adolescents, versus pregnant women), as well as the local context in which individuals use social media, before developing social media communication strategies.
- The negative relationship between the extent of social media usage and views about vaccination should certainly be evaluated further, especially as social media are an important communication channel in public health. These findings may reflect the fact that information on social media has traditionally been more negative concerning vaccination: as users are more often exposed to negative information and views concerning vaccination online, they themselves become more hesitant to vaccinate [13,22].

6.2 Methodologies to monitor social media in relation to vaccination

This scoping review found a large number of studies published on social media monitoring and analysis around vaccination, with significant increase in the number of articles published since 2015. This increase exposes a growing academic interest in the field of social media in health, particularly within the context of ‘fake news’ and ‘post-factual societies’ [155]. The large number of studies analysing social media relating to vaccination may also represent an acknowledgement of the contribution of social media to growing vaccine hesitancy and a need to better understand how users communicate about vaccination on social media and how information about vaccination spreads between and within online social networks [156].

However, social media monitoring still represents a new methodological approach for health research, with a lack of standardised methodology for collecting and analysing data. While the large number of articles identified via the scoping review provided sufficient evidence to summarise methods (e.g. tools for retrieving social media data, or methods for sentiment and location) that have been used to monitor social media, almost none of the articles...
evaluated the precision and accuracy of their monitoring and analysis methodologies. Lack of evaluation and standardisation is reflected in the fact that articles published on social media monitoring are extremely varied in style, methodology, and complexity. Social media monitoring constitutes a new research methodology, with many challenges for defining methodologies but also opportunities for public health.

A discussion of the findings from the social media monitoring studies is presented below based on the three social media monitoring phases – 1) preparation 2) data extraction and 3) data analysis.

1) Preparation

**Purpose of social media monitoring**
The purpose of social media monitoring in relation to vaccination dictates the platform/s to be monitored, period of monitoring, analysis and messaging to be conducted.

**Representativeness**
Generally, the aim of social media monitoring studies was to provide a better understanding of how the population thinks and talks about vaccination, thereby requiring representativeness to be able to generalise the analysis results to whole populations. Studies where the objectives are to obtain an overview of the use of social media and perceptions of vaccination tend to position social media monitoring as an alternative to surveys or qualitative interviews in obtaining data on vaccination beliefs and opinions, without acknowledging that the notion of representativeness radically changes with social media. There are limitations on the lack of representativeness of social media populations. There is evidence that social media users, especially those discussing vaccination, tend to represent particular population groups (e.g. younger, often female individuals) [87]. In this way, social media monitoring cannot be used as a research tool to increase representativeness and access entire populations, but it can be a research methodology for studying a new type of population.

Social media users could be considered as a new independent population group, and the field of social media monitoring could be seen as an opportunity to understand what information social media users are exposed to and how information about vaccination is shared and spread online. However, social media monitoring comes with challenges in terms of representativeness, as access to data is often limited due to inaccessible private content, the challenge of studying all social media platforms at once, or limitations imposed by automated software. Redefining social media monitoring for vaccination as studying a new type of population may prove valuable for public health, recognising that social media offer opportunities that go beyond updating existing research methodologies. Social media monitoring opens the door to more dynamic research that continuously evolves and responds to a constantly evolving world.

**Twitter bias**
One of the main reasons why there has been such a bias towards the use of Twitter in a majority of studies within this review may be that Twitter provides the most openly available API, both for free and paid access for developers and researchers. There is a need to apply caution to results collected solely from Twitter. Studies using these freely collected tweets only represent a small 1% sample of all tweets posted and are therefore not representative of all posts on vaccine hesitancy [157]. Accessing the free Twitter API also involves issues related to periodical collection – the API itself is restricted to intermittent collection points, so that Twitter’s servers are not overloaded with requests. This means that any collections are limited to pockets of time and do not represent continuous data collection. Therefore even with access to a 1% sample over a period of seven days, there will be gaps in the stream of tweets collected, as Twitter moderates collection times – meaning that even the 1% sample is truncated [158]. Furthermore, population groups are known to access different types of social media platforms, and a focus on Twitter may overlook the concerns of younger individuals, such as teenagers, who more commonly use Instagram or Snapchat [159].

**Ethical considerations around social media monitoring**
It is worth noting that most studies included in this report did not seek ethics approval, as it is often considered that information on social media is public (unless otherwise stated, for instance in private profiles on Facebook). The argument is that social media users who make their data public do not constitute human research subjects, who would be defined as ‘living individuals about whom an investigator obtains data through interaction with the individual or identifiable private information’ [160].

Even though researchers in previous studies may not have been legally compelled to obtain full social media ethics approval, the lack of guidance on good ethical conduct when using social media information can be considered a cause for concern. Issues of confidentiality and anonymisation of data still arise, as some studies included in this review published screenshots of users’ data that included users’ profile names. Another issue relates to data coming from minors, which should be considered more carefully, even when publicly available [160]. While these concerns should not unduly hinder the development of social media monitoring as a research field, they should however highlight that there is a need for guidelines to ensure ethical conduct, respect for social media users, and therefore the importance of submitting research proposals on social media monitoring to ethics boards for approval. While some guidelines have been published on ethical conduct regarding studies recruiting participants online, such as those from the British Psychological Society [136], there is still a large gap regarding social media monitoring.
Recent controversies with regard to the exploitation of users’ data in the Facebook and Cambridge Analytica scandal, and the public outcry of users feeling unnerved about being monitored and manipulated, have indeed opened up discussions and initiatives for legislation concerning the ethics of handling user data from social media in both corporate marketing and research [161]. Facebook announced a number of API changes designed to better protect user information between 2017 and 2019. As a result, these restrictions, along with GDPR laws, pose further limitations on the research that can be conducted on social media platforms [162,163].

**General Data Protection Regulation (GDPR)**

The overall aim of the recently implemented GDPR is to increase people’s control over their own personal data and ‘to protect all EU citizens from privacy and data breaches in an increasingly data-driven world’ [164]. For companies, organisations and researchers this means obtaining consent to use and retain customers’ personal data; while granting more rights to the ‘data subject’ to be informed and to control how their personal data are used. In light of this, digital analytics companies have had to legally adopt the GDPR into data access policies in order to harvest social media data where there is automated access to social media APIs, such as the Twitter Firehose, and the Instagram API. Moreover, social media platforms themselves have had to adapt how data are shared with third parties [135]. Such recent policy changes may in turn change the way that researchers who used automated software to sample social media, will have to anonymise data in the future. They may also restrict which sections of social media platforms (e.g. public Facebook pages versus private groups) are available for research [165]. There have also been steps within the research community to devise ways of anonymising user data in social media research, by differentiating research use of these data from marketing analytics, and devising ways to make sure academic use falls both within GDPR and wider ethical guidelines [135].

2) **Data extraction**

**Complexity of monitoring social media on different platforms over long periods of time**

This scoping review has found that information on vaccination is available across different social media platforms, and that different methods and formats of communication are currently being used to post, share and spread information about vaccination online (e.g. tweets, Facebook and forum posts and comments, images, followers, videos and Pinterest clippings). This makes it hard to have a standardised way of collecting and analysing data, or to obtain a continuous sample of what people are discussing or sharing with regard to vaccine hesitancy.

The majority of studies that had the largest datasets, collected over longer time periods, tended to be those that had access to the API of a social platform such as Twitter, or to automated data collection and media monitoring tools. Studies with smaller samples experienced more limitations and used less sophisticated keyword searches, often relying on manual data collection, and were thus constrained by time, resources, and the limitations of the browser tools being used within the social media platforms.

It was found that the studies using browser search tools within the social media platforms they were analysing had smaller samples that were less representative of the overall population they were studying, while the periods of collection were shorter. The use of browser search tools in general can limit the size and time period of data collected, as these search tools are built for basic searches by the platform’s users, who use them on a smaller scale for general search queries, rather than more detailed comprehensive data retrieval and analysis.

More intensive use of social media APIs requires a strong knowledge of programming, analytics and data harvesting. The use of automated software for media monitoring through commercial social media analytics platforms offers access to such data, however these can be cost-prohibitive, or do not give public health organisations and researchers the kind of data that they require. This is because most automated digital analytics platforms are built with corporate marketing analysis and branded content in mind – and thus not able to directly tackle, annotate or analyse research questions through a social sciences or public health lens [157]. Once harvested, the data need to be cleaned and analysed in a way that answers public health questions, rather than those linked to brand marketing (e.g. brand strength, brand influencers, and brand trends) or product trends [157] [166].

In recent years there have been increasing opportunities for academics to work in partnership with data analytics companies to forge a better understanding of how to look at social media images and text from a social sciences and public policy perspective [167]. While manual searches using browser-based tools within social media platforms have been found to yield smaller sample sizes over shorter periods of time, it might be assumed that studies that have used the paid version of the Twitter API (the ‘firehose’) via automated monitoring, have a more representative sample. This is because access to paid data has been found to offer researchers an array of tweets/posts, users, and more data for analysis, usually with access to all historical and current tweets. However, there are still issues with the relative openness of the paid access to Twitter, Facebook or YouTube APIs, which themselves are still proprietary, and do not advertise the mechanisms behind collection or output of data. Thus, public health organisations and researchers do not know the full details of commercial API sample data, or indeed what percentage of all data they are given. Thus, the commercial/automated API acts as a ‘blackbox’ filter that may not yield representative data [168,169]. Therefore, not only does the commercial API preclude analysis as to the representativeness of the sample but it also prevents public health officials and researchers from fully comparing studies over time, as the API sampling algorithm itself will change.
Studies of social media may often fail to use standardised methods that permit interpretation beyond individual studies. In developing methods to analyse social media data, researchers have not drawn on a coherent body of agreed-upon methodologies. Rather, analysis of the literature shows that methodological choices differ considerably from one paper to another, and the validity of the chosen methodologies often cannot be adequately demonstrated [170]. This may be due to the ever-changing landscape of social media platforms, in terms of the structuring, formatting and access to data. Thus, while there is no standardisation of methods for conducting social media monitoring, it has been found that studies tend to try a little bit of everything – creating an amalgamation of research methods and analyses. There are currently no standards for the right sample size per social network, no recommended time period for different types of analysis per platform, and no recommendations for studying outside or within the extremes of positive or negative views (which are not always representative of the general population). There is also currently no general standardisation of which specific API tools or analytical classifiers should be used for good overall analysis of network discourse, interaction or trends, within the academic or commercial data analytics sphere. However, despite all of these drawbacks, this review has found that the fast-evolving nature of different social media platforms, the cross-over of shared data, boundaries to privacy, and public policy surrounding public discourse on vaccine hesitancy and disease outbreaks, may necessitate a more methodologically diverse approach to keep up with ever-changing developments. It may also be appropriate for methodologies to remain flexible, as the nature and access to social media discourse on vaccines and public health changes.

Changes in platform content
In terms of data flows, as concerns grow about the presence of anti-vaccine sentiments on social media and the effect this has on real-world vaccine uptake, social media platforms are beginning to listen to requests from public bodies and are gradually altering their content. One such platform is Pinterest, which has recently taken anti-vaccine items off its platform [171]. Facebook and YouTube have also pledged to remove anti-vaccine videos from their platforms [172]. YouTube has taken revenue-generating ads off anti-vaccine videos, in a pledge to de-monetise anti-vaccine groups [173]. Facebook has additionally banned anti-vaccine ads targeting specific groups [174], while Twitter has included a ‘Know the Facts’ box for users searching for anti-vaccination tweets [175], and Instagram is using AI to filter anti-vaccine content via an information box directing users to information on vaccines [176].

These actions from social platforms may change what users see and what researchers study in terms of sentiment and vaccine sentiment. Anti-vaccine groups may migrate from platforms that no longer monetise or make it easy for them to share information, to other platforms from which it may be harder to gather data or analyse, as is possible with Twitter and Facebook APIs. As platforms such as Pinterest, YouTube and Facebook change due to political pressure, and begin to moderate the sharing of anti-vaccine and far-right content on their platforms, certain discussions may potentially become even more diversified and complex as a result of the way in which they are shared, engaged and enacted upon within the ever-changing landscape of the internet and social media [177].

The importance of search queries and the choice of keywords
Overall, studies with platforms such as Pinterest or YouTube used simpler monitoring methods (i.e. using the browser search tools) due to restrictions in accessing these platforms’ APIs compared to Twitter. For example, Pinterest necessitates manual sample collection because no API is publicly available to collect pins by either keyword or account handle [125]. In studies using browser search tools, the keyword search queries were much more simplistic, with just one to three keywords used, which means that the quality of the data output may be less stringent than data accessed using more rigorous Boolean search queries when accessing data from the Twitter API. The small number of studies looking at other social media platforms compared to the large bias towards Twitter may again be because Twitter has made its API more easily available, and the data output more rigorous. This makes it an attractive, if not necessarily more representative sample of conversation around vaccine hesitancy across social media.

Poor keyword searches can result in data that are not necessarily representative of the real conversations on the social network being studied. There has been a recent call to better standardise practices of keyword search terms in health research on social media, so that the quality of the data query matches the quality of the data that the platforms give out, and therefore the resulting study [178]. However, there should be enough flexibility to acknowledge the constantly evolving, context-specific nature of social media. It is important to ensure that research questions are also grounded within non-digital empirical research and public health frameworks, so that any social media research around vaccines also demonstrates an awareness of the wider social milieu, and is not unduly skewed or restricted in scope by the constraints of the social platforms or devices used [179].

Visualisation of data
The lack of methodological standardisation discussed above also constitutes a problem in terms of visualisation of data. Studies using sophisticated APIs to retrieve data can also benefit from sophisticated tools to analyse data, such as comprehensive social network analysis charts showing key conversation clusters, influential groups, and scatter plots of influence over time. The less sophisticated the keywords search or tool of analysis, the less detailed and informative the data visualisation may be, with simpler diagrams and tables able to show data for smaller data samples, but these may not necessarily be as representative.
3) Data analysis

The challenge of obtaining location information
Another challenge posed by social media monitoring is the geographical scope of data. Most of the studies identified in this review were either conducted globally or chose not to restrict data to a specific country. One of the challenges is for social media APIs and other monitoring tools to provide easier ways of locating tweets, without infringing on the privacy rights users have chosen. Until this is resolved, social media monitoring with a national or regional scope will remain extremely difficult to conduct.

It is difficult to obtain geo-location data from social media. Many users may decide to keep their location private, which means some studies had to resort to consulting the users’ profile pages or other manual techniques to identify locations (raising ethical considerations). Other studies restricted results by language, generally by using language-specific keywords. As the specific nature of vaccine hesitancy is country- and context-specific, and should be addressed as such, the difficulty in obtaining national social media data on vaccination will also pose challenges when using social media information to inform vaccination interventions and communication strategies.

Analysing complex sentiments
The difficulty of assessing sentiment in the context of public health remains a key problem in almost all articles, where it was found necessary to code social media data so that they could be analysed beyond the basic negative or positive sentiment of marketing analysis. There is a difficulty in coding sentiments such as sarcasm and hesitancy, whether using manual or automated coding [66]. When multiple researchers are used, manual coding and analysis of sentiments, especially complex ones, is often prone to subjectivity biases, and can be extremely time-consuming. However, setting up automated algorithms to analyse data through machine learning requires advanced computing and programmatic skills.

Coding of images
The coding of images on platforms such as Pinterest and Instagram also poses a challenge with automated coding of sentiment, as image coding algorithms are still in their infancy, and not always readily available on a large scale outside of Google’s DeepMind, expensive facial recognition packages or image search. APIs for visual social media platforms such as Instagram and Snapchat are restrictive or even non-existent, even though those platforms are increasingly being used, particularly by younger individuals. Studies analysing videos, for example on YouTube are also more time-intensive and time-costly for researchers, as each video needs to be watched and annotated. This may change now that as of 2018, YouTube allows the download of transcripts (where available), and these transcripts can in turn be put into automated software to analyse sentiment [180].

Methodologically, over the last 10 years, it has been challenging to study vast amounts of visual social media data concerning vaccine hesitancy - studies have focused on examining text [181]. However, while the process of studying large amounts of video and images has previously been labour-intensive, with the need to use human coding of images to discern themes and subjects, the progress of image recognition and AI technology over recent years has meant that conducting rich content analysis studies of big data from images or videos is becoming more prevalent [182]. There will be new insights into public health discourse coming from new and continuing research in the field of multimodal sentiment analysis using video, images, and captioned text analysis [183-186].

Summary of the key findings on social media monitoring
- There is a growing research interest in social media monitoring concerning vaccination, acknowledging the role of social media in vaccine hesitancy.
- Social media monitoring is a new area of research methodology, which can help national health authorities understand how information about vaccination is shared and spread online.
- Social media monitoring should take into account important ethical considerations in terms of access to public and private data, the use of human research subjects, and confidentiality and anonymity (particularly for vulnerable populations).
- At present, there are no standardised methods for monitoring and analysing social media in relation to vaccination, and more tools need to be evaluated.
- Social media can easily be monitored manually by researchers or health authorities but this can be time-consuming, and the results can be of limited accuracy or completeness, limiting analysis to small non-representative samples. Automated software can provide better results but it requires highly technical computational skills and can be expensive.
- Most automated analyses are limited to Twitter, which creates an unbalanced representation of online content. Researchers and health authorities should pay attention to the platforms used specifically by their population of interest.
- Vaccine hesitancy is context- and country-specific and social media monitoring should be conducted to reflect this. However, there is still a lack of methods for obtaining location information on social media.
- Sentiment analysis is an important tool for analysing social media content concerning vaccination but is prone to subjectivity biases, especially when conducted manually. While it should go further than simple negative/positive categorisation of sentiments to reflect the complexity of sentiments around vaccination, it can be difficult to code sentiments, such as sarcasm or hope.
• Social media monitoring has public health implications. It can be used to detect increases in online activity, shifts in sentiments or other signals of decreasing confidence in vaccination; as a tool for health authorities to increase their presence and popularity on social media; and finally as a real-time listening tool to anticipate, understand and respond to public questions and concerns.

• Social media monitoring should be seen as a constantly evolving area of research methodology, to reflect the continuous growth of the social media environment, and the constant shift of users and content to newer platforms.

Suggestions for future research

• Evaluation of the different social media monitoring tools (e.g. methods for coding and analysing sentiments could be compared, to identify those offering more valid and reliable results.) This would allow researchers to develop a gold standard or best practice guide on how to conduct media monitoring for health research.

• Visualisation of social media analytics in public health. A growing body of research, both within this review and within social sciences in general, is concerned with developing innovative solutions to the data visualisation problem, looking at both the visualisation of social media discourse and the research field of visual analytics itself. This may have a more cohesive effect on the visualisation of data over time [187].

• Development and improvement of methods for geo-locating tweets.

• Improvement of the understanding of complex themes such as hesitancy, promotional content and discouraging content and development of measurement methods for risk perception, or patterns of change in sentiment over time [188]. This is particularly important for discussions concerning vaccination, which can elicit complex sentiments.

• Coding of more complex sentiments on social media to be able to understand the nuances in sentiments with a view to providing better responses to vaccine hesitancy.

6.3 Review how social media monitoring methods and information gathered from monitoring can be used to inform communication strategies

The studies from the scoping review did not formally evaluate how social media monitoring methods and information gathered can be used to inform communication strategies. However, based on various findings, some studies recommended that health authorities, governments and/or healthcare professionals can monitor social media in order to detect increases in online activity, shifts in sentiments, or other signals that may have an influence on vaccination uptake or confidence in real time. The studies also recognised that social media monitoring could help health authorities anticipate, understand and respond to public questions and concerns. For example, a study was conducted by the European Medicines Agency in 2015 to monitor online discourses around HPV vaccination in Europe ahead of the release of new safety data [189]. Findings from the study were used to identify common public concerns and questions concerning HPV vaccination, which were then addressed during a press conference. The study demonstrated the utility of media monitoring to support communication preparedness. In addition, there are benefits that health authorities could gain from increasing their presence, and their popularity on social media, such as an increase in public trust and recognition.

There is, however, a need for public health risk communicators, researchers and officials to be aware that not all posts are necessarily made by humans, and that sophisticated automated bots and human trolls (posters of polarising content) are actively involved in online public health discourse. Research and algorithmic approaches have found that it is not easy to identify sophisticated bots or trolls, especially as some post both pro- and anti-vaccination narratives, consistent with a strategy of promoting political discord [57].

Summary of key findings on how social media monitoring methods and information gathered from the monitoring can be used to inform communication strategies

• Monitoring can be a useful listening tool for public health institutes to gain a broad understanding of prevailing issues of interest and concerns in certain communities and to detect key themes or questions concerning vaccination among the population.

• Continuous monitoring can be used to investigate how public concerns change over time and how questions about vaccines have tended to change with periodical consistency, enabling health authorities to develop tailored, targeted, cost-effective and responsive public engagement.

• Consistent, long-term communication activity may be more beneficial than reactive or event-driven public health communication, a finding that may be useful for planning policy around public health interventions to increase vaccine confidence.
• Other beneficial uses of monitoring to support health authorities in developing communication strategies include:
  - semantic network analysis of sentiments;
  - identifying the platforms people use to gather information about vaccines;
  - measuring engagement to detect more popular content and better understand how it is shared;
  - examining the effectiveness of vaccine promotion strategies;
  - flagging anti-vaccine websites;
  - information on adverse-events following immunisation surveillance;
  - producing spatio-temporal indicators to determine where and when concerns are growing;
  - during vaccine-preventable disease outbreaks, creating adaptive messages at different stages of the crisis.

Suggestions for future research
• More detailed evaluations of how social media monitoring methods and information gathered from monitoring have informed different communication strategies
• Detailed sharing of practices and country experiences of utilising social media monitoring and analysis in forming communication messages and strategies.

6.4 Understanding the uses, benefits and limitations of using social media as an intervention around vaccination

Three types of intervention using social media to address vaccination have been identified through this systematic scoping review - interventions that use social media as a communication channel to share information with the public; interventions that engage the public using online group discussions and interventions that use interactive websites with an integrated social media component to provide information and engage users.

Effect of social media interventions on vaccine uptake

None of the interventions summarised in this scoping review were found to significantly increase vaccine uptake. However, we should be careful when interpreting this finding. First of all, it is very rare to be able to point to an intervention and say with precision that an individual was vaccinated specifically because of that intervention (or its social media component). Furthermore, the results from this review may not specifically reflect the benefits and limitations of social media as a communication channel since they are dependent on the type of content and messaging strategies used in these interventions and the fact that social media are only one of many channels for communicating with the public. This demonstrates the complexity of establishing the benefits and limitations of social media as a tool for addressing vaccination, and the importance of other factors that may influence vaccine uptake when communicating (such as targeted messaging, choice of language, style and framing of messages, engagement of users, or source of information.)

One study showed that loss-framed messages on Facebook were associated with a significantly higher intention to get vaccinated than gain-framed messages [142]. Another study showed that whenever adverse events are mentioned in a narrative manner, intentions to vaccinate decrease – no matter whether the information comes from pro- or anti-vaccination sources [140]. These results highlight the fact that social media should not be seen as a magic bullet for addressing vaccine hesitancy but should be used as part of a broader communication strategy that acknowledges the influence of these other factors. If used adequately, social media have been seen to successfully mitigate vaccine hesitancy. For example, Denmark's and Ireland's successful strategies of using social media platforms to engage with vaccine-hesitant parents and restore confidence in HPV vaccination eventually led to an increase in HPV vaccine coverage [33,34].

Effect of social media interventions on attitudinal change

The impact of social media interventions on attitudinal change seemed easier to verify than on vaccine uptake. Some interventions conducted with the aim of providing information about vaccination on Facebook in the US were found to significantly increase knowledge in relation to the HPV vaccine, while decreasing perceived barriers to HPV vaccination and perceptions of risk [142-144]. Facebook-assisted teaching methods were also found to increase knowledge and intentions to be vaccinated in Taiwan [148]. A randomised-controlled trial in the US found that interactive websites with a space for parents to contribute with content and discuss concerns significantly reduced parental concerns concerning vaccination – although no impact was found on vaccine-related attitudes [151].

Many of the metrics that measure user engagement should be analysed carefully, as stated by the concept of 'vanity metrics' where positive feedback (such as views and likes) does not necessarily reflect the real performance of a social media strategy. Much of the data attached to social media are not intrinsically useful for furthering the aims of specific campaigns. While numbers may look appealing (e.g. a large number of likes and viewers), it is hard to say how they might be linked to particular behaviour. More detailed evaluations and surveys are needed to confirm those results.

Outcomes of social media interventions and their content messaging were found to vary by nationality and local culture and it is therefore difficult to summarise the benefits and limitations of using social media as an intervention tool in relation to vaccination. Furthermore, local cultures and politics filter through an international
arena where geography does not explicitly matter. Hence, local concerns and politics about vaccines exist offline and then encounter each other in various fora which are completely location-agnostic. That may pose challenges when considering country-specific interventions; knowing how specific campaigns targeted specific geographies or handled this challenge would be particularly interesting.

Another reason why this scoping review cannot identify the benefits and limitations of social media interventions to address vaccine hesitancy is the lack of standardised approach, the different methodologies used and the range of research questions. While this richness in research contributes greatly to the understanding of how vaccine hesitancy and confidence can be addressed, the downside is that it makes it difficult to compare and establish common ground for interventions.

**Summary of the key findings on social media interventions to address vaccine hesitancy**

- Although no social media intervention was found to significantly increase vaccine uptake, it may be difficult to accurately link an individual's vaccination status to a specific component of an intervention. This is particularly true as social media are only the channel for communication and other factors, such as the content or style of messages (loss-framed vs gain-framed messages, narratives vs. scientific facts) also influence beliefs and behaviour.
- Social media interventions were found to positively influence attitudes related to vaccination, including knowledge, perceived barriers and risk perceptions.
- Results vary by country and population group and it would be very helpful if national health authorities that have used social media to respond to vaccine confidence evaluated the impact of their interventions and shared their findings.

**Suggestions for future research**

- More detailed evaluations and surveys are needed to see how metrics, such as number of likes and viewers, might inform specific strategies and drive particular behaviour.
- Further research is needed on different types of communication strategies and how they influence vaccine uptake, such as targeted messaging, choice of language, style and framing of messages, engagement of users, or the source of the information.
- More studies are needed to confirm the effects of social media interventions in different contexts and there should be more sharing of experience across different countries.

**6.5 Limitations of this systematic scoping literature review**

The findings from this systematic scoping review should not be discussed without mentioning some study limitations. While an extensive search strategy was used to identify articles - screening multiple databases and using a comprehensive set of keywords - the search was only conducted using English keywords. This could have influenced the finding that most articles use English keywords to monitor social media. Articles in Spanish and Italian were included for analysis, and although no articles were found in other languages, a more comprehensive search using keywords in other languages could have identified a larger number of articles.

In order to strengthen the selection process, two reviewers independently screened all articles by title and abstract, and then by full text. However, it is important to note that data extraction was conducted by four researchers, who divided the 115 articles among themselves. Although they used the same data extraction sheet, this could have led to some inconsistencies in data extraction.

While the search for interventions and social media monitoring strategies was conducted in a systematic manner that should have identified all articles published on these topics, some articles may have been missed on social media users' preferences and vaccination information sources. It is possible that articles which did not specifically mention social media as a finding in their abstract might have been overlooked and excluded from the study. The number of articles included in the report for this category should therefore be treated with caution.

Finally, the use of social media to address vaccine hesitancy (whether in the form of social media monitoring or interventions developed to communicate using social media) is still relatively new. Many experiences and real-life cases have not been published in publically available peer-reviewed journals or reports, and could therefore not be included in this review. The review may therefore not represent all the methods and interventions that have been developed to monitor social media and address vaccine hesitancy.
7. Conclusions and the way forward

As social media are becoming part of everyday life, exposure to online information about vaccination, often negative, is becoming more common. This has been shown to contribute to a decrease in public confidence in vaccination. Vaccine hesitancy is now seen by many national and international immunisation specialists as a major threat to public health.

The increasing use of social media by individuals to find information about vaccination, together with the ever-growing volume of information against vaccination available on social media should constitute a call for action. Vaccine hesitancy cannot be addressed unless we are better able to understand the role that social media play in vaccine decision-making, the type of information that social media users are exposed to and the way in which this information is spread and shared across the world.

This review has found that while many studies have been conducted with the aim of analysing online content relating to vaccination, the methodologies used are extremely varied. As a minimum, it is recommended that health authorities, health professionals or others with an interest in monitoring social media around vaccination collect data relating to the sentiments and content of social media posts, the reach and influence of these posts, and if available, geo-location data. Even though automated systems (whether for collecting or analysing data) require some computational skills and have certain limitations, such as access to certain platforms, they provide the most robust data and are less time-intensive than manual systems. Different APIs or other software may be used and will be particularly helpful for ongoing continuous surveillance systems used to detect signals of decreasing confidence in vaccination. Sentiment analyses, whether conducted using a manual or automated system, should also aim to move beyond a positive versus negative model to truly reflect the content and emotions of social media posts. Decisions around sample sizes and periods of data collection monitored will be highly dependent on the resources available and health authorities should therefore consider the recruitment of staff dedicated to these new types of surveillance systems. Research into the platforms used by local populations in different countries should inform the decision to monitor specific social media platforms. For example, monitoring Instagram or Snapchat will be more beneficial to understand how adolescents share information concerning vaccination.

More evaluation of social media monitoring and analysis techniques, from data collection to content and sentiment analyses, is still needed in order to inform the development of validated standardised approaches. In the context of GDPR and discussions around the privacy of online information, an ethical code of conduct relating to media monitoring should also be developed to ensure the respect and anonymity of social media users.

It is crucial that health authorities and immunisation managers start incorporating social media monitoring as part of their traditional vaccination surveillance strategies – and not only after a confidence crisis occurs. While a gold standard of evaluated and effective methodologies to monitor social media may be useful for health authorities, it is also important that automated software, facilitating more accurate and comprehensive social media monitoring and analysis, is made more accessible and user-friendly, to allow health authorities or those without computational skills to perform media monitoring.

Finally, the purpose and value of social media monitoring should be clearly defined – by both researchers and immunisation specialists. While some may try to use social media as a proxy for what the public thinks about vaccination, the reality is often much more complex. Social media monitoring should therefore be seen as a way of capturing the essence and the movement of online discourse around vaccination in order to better understand how it can influence public perceptions and decision-making concerning vaccination. Such evidence could then inform the development of targeted interventions to maintain or restore public confidence in vaccination.

The purpose of this review was to analyse the social media monitoring techniques and interventions. A potential next step could be to conduct a deeper analysis of the key themes retrieved from the results of the studies addressing social media monitoring of vaccination and how these results can further support public health institutes with monitoring and communication related to vaccine hesitancy.
References

1. London School of Hygiene and Tropical Medicine. Vaccine Confidence Project [internet]. Available from: https://www.vaccineconfidence.org/


5. Fila A, Bella A, Del Manso M, Baggieri M, Magurano F, Rota MC. Ongoing outbreak with well over 4 000 measles cases in Italy from January to end August 2017– what is making elimination so difficult? Eurosurveillance. 2017;22(37).


45. Luis MLR. Who gives a “Like” about the HPV vaccine? Kansan parent/guardian perceptions and social media representations. Dissertation Abstracts International Section A: Humanities and Social Sciences. 2018;79(4-A(E))


164. EU GDPR. GDPR Key Changes: An overview of the main changes under GDPR and how they differ from the previous directive 2015. Available from: https://eugdpr.org/the-regulation/


## Annex 1.

### Search strategy developed for Embase and adapted to different databases

| 1 | ("health 2.0" or "medicine 2.0" or "web 2.0" or "web 2.0s" or "43 things" or "500ps" or "about.me" or "academia.edu" or acfun or advogato or afreecatv or "afreeca tv" or "album2" or android or anobii or aparat or "archive.org" or asianavenue or "asian avenue" or asmallworld or "a small world" or athlinks or "audimated.com" or "baud tieba" or baying or bbm or bebo or bibsonomy or "biane.no" or billibili or bitchute or blackplanet or "black planet" or "bilip.tv" or blog* or "bolt.com" or bookmarksync or "bookmark sync" or "break.com" or busuu or buzznet or cafemom or "care2" or caringbridge or citelike or "classmates.com" or cloob or "commons.wikimedia.org" or "community manag*" or connotie or couchsurf* or "couch surf*" or cozytoc or crankyroll or cucumbertown or "cyber spac*" or cyberspace or cyworld or dacast or dailybooth or dailymotion or daum or dayviews or "de.linho.us" or delinious or "del.icio.us" or delicious or deviantart or diaspora* or digg or disq or disaboom or "distribution list*" or "do2day" or doctissimo or dontstain or douban or "exoxmed" or "draugiem.lv" or "dreamwidth" or "dronestagram" or ".oxy.co" or "e health*" or ehealth or "e-health" or elofton or elixio or ello or engagemedia or "engage media" or "english, baby!" or "eons.com" or etoro or "e-toro" or "experience project" or expov or "expo TV" or facebook or faves or fettife or filmaffinity or "film affinity" or filmow or flickrethinking or "flewing wing" or flickr or fluster or "focus.com" or folksnom* or fora or forums or futuki or fotolog* or "fotopic.net" or foursquare or friendica or friends reunit* or friendship or fuellyblog or "funnyordie.com" or funshion or furl or fyuse or "gab.ai" or "gaia online" or gamedra or "gamer DNA" or "gapyear.com" or "gathern.com" or "gays.com" or "gazopa bloom" or "geni.com" or gentlemint or "geograph britain and ireland" or getlue or gifycat or gifboom or girlsguy or gns or gnotube or gogoyo or goodnestvs or goodreads or goodvistas or google or google or "grpetto" or "grpetto share" or "hr share" or "hr3" or "hospitality club" or hootlist or "hr.com" or "hub culture" or "ibibo or "idents.ca" or imageshack or imgesaeq* or imgr or "imm.fo" or "in da bang" or influencer or instagram* or ip or ipads or ipernity or iphone* or "irc-galleria" or italki or itsmy or jadu or jalibum or jiepang or "kaixin001" or kakao talk or "king of glory" or kwibox or "kodak gallery" or laibhaari or "last.fm" or "late night shots" or "leagie of legends" or letv or librarything or lifeknot or linkedin* or linksapts or listography or liveljourn or livestreak or livemocha or lockerz or "ma.gnolia" or makeoutclub or mashup* or "mash up*" or mayomo or meetup or meettheboss or meetupup or "meet up*" or mfeedia or megavideo or mendelei or mevio or "micropub*" or microblog* or millatfacebook or mix* or "mobile media gallery" or moco space or "mouthshut.com" or multi or musnnet or "muzu.tv" or "my opera" or myheritage or myspace or "my space" or myvideo or "nasza-klaosa.pl" or naver or netlog or "new media" or newgrounds or newsvine or nexpia or "nico doiga" or ring or "ondoklassniki" or one drive or oneworldbd or "online commun*" or "on-line commun*" or "open diary" or openfilm or "ora tv" or orkut or outeverwhere or "ovi share" or panoramaio or partyflock or patientslike" or patients like me or peernet or phanfare or photoblog* or phottobucket or "photo sharing" or picasa or pinboard or pingsta or pintrest or pixedy or pixor or plaxo or playfire or "playlist.com" or plunker or podcast* or pololo or "pq video" or queueup or quora or qzone or "radiator.net" or rapt or ravely or "rdf site" or "real simple syndication" or "really simple syndication" orreddit or rediff or renren or retweet* or "re -tweet*" or "reverbnation.com" or revver or "rich playlist.com" or plurk or podcast* or poolwo or "qq video" or quechup or quora or qzone or "radar.net" or raptr or ravelry or "rdf site" or rooster teeth or "rss feed*" or rumble or rutube or ryze or "sapo videos" or schooltube or sclension or "second life" or securetribe or sevenload or sharethemusic or "share the music" or shellfri or shutterfly or simple or "sina weibo" or sitebar or sitebarr or skoob or skype or skyrock or smartphone* or smugmug or snapshot* or snapfish or "social media" or "social media" or "social network*" or socialvibe* or "sonico.com" or soundcloud or "sound cloud" or "spot.im" or "spring.me" or "stage 32" or stickam or streamzoo or streame or "street life*" or "students circle network" or starch and reunit* or stranger or stewart or stewart or stewart or "students circle network" or steventhenow or "students circle network" or studwix or stumbleupon or talkbiznow or "taping.tv" or "taringal" or teateachstreet or telegram or "tencent qq" or "tencent zone" or termwiki or "the sphere" or thestudentroom or "the student room" or tinder or tingly or "travbuddy.com" or travellerspoint or "tribe.net" or triluliu or "trombi.com" or troopet or trovebox or tsu or tuduo or tuenti or tumblr or "tv uod" or twitter or tuvine or twitch or twitter or tyted or unsplash or untapped or uplink or "user generated content" or "vampirefreacks.com" or "vbbox7" or vechi or viadeo or viber or viddor or viddsee or videoegg* or vidme or vidyak or vimeo or vix or vine or vix or vix or vr or virtual community* or "vlog" or vox or wattpad or wayz or we heart it* or "web 2" or "web page*" or "web site*" or "weblog*" or "webcast*" or webmd or webpage* or webscan or "website*" or weheartit* or weheartit* or weheartit* or "we heart it" or web or webpage* or "weheartit*" or weheartit* or weheartit* or "world wide web" or "writeaprisoner.com" or xanga or xing or xmarks or "xt3" or yammer or yfrog or yookos or youku or youtube* or "you tube*" or zalo or "zing.vn" or "zoo om" or "zoomon)).t,ab. | 2 |
| mobile phone/ or smartphone/ or blogging/ or social media/ or webcast/ | 1 or 2 |
| vaccin* or in*oculat* or immuniz* or immunis* or jab or jobs or shot or shots).t,ab. | 4 |
| vaccination/ or immunization/ | 6 |
| 3 and 6 | 7 |
| limit 7 to yr="2000 -Current" | 8 |
## Annex 2.

### Description of studies that consider the preferences for using social media platforms as a source of information and influence on perceptions of vaccination

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Using social media to gain/share information about vaccines</th>
<th>Social media influencing vaccine attitudes and/or uptake</th>
</tr>
</thead>
</table>
| Ahmed 2018[39]   | Examine the relationship between social media use and vaccine uptake and determine if there are differences by social media platform. | Social media type: Facebook, Twitter  
Vaccine: Influenza  
Country: United States   | With regard to social media use, the study found that Facebook was a more popular platform (62% of participants) than Twitter (15%) to find information on the influenza vaccine. | This study considered the relationship between social media use and vaccine uptake. Researchers found that individuals who used Facebook or Twitter as sources of health information were more likely to be vaccinated than those who did not use Facebook or Twitter as a source of health information. However, the analysed data also revealed that Twitter users were less likely to be vaccinated than non-Twitter users. |
| Campbell 2017[41] | Understand parents’ opinion on vaccines and vaccine-preventable diseases, their vaccination experiences and what affects their vaccination decisions | Social media type: Facebook, Twitter, Discussion forums  
Vaccine: General childhood vaccines  
Country: United Kingdom | This study found 34% of parents used the Internet to find information about immunisations. Within this group (626 parents), 13% used Facebook or Twitter and 6% used discussion for. | This study found that parents who used chat rooms/discussion fora to find information about immunisation were more likely to report that they had seen or read something that made them doubt vaccinations (31% of parents who used chat rooms/discussion forums versus 8% of all parents). This was also true for parents who used Facebook or Twitter (23%). |
| Dilley 2018[38]  | Develop a comprehensive assessment of HPV vaccination in Alabama, with the goal to make recommendations for tailored multilevel interventions | Social media type: N/A  
Vaccine: HPV  
Country: United States | Multiple study participants (5 of 7 parents) cited social media as a common resource for information. | The study found misinformation on social media to be a significant barrier to getting vaccinated, but also suggested social media as a potential facilitator by providing an avenue to propagate positive messaging about the HPV vaccine. |
| Edelstein 2014[50] | Ascertain what strategies the National Health Service (NHS) trusts in England have used to increase influenza vaccine uptake in their HCWs between 2008/2009 and 2011/2012 and to identify which specific interventions were associated with an increased vaccine uptake overall and by staff group, in order to inform future HCW vaccination strategies. | Social media type: Facebook, Twitter  
Vaccine: Influenza  
Country: United Kingdom | The study reported an increase in the use of social media interventions on Facebook and Twitter to increase vaccine promotion. | In this study, use of Facebook and Twitter were associated with a significantly reduced uptake of vaccines (22% and 24%). |
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Using social media to gain/share information about vaccines</th>
<th>Social media influencing vaccine attitudes and/or uptake</th>
</tr>
</thead>
</table>
| Ford 2018[42] | Determine if the use of social networking sites to gain information on pregnancy vaccinations is associated with women's uptake of the influenza and pertussis vaccines during pregnancy. | **Social media type:** N/A  
**Country:** United Kingdom | This study focused on pregnant women using social networking sites to make decisions on vaccinations during pregnancy. 21% of the participating women reported using social media to find information on vaccinations during pregnancy, with Facebook and WhatsApp being the most used platforms. | 12% of the participants reported that the information they gathered from social media influenced their vaccination decisions. The study found that women who used social media to gather information on vaccinations during pregnancy were 56% less likely to receive the pertussis vaccination during their pregnancy. No significant relationship was found between social media usage and the influenza vaccination during pregnancy. However, the study also found some platforms for social media were not necessarily associated with a decreased vaccination uptake – for example, women who used WhatsApp and LinkedIn were statistically more likely to receive the pertussis and influenza vaccines in pregnancy. |
| Hwang 2018[49] | Investigate the associations between evaluations of health information sources, parental perceptions of childhood vaccination benefits, and the maintenance of vaccination schedules for children (incorporates social media as a health information source) | **Social media type:** N/A  
**Country:** United States | n/a                                                                                                                                                                                                                                                                         | This study found that using social media as a source for health information was negatively associated with parents’ perceptions of the benefits of vaccines. |
| Kim 2018[40] | Examine the relationships between multidimensional health beliefs and HPV vaccine acceptance, and what information sources effectively foster HPV vaccination-related health beliefs. | **Social media type:** Facebook, Twitter, Instagram, etc.  
**Country:** South Korea | The study surveyed undergraduate students in Seoul, South Korea found that 30% of the participants cited social media as a source of HPV information.                                                                 | The findings from this study showed that hearing about HPV and/or the HPV vaccine on social media increased participants’ perception of barriers relating to social norms and talking about HPV/the vaccine. |
| Luisi 2018[45] | Explore how Kansan parents/guardians of HPV vaccine-eligible children perceive the vaccine in the contexts of the health belief model and the social amplification of risk framework, parent/guardian engagement with HPV vaccine-related information, and Facebook representations by general users and the Centers for Disease Control and Prevention during the vaccine's first decade on the market. | **Social media type:** Facebook  
**Country:** United States | In this study 4% of respondents reported that social media was their main source for learning about the HPV vaccine. Additionally, 63% of respondents reported that they had seen some information about the HPV vaccine on social media. Out of the 50 parents and guardians that participated in the study, 28% reported searching for information on the HPV vaccine on social media and 28% reported posting or sharing information about the HPV vaccine on social media. | Approximately 10% of the participating parents and guardians (n = 50) felt that social media increased the fear they have of their children having the HPV vaccine. |
| Margolis 2019[46] | Understand exposure to HPV vaccine-related stories.                                                                                                                                                        | **Social media type:** N/A  
**Vaccine:** HPV  
**Country:** United States | This study found that 11% of parents who heard HPV vaccine stories came across them on social media. Negative accounts or ‘stories of harm’ were more often found on social media (and traditional media) than through other channels of information. | n/a |
| Mena 2012[48] | Analyse willingness of medical students to use technical and informal Facebook pages promoting influenza vaccination of HCWs and determine how many students would actively follow and participate in these pages. | **Social media type:** Facebook  
**Vaccine:** Influenza  
**Country:** Spain | This study explored university medical students usage of the Internet and Facebook to find information on the influenza vaccination of healthcare workers. Approximately 63% of students would accept an invitation to follow a Facebook page with formal, technical content on the influenza | n/a |
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Using social media to gain/share information about vaccines</th>
<th>Social media influencing vaccine attitudes and/or uptake</th>
</tr>
</thead>
</table>
| Moore 2017[44] | Examine the uptake of the MenACWY vaccine amongst a representative population of first-time university students, attending universities in Northern Ireland, and ascertain how effectively the advice to request the vaccine was conveyed and the reasons as to why students did not take up the offer of the vaccine. Ascertain the level of meningitis awareness in this student cohort and identify the best practice mechanisms to promote such awareness in the future. | Social media type: N/A  
Vaccine: Menoplococcal ACWY  
Country: United Kingdom | This study of university students in Northern Ireland found that social media was the least preferred method of communication to promote meningitis/vaccine awareness. | n/a |
| Palanisamy 2018[51] | Assess the influence of social capital and trust in health information on the status of Measles−Rubella vaccination campaign in Tamil Nadu. | Social media type: N/A  
Vaccine: Measles-Rubella  
Country: India | n/a | This study found that parents who refused the measles-rubella vaccine placed greater trust on information gained through WhatsApp and other social media platforms. |
| Robichaud 2012[43] | Examine attitudes of first year medical students to seasonal influenza immunisation and impact of the most popular vaccine-critical YouTube videos on their attitudes towards the seasonal influenza vaccine. | Social media type: N/A  
Vaccine: Influenza  
Country: Canada | At the beginning of this study conducted with medical students, 42% of participants reported using YouTube for health-related purposes and 12% used YouTube to search for health information. Additionally, 68% of participants reported that they never used social networking sites (Facebook, MySpace, etc.) to obtain health-related information. | n/a |
| Zhang 2015[47]  | Examine female college students’ attitudes, subjective norms and perceived behavioural control associated with forwarding information about HPV and chatting about HPV. | Social media type: Facebook  
Vaccine: HPV  
Country: United States | In this small study of female college students, none of the participants shared HPV vaccine information on Facebook. However, 71% expressed willingness to share HPV vaccine information on Facebook. | n/a |
## Annex 3.

### Description of studies on social media monitoring around vaccination

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Methodology</th>
<th>Results (taken from the article’s abstract)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ache2008[93]</td>
<td>Analyse how HPV vaccination is portrayed in video clips and comments on YouTube.</td>
<td>Social media type: YouTube Vaccination: HPV Country: Global/Not specified Period monitored: 8 February 2008</td>
<td>Search strategy: Manual Sentiment analysis: Manual (negative, neutral, positive)</td>
<td># results: 146 videos &quot;Three quarters (n=109; 74.7%) of the video clips portrayed HPV vaccination in a positive manner. One third (n=47; 32.2%) of the video clips had generated at least one posted comment.&quot;</td>
</tr>
<tr>
<td>Addawood2018[52]</td>
<td>Analyse scientific information sharing behaviours on Twitter regarding the controversy over the supposed linkage between MMR vaccine and autism.</td>
<td>Social media type: Twitter Vaccination: Measles Country: Global/Not specified Period monitored: 1 January - 28 November 2016</td>
<td>Search strategy: Automated (Crimson Hexagon) Sentiment analysis: Manual (anti-vaccine, pro-vaccine)</td>
<td># results: 36,428 tweets &quot;People with anti-vaccine attitudes linked many times to the same URL while people with pro-vaccine attitudes linked to fewer overall sources but from a wider range of resources, and they provided fewer total links compared to people with anti-vaccine attitudes. Moreover, our results showed that vocal journalists have a huge impact on users’ opinions.&quot;</td>
</tr>
<tr>
<td>Aquino2017[133]</td>
<td>Estimate the correlation between MMR vaccination coverage in Italy and online search trends and social network activity on autism and MMR vaccine.</td>
<td>Social media type: Mix: Facebook, Twitter Vaccination: Measles Country: Italy Period monitored: 1 January 2010 - 31 December 2015</td>
<td>Search strategy: Manual Sentiment analysis: Manual (anti-vaccination, neutral, pro-vaccination)</td>
<td># results: 19 Facebook pages/groups &quot;A significant inverse correlation was found between MMR vaccination coverage and Internet search activity, tweets and Facebook posts. New media might have played a role in spreading misinformation.”</td>
</tr>
<tr>
<td>Bahk2016[53]</td>
<td>Describe a publicly available platform for monitoring vaccination related content, called the Vaccine Sentimeter.</td>
<td>Social media type: Twitter Vaccination: Polio and HPV Country: Global/Not specified Period monitored: October 2012 - November 2014</td>
<td>Search strategy: Automated (Twitter API+ HealthMap data) Sentiment analysis: Automated (negative, neutral/unclear, positive)</td>
<td># results: Polio: 39,308 relevant polio tweets and 1,534 relevant HPV tweets &quot;For the first event (polio), Twitter response to the attacks on health care workers decreased drastically after the first attack, in contrast to mainstream media coverage. For the second event (HPV), the mainstream and social media response was largely positive about the HPV vaccine, but anti-vaccine conversations persisted longer than the pro vaccine reaction. Using the Vaccine Sentimeter could enable public health professionals to detect increased online activity or sudden shifts in sentiment that could affect vaccination uptake”</td>
</tr>
<tr>
<td>Basch2016[94]</td>
<td>Identify the most popular videos on YouTube related to HPV and describe their content.</td>
<td>Social media type: YouTube Vaccination: HPV Country: Global/Not specified Period monitored: not reported</td>
<td>Search strategy: Manual Sentiment analysis: Manual (discouraging, encouraging, neutral)</td>
<td># results: 70 videos &quot;The majority of videos (81.4%) provided general information related to HPV, discussed the association of HPV infection and the development of cancer (81.4%), and addressed HPV screening (64.3%). Just under one-half (n=34) of the videos addressed vaccination. Fifteen of these were neutral, while six were encouraging and 13 were discouraging. The videos included in this study were viewed ~17 million times, which indicates their potential for influencing public awareness and opinions. Of the videos devoted to HPV vaccination, few were encouraging.”</td>
</tr>
<tr>
<td>Basch2017[95]</td>
<td>Examine YouTube videos dealing with vaccines.</td>
<td>Social media type: YouTube Vaccination: Any Country: Global/Not specified Period monitored: 4 September 2007 - 17 October 2015</td>
<td>Search strategy: Manual Sentiment analysis: Manual (discouraging, encouraging, neutral)</td>
<td># results: 87 videos &quot;The range of view counts was 25,532 to 6,229,835, with a median of 62,075 views per video. Most videos (n=74, 85.1%) were devoted exclusively to the topic of vaccination. The three most common sources of these YouTube videos were consumers (27.6%), TV-based or Internet-based news (26.4%) and individual health professionals (25.3%). Top topics covered were autism causality (47.1% of videos), undiagnosed or poorly understood risks (42.5%), adverse reactions (40.2%) and thimerosal or mercury in vaccines (36.8%). The majority of videos (65.5%) discouraged the use of vaccines.”</td>
</tr>
</tbody>
</table>
| Becker2016[54]     | Explore the value of monitoring social media to understand international public discussion on the paediatric pentavalent vaccine (DTP-HepB-Hib) programme by analysing Twitter messages. | Social media type: Twitter Vaccination: Pentavalent (DTP-HepB-Hib) Country: Global/Not specified | Search strategy: Automated (Twitter API) Sentiment analysis: Manual (negative, neutral/positive) | # results: 7,657 tweets "Only 3.1% of the messages were reactions to other messages, and 86.6% referred to websites, mostly news sites (70.7%), other social media (9.8%), and health-information sites (9.5%). Country mentions were identified in 70.4% of the messages, of which India (35.4%), Indonesia (18.3%), and Vietnam (13.9%) were the most prevalent. In the
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Methodology</th>
<th>Results (taken from the article’s abstract)</th>
</tr>
</thead>
</table>
| Bello-Orgaz2017[55] | Detect communities in Twitter, which are disseminating vaccine opinions in order to analyse how it could be influencing to the rest of users in a particular community, zone, or country. | Social media type: Twitter  
Vaccine: Any  
Country: Global/Not specified  
Period monitored: 15 April - 8 November 2014 | Search strategy: Automated (Twitter API)  
Sentiment analysis: n/a | # results: 1,488,010 tweets  
"Firstly, a preliminary analysis using data from Twitter and official vaccination coverage rates is performed, showing how vaccine opinions of Twitter users can influence vaccination decision-making. Then algorithms for community detection are applied to discover user groups opinions about vaccines. The experimental results show that these techniques can be used to discover social discussion communities providing useful information to improve immunisation strategies." |
| Blankenship2018[56] | Investigate if tweets with different sentiments toward vaccination and different contents attract different levels of Twitter users’ engagement (retweets). | Social media type: Twitter  
Vaccine: Any  
Country: Global/Not specified  
Period monitored: 4 February 2010 - 10 November 2016 (Study A) & 1 January 2014 - 30 April 2015 (Study B) | Search strategy: Automated (Twitter API, Gnip Inc.)  
Sentiment analysis: Manual (anti-vaccine, neutral, pro-vaccine) | # results: 1,545 tweets  
"Among #vaccine tweets, provaccine tweets (adjusted prevalence ratio = 1.5836, 95% confidence interval = 1.2130-2.0713, p < 0.001) and anti-vaccine tweets (adjusted prevalence ratio = 4.1280, 95% confidence interval = 3.1183-5.4901, p < 0.001) had more retweets than neutral tweets. No significant differences occurred in retweet frequency for content categories among anti-vaccine tweets. Among #111 links in provaccine tweets, Twitter (53; 12.9%), content curator Trap.it (14; 3.4%), and the Centers for Disease Control and Prevention (8; 1.9%) ranked as the top 3 domains. Among 325 links in anti-vaccine tweets, social media links were common: Twitter (44; 14.9%), YouTube (25; 8.4%), and Facebook (10; 3.4%). Among highly retweeted #vaccineswork tweets, the most common theme was childhood vaccinations (40%; 81/201); 21% mentioned global vaccination improvement/efforts (42/201); 29% mentioned vaccines can prevent outbreaks and deaths (58/201)." |
| Briones2012[96]    | Analyse the content of YouTube videos related to the HPV vaccine.            | Social media type: YouTube  
Vaccine: HPV  
Country: US  
Period monitored: 1 November 2010 | Search strategy: Manual  
Sentiment analysis: Manual (ambiguous, negative, neutral, other, positive) | # results: 172 videos  
"We found that most of these videos were news clips or consumer-generated content. The majority of the videos were negative in tone, disapproving of the HPV vaccine. In addition, negative videos were liked more by the viewers than positive or ambiguous ones. Accusations of conspiracy theory and infringement of civil liberties were manifested in these videos. The videos also presented mixed information related to the key determinants of health behaviour, as stipulated in the Health Belief Model." |
| Broniatkowski2018[57] | Understand how Twitter bots and trolls promote online health content.       | Social media type: Twitter  
Vaccine: Any  
Country: Global/Not specified  
Period monitored: 14 July 2014 - 28 September 2017 | Search strategy: Automated (Twitter API)  
Sentiment analysis: Manual (anti-vaccine, neutral, pro-vaccine) | # results: 793,690 tweets  
"Compared with average users, Russian trolls (\(c^{2}(1) = 102.0; P < .001\)), sophisticated bots (\(c^{2}(1) = 28.6; P < .001\)), and "content polluters" (\(c^{2}(1) = 7.0; P < .001\)) tweeted about vaccination at higher rates. Whereas content polluters posted more anti-vaccine content (\(c^{2}(1) = 11.18; P < .001\)), Russian trolls amplified both sides. Undetectable accounts were more polarised (\(c^{2}(1) = 12.1; P < .001\)) and anti-vaccine (\(c^{2}(1) = 35.9; P < .001\)). Analysis of the Russian troll hashtag showed that its messages were more political and divisive." |
| Buchanan2014[104]  | Assess the magnitude, interest, purpose and validity of information regarding vaccination available on Facebook and assess whether this information varies by site viewpoint. | Social media type: Facebook  
Vaccine: Any  
Country: Global/not specified  
Period monitored: August 2012 (one point in time) | Search strategy: Manual  
Sentiment analysis: Manual (anti, neutral, pro) | # results: 520 Facebook pages, 196 Facebook places and 187 Facebook groups  
"Of 20 sites, 43% (n=13) were anti-vaccination, 7% (n=2) neutral and 50% (n=15) pro-vaccination. Most sites were most popular with American users. Median members were similar between anti-vaccination (2703 members, range 337–33 631 members) and pro-vaccination sites (2142 members, range 456–61 565 members, P = 0.262); however, anti-vaccination sites accumulated more posts per week by authors (median 15 vs. 3, P=0.031) and members (median 33 vs. 1, P <0.001). Pro-vaccination sites more commonly had commercial purpose (53% (n = 8) vs. 8% (n=1), P=0.02). Anti-vaccination sites more commonly gave medical advice (94% (n=7) vs. 0%, P=0.004). Overall, 48% (n=22) of author posts were concordant with regulatory recommendations; concordance was more common on pro-vaccination sites (78% (n=21) vs. 5% (n=1), P=0.0002)." |
| Cambra2016[97]     | Monitor online discussion on vaccination in Spain on YouTube with the objective of developing an interpretative theoretical framework. | Social media type: YouTube  
Vaccine: Any  
Country: Global/Not specified | Search strategy: Manual | # results: 81,100 videos  
"The results indicate that there are fewer negative videos, but with a longer duration than the positive ones. Countries of origin are mainly from Latin America, particularly Mexico." |
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Methodology</th>
<th>Results (taken from the article’s abstract)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chakrabarty2017[58]</td>
<td>Systematically analyse Twitter messages to obtain a unique view into public sentiment around HPV vaccination.</td>
<td>Social media type: Twitter Vaccine: HPV Country: US Period monitored: 7-13 February 2015</td>
<td>Search strategy: Automated (Twitter API, Python (x,y) and Twython) Sentiment analysis: Manual (negative, neutral, positive)</td>
<td>Finally, YouTube characteristics were valued to share health education messages and to design digital programs of Public Health.*</td>
</tr>
<tr>
<td>Chen2015[127]</td>
<td>Examine media and public reactions to the media coverage of suspected vaccine adverse events and relevant policy changes in the interactive media environment, investigate the relations between online media coverage, Weibo posts and search engine searches, explore public sentiments towards vaccination on Weibo during a Hepatitis B crisis in China.</td>
<td>Social media type: Weibo Vaccine: Hepatitis B Country: China Period monitored: 5 December 2013 - 10 January 2014</td>
<td>Search strategy: Manual Sentiment analysis: Manual (negative, neutral, positive)</td>
<td># results: 20,408 tweets “To maintain feasibility, we used a computerized random generator to obtain a sub-sample of 2,000 of these tweets for in-depth qualitative coding. The four categories that accounted for the largest proportion of tweets included news and media coverage of current events related to the HPV vaccine, discussion of possible associations between receiving the vaccine and sexual behavior, safety of the vaccine, and effectiveness of the vaccine. Multiple inaccurate myths surrounding the vaccine, such as the misconception that it is only appropriate for females, were noted.&quot;</td>
</tr>
<tr>
<td>Chen2018[59]</td>
<td>Understand how images are used in vaccine-related tweets and provide guidance with respect to the characteristics of vaccine-related images that correlate with the higher likelihood of being retweeted.</td>
<td>Social media type: Twitter Vaccine: Any Country: Global/Not specified Period monitored: 11 November 2014 - 8 August 2016</td>
<td>Search strategy: Automated (Twitter API) Sentiment analysis: n/a</td>
<td># results: 277,091 Weibo posts “A total of 17 infant deaths were reported to be associated with Hepatitis B vaccination. Three major waves of high media and public attention were detected. The daily indicators reached their peaks in the second wave after the relevant vaccine was suspended by the authority (from December 20 to December 29, 2013) with 23,200 daily online news reports, 34,018 Sina Weibo posts and 17,832 Baidu search indices. There were significant correlations between the daily amount of online news, Weibo posts, and Baidu searches (p &lt; .001). The contents analysis suggested 1343 out of 168 (83.5%) original Weibo posts expressed negative sentiment with almost 90% in the second wave.”</td>
</tr>
<tr>
<td>Covolo2017[32]</td>
<td>Examine the content of Italian YouTube videos related to paediatric vaccinations and understand the potential of messages in influencing public awareness and opinions.</td>
<td>Social media type: YouTube Vaccine: Any (childhood vaccines) Country: Italy Period monitored: June 2014 - September 2015</td>
<td>Search strategy: Manual Sentiment analysis: Manual (ambiguous, negative, neutral, positive)</td>
<td># results: 1,137,172 tweets “Most vaccine-related images are duplicates (125,916/237,478; 53.02%) or taken from other sources, not necessarily created by the author of the tweet. Almost half of the images contain embedded text, and many include images of people and syringes. The visual content is highly correlated with a tweet's textual topics. Vaccine image tweets are twice as likely to be shared as non-image tweets. The sentiment of an image and the objects shown in the image were the predictive factors in determining whether an image was retweeted.”</td>
</tr>
<tr>
<td>D’Andrea2017[89]</td>
<td>Monitor Italian public opinion from tweets analysis, with reference to the vaccination topic.</td>
<td>Social media type: Twitter Vaccine: Any Country: Italy Period monitored: 1 September - 30 November 2016</td>
<td>Search strategy: Automated (Twitter API + Java Library: Get Old Tweets) Sentiment analysis: Automated (negative, positive)</td>
<td># results: 17,937 tweets “An approach to monitor the Italian public opinion from tweets analysis, with reference to the vaccination topic. By employing the Simple Logistic classifier, we achieved a 75.5% average accuracy for discriminating negative opinions tweets (i.e., not in favour of vaccination) from the rest of tweets.”</td>
</tr>
<tr>
<td>D’Andrea2018[60]</td>
<td>Propose an intelligent system for real-time monitoring and analysis of public opinion about the vaccination topic on the Twitter stream.</td>
<td>Social media type: Twitter Vaccine: Any Country: Italy Period monitored: 1 September 2016 - 31 January 2017</td>
<td>Search strategy: Automated (Twitter API + Java Library: Get Old Tweets) Sentiment analysis: Automated (negative, positive)</td>
<td># results: 112,397 tweets “In tuning the system, we tested multiple combinations of different text representations and classification approaches: the best accuracy was achieved by the scheme that adopts the bag-of-words, with stemmed n-grams as tokens, for text representation and the support vector machine model for the classification. By presenting the results of a monitoring campaign lasting 10 months, we show that the system may be used to track and monitor”</td>
</tr>
<tr>
<td>Reference</td>
<td>Study aim(s)</td>
<td>Study details</td>
<td>Methodology</td>
<td>Results (taken from the article’s abstract)</td>
</tr>
<tr>
<td>-----------</td>
<td>--------------</td>
<td>---------------</td>
<td>-------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td>Deiner2017[129]</td>
<td>Examine Facebook and Twitter discussion of vaccination in relation to measles in a period of several widely publicised outbreaks.</td>
<td>Social media type: Mix</td>
<td>Automated (in favour of vaccination, neutral, not in favour of vaccination)</td>
<td>the public opinion about vaccination decision making, in a low-cost, real-time, and quick fashion. Finally, we also verified that the proposed scheme for continuous tweet classification does not seem to suffer particularly from concept drift, considering the time span of the monitoring campaign.&quot;</td>
</tr>
<tr>
<td>Donzelli2018[98]</td>
<td>Carry out a quantitative analysis of Italian videos available on YouTube about the link between vaccines and autism or other serious side effects in children.</td>
<td>Social media type: YouTube</td>
<td>Automated, Brightview classifier (hesitancy, pro-vaccination)</td>
<td>&quot;Pro-vaccination posts were correlated with the US weekly reported cases (Facebook: Spearman correlation 0.22 (95% confidence interval: 0.09 to 0.34), Twitter: 0.21 (95% confidence interval: 0.06 to 0.34)). Vaccine-hesitant posts, however, were uncorrelated with measles cases in the United States (Facebook: 0.01 (95% confidence interval: −0.13 to 0.14), Twitter: 0.0011 (95% confidence interval: −0.12 to 0.12)).&quot;</td>
</tr>
<tr>
<td>Dredze2017[61]</td>
<td>Examine how different candidates during the 2016 presidential campaign commanded the attention of Twitter users who communicated about vaccination on Twitter.</td>
<td>Social media type: Twitter</td>
<td>Automated (anti-vaccination)</td>
<td>&quot;Before the election, the number of tweets expressing vaccine scepticism and mentioning Trump was three times that of any other candidate. After the election, the daily median number of tweets mentioning Mr. Trump increased from 5 to 22, whereas median mentions of other candidates remained unchanged. During the eight time periods with the highest total volume of vaccine sceptical tweets, 5 were about Mr. Trump, 1 was about Secretary Clinton, 1 was about Dr. Stein, and 1 included both Mr. Trump and Secretary Clinton. In every case, the reactions were positive concerning Mr. Trump (e.g., praising his mention of vaccines in a debate, asking him to assist in supporting the documentary &quot;Vaxxed&quot;), negative towards Ms. Clinton (when she voiced support for vaccines), and mixed towards Dr. Stein. From a subset of 100 randomly selected post-election tweets that mentioned Mr. Trump and an anti-vaccine hashtag, 59% expressed that Mr. Trump would bring policy change favourable to vaccine refusal. The most common themes were investigating the CDC, allowing exemptions or removing mandates, and repealing the National Childhood Vaccine Injury Act, which limits legal and financial risk for vaccine manufacturers.&quot;</td>
</tr>
<tr>
<td>Du2017a[64]</td>
<td>Leverage a hierarchical machine learning based sentiment analysis system to extract public opinions towards HPV vaccines from Twitter.</td>
<td>Social media type: Twitter</td>
<td>Automated (against, not applicable, pro)</td>
<td>&quot;The evaluation of the unannotated tweets corpus showed that the micro-averaging F scores have reached 0.786. The learning system deduced the sentiment labels for 184,214 tweets in the collected unannotated tweets corpus. Time series analysis identified a coincidence between mainstream outcome and Twitter contents. A weak trend was found for &quot;Negative&quot; tweets that decreased firstly and began to increase later; an opposite trend was identified for &quot;Positive&quot; tweets. Tweets that contain the worries on efficacy for HPV vaccines showed a relative significant decreasing trend. Strong associations were found between some sentiments (&quot;Positive&quot;, &quot;Negative&quot;, &quot;Negative-Safety&quot; and &quot;Negative-Others&quot;) with different days of the week.&quot;</td>
</tr>
<tr>
<td>Du2017b[63]</td>
<td>Propose a machine learning system that is able to extract comprehensive public sentiment on HPV vaccines on Twitter with satisfying performance.</td>
<td>Social media type: Twitter</td>
<td>Automated (negative, neutral, others, positive)</td>
<td>&quot;A hierarchical classification scheme that contains 10 categories was built to access public opinions toward HPV vaccines comprehensively. A 6,000 annotated tweets gold corpus with Kappa annotation agreement at 0.851 was created and made public available. The hierarchical classification model with optimised feature sets and model parameters has increased the micro-averaging and macro-averaging F score from 0.6732 and 0.3967 to 0.7442 and 0.5883 respectively, compared with baseline model.&quot;</td>
</tr>
<tr>
<td>Reference</td>
<td>Study aim(s)</td>
<td>Study details</td>
<td>Methodology</td>
<td>Results (taken from the article’s abstract)</td>
</tr>
<tr>
<td>-----------</td>
<td>-------------</td>
<td>---------------</td>
<td>-------------</td>
<td>-------------------------------------------</td>
</tr>
</tbody>
</table>
| Du2018[62] | Develop a scheme for a comprehensive public perception analysis of a measles outbreak based on Twitter data and demonstrate the superiority of the convolutional neural network (CNN) models on measles outbreak-related tweets classification tasks. | **Social media type:** Twitter  
**Vaccine:** Measles  
**Country:** Global/Not specified  
**Period monitored:** 1 December 2014 - 30 April 2015 | **Search strategy:** Automated (DiscoverText.com)  
**Sentiment analysis:** Automated (negative, neutral, others, positive) | # results: 6,000 tweets  
"Cohen kappa intercoder reliability values for the annotation were: 0.78, 0.72, and 0.80 on the 3 dimensions, respectively. Class distributions within the gold standard were highly imbalanced for all dimensions. The CNN models performed better on all classification tasks than k-nearest neighbours, naive Bayes, support vector machines, or random forest. Detailed comparison between support vector machines and the CNN models showed that the major contributor to the overall superiority of the CNN models is the improvement on recall, especially for classes with low occurrence. The CNN model with the 2 embedding combination led to better performance on discussion themes and emotions expressed (microaveraging F1 scores of 0.7811 and 0.8592, respectively), while the CNN model with Stanford embedding achieved best performance on attitude toward vaccination (microaveraging F1 score of 0.8642)." |
| Dunn2015[65] | Examine the association between exposure to negative opinions about HPV vaccines and expression of negative opinions about HPV vaccines among Twitter users. | **Social media type:** Twitter  
**Vaccine:** HPV  
**Country:** Global/Not specified  
**Period monitored:** 1 October 2013 - 1 April 2014 | **Search strategy:** Automated (Twitter API)  
**Sentiment analysis:** Automated (negative) | # results: 83,551 tweets  
"During the 6-month period, 25.13% (20,994/83,551) of tweets were classified as negative; among the 30,621 users that tweeted about HPV vaccines, 9046 (29.54%) were exposed to a majority of negative tweets. The likelihood of a user posting a negative tweet after exposure to a majority of negative opinions was 37.78% (2780/7361) compared to 10.92% (1234/11,296) for users who were exposed to a majority of positive and neutral tweets corresponding to a relative risk of 3.46 (95% CI 3.25-3.67, P < .001)." |
| Dunn2017[66] | Determine whether state level differences in exposure to information on Twitter about HPV vaccine were associated with state level differences in HPV vaccine coverage in the US. | **Social media type:** Twitter  
**Vaccine:** HPV  
**Country:** US  
**Period monitored:** 1 October 2013 - 30 October 2015 | **Search strategy:** Automated (Twitter API)  
**Sentiment analysis:** n/a | # results: 258,418 tweets  
"Topics corresponding to media controversies were most closely correlated with coverage (both positively and negatively); education and insurance were highest among socioeconomic indicators. Measures of information exposure explained 68% of the variance in one dose 2015 HPV vaccine coverage in females (males: 63%). In comparison, models based on socioeconomic factors explained 42% of the variance in females (males: 40%)." |
| Ekram2018[99] | Examine the tone of videos for HPV vaccine and accuracy of information shown of YouTube videos. | **Social media type:** YouTube  
**Vaccine:** HPV  
**Country:** Global/Not specified  
**Period monitored:** 13 November 2006 - 14 April 2014 | **Search strategy:** Manual  
**Sentiment analysis:** Manual (negative, neutral, positive) | # results: 35 videos  
"Most videos were negative in tone toward the vaccine. The tone of the video was not a predictor of video popularity. Pro-vaccine videos were 4 times more likely to report information accurately than anti-vaccine videos. Anti-vaccine videos were more likely to report information incorrectly and omit information. The most frequent commentary themes were concerning serious side effects, conspiracy theories, and vaccines generally being unhealthy." |
| Faasse2016[105] | Investigate the types of arguments and language used by pro- and anti-vaccination individuals within the same conversational context in an effort to better understand underlying thought processes and inform future attitude- and behaviour-change attempts. | **Social media type:** Facebook  
**Vaccine:** Any  
**Country:** Global/Not specified  
**Period monitored:** One week in January 2016 | **Search strategy:** Manual  
**Sentiment analysis:** Manual (anti-vaccination, pro-vaccination, unrelated/unclear) | # results: 1490 Facebook comments  
"Both pro- and anti-vaccination comments used more risk-related and causation words, as well as fewer positive emotion words compared to control comments. Anti-vaccine comments were typified by greater analytical thinking, lower authenticity, more body and health references, and a higher percentage of work-related word use in comparison to pro-vaccine comments, plus more money references than control comments. In contrast, pro-vaccination comments were more authentic, somewhat more tentative, and evidenced higher anxiety words, as well as more references to family and social processes when compared to anti-vaccination comments." |
| Fadda2015[118] | Analysing Italian online debates on paediatric immunisations through a content analytic approach. | **Social media type:** Forums  
**Vaccine:** Any (childhood vaccines)  
**Country:** Italy  
**Period monitored:** January 2008 - June 2014 | **Search strategy:** Manual (Google Search)  
**Sentiment analysis:** n/a | # results: 340 forum threads with 6544 posts  
"The analysis included 6544 posts mentioning 6223 arguments about paediatric vaccinations and citing 4067 sources. The analysis of argument posting patterns included users who published a sufficient number of posts; they generated 85% of all arguments on the forum. Dominating patterns of three groups were identified: (1) an anti-vaccination group (n = 280) posted arguments against vaccinations, (2) a general pro-vaccination group (n = 222) posted substantially diverse arguments supporting vaccination and (3) a safety-focused pro-vaccination group (n = 158) mainly forwarded arguments that questioned the negative side effects of vaccination. The anti-vaccination group was shown to be more active than the others. They use multiple sources, own experience and media as their cited sources of..." |
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Methodology</th>
<th>Results (taken from the article’s abstract)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Furini2018[106]</td>
<td>Understand specific features of the language used to talk about vaccinations on social media platforms.</td>
<td><strong>Social media type:</strong> Facebook <strong>Vaccine:</strong> Any <strong>Country:</strong> Italy <strong>Period monitored:</strong> July 2009 - October 2017</td>
<td><strong>Search strategy:</strong> Automated (Facebook API) <strong>Sentiment analysis:</strong> Automated (anger, anxiety, negative, positive)</td>
<td># results: 237,112 Facebook posts “The obtained results show that anti-vaccination groups use a language that is difficult to refute (e.g. not anxious, not focused on specific health issues or on specific diseases), whereas the analysis of pro vaccination groups reveals much more anxiety and specificity (e.g. family cases, specific diseases or vaccines).”</td>
</tr>
<tr>
<td>Goh2017[115]</td>
<td>Use the elaboration likelihood model (ELM) to investigate the central and peripheral message cues generated by Chinese parents in their online discussions about the rotavirus vaccine.</td>
<td><strong>Social media type:</strong> Forums (Babytree.com) <strong>Vaccine:</strong> Rotavirus <strong>Country:</strong> China <strong>Period monitored:</strong> 2007-2015</td>
<td><strong>Search strategy:</strong> Manual <strong>Sentiment analysis:</strong> n/a</td>
<td># results: 136 forum discussion threads “The results indicated that forum users employed both central and peripheral cues as a joint process when generating information intended to help other parents gain knowledge and make vaccination decisions. Issue-relevant arguments important to vaccination decision included the vaccine’s necessity, side effects and efficacy. Peripheral cues including site-generated sorting cues were associated with posts featuring greater elaboration. New parents had the most doubts, asking the most questions about vaccine issues. Their elaboration, however, was the weakest.”</td>
</tr>
<tr>
<td>Guidry2015[125]</td>
<td>Identify how vaccinations are portrayed on Pinterest, how users engage with vaccination content on the platform, how are HBM constructs represented in vaccination-focused pins and to what extent vaccination-related pins mention issues related to conspiracy theories and civil liberties.</td>
<td><strong>Social media type:</strong> Pinterest <strong>Vaccine:</strong> Any <strong>Country:</strong> Global/Not specified <strong>Period monitored:</strong> 19-21 March 2014</td>
<td><strong>Search strategy:</strong> Manual <strong>Sentiment analysis:</strong> Manual (anti-vaccine, neutral, pro-vaccine)</td>
<td># results: 800 selected pins “The majority of the pins were anti-vaccine, and most were original posts as opposed to repins. Concerns about vaccine safety and side effects were oft-repeated themes, as was the concept of conspiracy theory. Pro-vaccine pins elicited consistently more engagement than anti-vaccine pins.”</td>
</tr>
<tr>
<td>Hernandez- Garcia2018[100]</td>
<td>Determine the characteristics of YouTube videos which provide information in Spanish about the meningococcal B vaccine.</td>
<td><strong>Social media type:</strong> YouTube <strong>Vaccine:</strong> meningococcal B <strong>Country:</strong> Global/Not specified <strong>Period monitored:</strong> 19-21 February 2018</td>
<td><strong>Search strategy:</strong> Manual <strong>Sentiment analysis:</strong> Manual (ambiguous, negative, neutral, positive)</td>
<td># results: 62 videos “A total of 62 videos were analysed, of which 45.2% were produced by television channels, and 58.1% supported the use of the vaccine. Only 11.3% mentioned at least one of the vaccination recommendations of the ministry. There were significant differences in the frequency of the vaccine mode of administration depending on the authorship (OR (95% CI:18.75 (1.73–203.21)), description of its posology (OR (95% CI: 6.36 (1.57–25.75)), and its price (OR(95% CI: 0.11 (0.01–0.95)), and in some vaccination recommendations by the ministry [deficit of properdin, treatment with ecilizumab, and asplenia: OR (95% CI: 9.19 (1.32–63.87)).]”</td>
</tr>
<tr>
<td>Huang2017[67]</td>
<td>Measure levels of flu vaccine uptake aggregated by time, geography, and demographic group, where geographic and demographic attributes are inferred from user profiles.</td>
<td><strong>Social media type:</strong> Twitter <strong>Vaccine:</strong> Influenza <strong>Country:</strong> Global/Not specified <strong>Period monitored:</strong> Three influenza vaccination seasons 2013-2016</td>
<td><strong>Search strategy:</strong> Automated (Twitter API) <strong>Sentiment analysis:</strong> Automated (Does this message indicate that someone received or intended to receive a flu vaccine? (yes, no))</td>
<td># results: 10,000 tweets “In this study, we build and employ several natural language classifiers to examine and analyse behavioural patterns regarding influenza vaccination in Twitter across three dimensions: temporality (by week and month), geography (by US region), and demography (by gender). Our best results are highly correlated official government data, with a correlation over 0.90, providing validation of our approach.”</td>
</tr>
<tr>
<td>Jang2019[132]</td>
<td>Investigate the flow of information about the vaccine-autism controversy between social media and mainstream online news; compare social media and online news in terms of the degree to which media pay attention to the vaccine-autism controversy; and examine different patterns shown in the content coming from the US, Canada and the UK.</td>
<td><strong>Social media type:</strong> Mix: Reddit, Twitter <strong>Vaccine:</strong> Any <strong>Country:</strong> Mix: Canada, UK, US <strong>Period monitored:</strong> 1 February 2015 - 30 September 2016</td>
<td><strong>Search strategy:</strong> Automated (Crimson Hexagon’s ForSight platform) <strong>Sentiment analysis:</strong> n/a</td>
<td># results: 220,458 tweets and 17,661 Reddit posts “Our time-series analysis shows that Twitter drives news agendas, and Reddit follows news agendas regarding the vaccine-autism debate. Additionally, the results show that both Twitter and Reddit are more likely to discuss the vaccine-autism link compared to online news content.”</td>
</tr>
<tr>
<td>Reference</td>
<td>Study aim(s)</td>
<td>Study details</td>
<td>Methodology</td>
<td>Results (taken from the article's abstract)</td>
</tr>
<tr>
<td>-------------</td>
<td>------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Kang2017[68] | Examine current vaccine sentiment on social media by constructing and analysing semantic networks of vaccine information from highly shared websites of Twitter users in the US and to assist public health communication of vaccines. | **Social media type**: Twitter  
**Vaccine**: Any  
**Country**: US  
**Period monitored**: 16 April - 29 May 2015 | **Search strategy**: Automated  
**Sentiment analysis**: Manual (negative, neutral, positive) | **# results**: 26,389 tweets  
"The semantic network of positive vaccine sentiment demonstrated greater cohesiveness in discourse compared to the larger, less-connected network of negative vaccine sentiment. The positive sentiment network centred around parents and focused on communicating health risks and benefits, highlighting medical concepts such as measles, autism, HPV vaccine, vaccine-autism link, meningococcal disease, and MMR vaccine. In contrast, the negative network centred around children and focused on organisational bodies such as CDC, vaccine industry, doctors, mainstream media, pharmaceutical companies, and United States. The prevalence of negative vaccine sentiment was demonstrated through diverse messaging, framed around scepticism and distrust of government organisations that communicate scientific evidence supporting positive vaccine benefits."  |
| Kaptijn2014[69] | Investigate discussions on Twitter around HPV vaccinations to find out what is an effective way to retrieve discussions on Twitter and what are the characteristics of HPV discussions on Twitter. | **Social media type**: Twitter  
**Vaccine**: HPV  
**Country**: Netherlands  
**Period monitored**: March - April 2013 | **Search strategy**: Automated (Twitter API)  
**Sentiment analysis**: Manual (anti-vaccination, doubt, negative, neutral, no opinion, pro-vaccination, positive) | **# results**: 1,639 tweets  
"We find that by tracking the conversations on Twitter relevant tweets can be found with reasonable precision. Although sentiments and opinions change regularly in a discussion, we find few cases of topic drift."  |
| Keelan2007[101] | Characterise the available information about immunisation on YouTube. | **Social media type**: YouTube  
**Vaccine**: Any  
**Country**: Global/Not specified  
**Period monitored**: 20 February 2007 | **Search strategy**: Manual  
**Sentiment analysis**: Manual (ambiguous, negative, positive) | **# results**: 153 videos  
" Seventy-three (48%) of the videos were positive, 49 (32%) were negative, and 31 (20%) were ambiguous. Compared with positive videos, negative videos were more likely to receive a rating, and they had a higher mean star rating and more views. Among the positive videos, public service announcements received the lowest mean (SD) ratings (2.6 (1.6) stars) and the fewest views (median, 213; interquartile range, 114-409). The most commonly discussed vaccine topic was general childhood vaccines (38 videos (25% of the total)). The most commonly discussed specific vaccine was the HPV vaccine (36 videos (24% of the total)). 20 of these were positive, 4 of which were industry sponsored. Of the HPV vaccine-related videos, 24 specifically referred to Merck or Gardasil. Of the negative videos, 22 (45%) conveyed messages that contradicted the reference standard. None of the positive videos made scientific statements that contradicted the reference standard."  |
| Keim-Malpass2017[70] | Evaluate the content of messaging regarding the HPV vaccine on Twitter, and describe the sentiment of those messages by type of user. | **Social media type**: Twitter  
**Vaccine**: HPV  
**Country**: Global/Not specified  
**Period monitored**: Two weeks in June 2015 | **Search strategy**: Automated (Toppsy)  
**Sentiment analysis**: Automated (Toppsy, sentiment score) and manual (negative, neutral, positive) | **# results**: 1,794 tweets  
"The majority of Twitter posts were written by lay consumers and were sharing commentary about a media source. However, when actual URLs were shared, the most common form of share was linking back to a blog post written by lay users. The vast majority of content was presented as polarising (either as a positive or negative tweet), with 51% of the Tweets representing a positive viewpoint."  |
| Krittanawong2017[71] | Assess patients' perception of the influenza vaccine and the reason for its underutilisation. | **Social media type**: Twitter  
**Vaccine**: Influenza  
**Country**: Global/Not specified  
**Period monitored**: 23 July 2009 - 22 October 2016 | **Search strategy**: Automated (Twitter API)  
**Sentiment analysis**: n/a | **# results**: 29,243 tweets  
"The tweets often pertained to self-reports after receiving the influenza vaccine (14%); the reason for not receiving the influenza vaccine (12%); emotional language with positive or negative sentiments (33%); and advertisement, news, or updated research (41%)."  |
| Lehmann2013[134] | Describe the news site and social media website content about influenza vaccination on the Internet, as well as the similarities and differences between these two types of media content. | **Social media type**: Mix: Facebook, Hyves, LinkedIn, Twitter  
**Vaccine**: Influenza  
**Country**: Netherlands  
**Period monitored**: February - April 2012 | **Search strategy**: Automated (Clipit)  
**Sentiment analysis**: n/a | **# results**: 3,552 posts  
"Three overarching themes were found in both media sources: (1) the (upcoming) influenza epidemic, (2) general information regarding the virus, its prevention and treatment, and (3) uncertainty and mistrust regarding influenza vaccination. Social media tended to report earlier on developments such as the occurrence of an influenza epidemic. The greatest difference was that in social media, influenza was not considered to be a serious disease, and more opposition to the flu shot was expressed in social media, as compared to news media."  |
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Methodology</th>
<th>Results (taken from the article’s abstract)</th>
</tr>
</thead>
</table>
| Lopez2017[123] | Identify what information is available to the Chilean population in Spanish on HPV on Wikipedia, Yahoo Answers and a website managed by the Chilean Ministry of Health. | **Social media type**: Yahoo Answers Vaccine: HPV  
**Country**: Chile  
**Period monitored**: 17 April - 3 May 2015 | Search strategy: Manual  
Sentiment analysis: n/a | # results: n/a  
"The information provided by the Spanish version of Wikipedia was accurate; nevertheless a few omissions were detected. The quality of the information provided by the Spanish version of Yahoo Answers was inaccurate and confusing. The Minsal website lacked important information on several topics about HPV even though it is managed and endorsed by the government." |
| Love2013[72] | Report a content analysis of Twitter posts about vaccinations, documenting the sources, the tone, and the medical accuracy of the conversation. | **Social media type**: Twitter Vaccine: Any  
**Country**: Global/Not specified  
**Period monitored**: 8-14 January 2012 | Search strategy: Automated (NodeXL, Social Media Research Foundation)  
Sentiment analysis: Manual  
(negative, neutral, positive) | # results: 6,537 posts  
"A set of 6,827 tweets indicates professional sources were shared most and treated positively. Two-thirds of shared medical content were substantiated. One-third of messages were positive, counter to other research and suggesting that users apply critical thinking when evaluating content." |
| Luisi2018[45] | Explore how Kansan parents/guardians of HPV vaccine-eligible children perceive the vaccine in the contexts of the health belief model and the social amplification of risk framework, parent/guardian engagement with HPV vaccine-related information, and Facebook representations by general users and the Centers for Disease Control and Prevention during the vaccine’s first decade on the market. | **Social media type**: Facebook Vaccine: HPV  
**Country**: US  
**Period monitored**: June - June 2016 | Search strategy: Manual  
Sentiment analysis: Manual  
(negative, neutral, positive) | # results: 19 forum discussions with 2264 comments  
"The analysis of the media releases revealed that the crisis communication of the authorities was timely and factual, yet failed both in using understandable concepts and responding to the emotional needs of people threatened by swine-flu and questioning the safety of the vaccination. These deficiencies intensified emotion-driven discussion, and when people opposed to vaccination managed to secure the central ‘issue arenas’ using the words ‘swine flu’ online, this led to online speculations and exaggeration of threat, excluding the perception of risk to one’s health that the HPV vaccine could cause. However, nearly forty percent of the posts amplified HPV vaccine risk (n = 2,568, 39.5%) and only a very few attenuated risks (n = 186, 2.9%). The vast majority of posts did not discuss ripples (n = 6,110, 93.9%) or impacts (n = 6,312, 97%) from the perceived risks of the HPV vaccine. The researcher also analysed the CDC Facebook posts. Most of the posts had a positive tone (n = 20, 64.5%)." |
| Luoma-aho2013[120] | Find out which issues related to swine flu interested citizens, how the authorities were discussed, what attitudes people harboured towards them and whether the interventions by Ministry of Social Affairs and Health affected the content of the debate. | **Social media type**: Forums (Italehti, KaksPlus) Vaccine: H1N1  
**Country**: Finland  
**Period monitored**: March - May 2010 | Search strategy: Manual  
Sentiment analysis: Manual | # results: 100 news articles on Google News and 100 articles on Twitter  
"Results indicate that 44.0% of the articles (88/200) about the HPV vaccination had a positive tone, 32.5% (65/200) maintained a neutral tone, while 23.5% (47/200) presented a negative tone. Protection against diseases 82.0% (164/200), vaccine eligibility for females 75.5% (151/200), and side effects 59.0% (118/200) were the top three topics covered by these articles. Google News and Twitter articles significantly differed in article source, topic, concerns covered, types of sources referenced in the article, and uses of interactive news articles."

| Ma2017[107] | Understand what contextual factors in a public anti-vaccination Facebook group potentially influence parental assessment of information sources when seeking and sharing experiences, information, and knowledge regarding vaccine safety. | **Social media type**: Facebook Vaccine: Any  
**Country**: US  
**Period monitored**: January 2015 - August 2016 | Search strategy: Automated (Facebook Python API)  
Sentiment analysis: n/a | # results: 122 posts with 1456 comments  
"Findings show that parental information seeking and sharing worked to create an isolated, sentimentalised information context favouring immediacy and emotional impact over scientific research and statistical evidence. Because participants shared fundamental beliefs and goals around vaccines, group members held cognitive authority despite the lack of expertise or evidentiary support in their postings." |
| Mahoney2015[73] | Explore how new media influences the type of public health information users access, as well as the impact to these platforms after a major controversy. | **Social media type**: Twitter Vaccine: HPV  
**Country**: Global/Not specified  
**Period monitored**: 1 August - 31 October 2011 | Search strategy: Automated (Topsy)  
Sentiment analysis: Manual  
(negative, neutral, positive) | # results: 100 news articles on Google News and 100 articles on Twitter  
"Results indicate that 44.0% of the articles (88/200) about the HPV vaccination had a positive tone, 32.5% (65/200) maintained a neutral tone, while 23.5% (47/200) presented a negative tone. Protection against diseases 82.0% (164/200), vaccine eligibility for females 75.5% (151/200), and side effects 59.0% (118/200) were the top three topics covered by these articles. Google News and Twitter articles significantly differed in article source, topic, concerns covered, types of sources referenced in the article, and uses of interactive news articles." |
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Methodology</th>
<th>Results (taken from the article's abstract)</th>
</tr>
</thead>
</table>
| Massey2016[75]     | Quantify HPV vaccine communication on Twitter, and develop a novel methodology to improve the collection and analysis of Twitter data. | Social media type: Twitter  
Vaccine: HPV  
Country: Global/Not specified  
Period monitored: 1 August 2014 - 31 July 2015 | Search strategy: Automated (Black and Colleagues and Microsoft Research)  
Sentiment analysis: Automated (negative, neutral, positive) | A total of 193,379 English-language tweets were collected, classified, and analysed.  
Associated words varied with each keyword, with more positive and preventive words associated with "HPV vaccine" and more negative words associated with name-brand vaccines. Positive sentiment was the largest type of sentiment in the sample, with 75,393 positive tweets (38.99% of the sample), followed by negative sentiment with 48,940 tweets (25.31% of the sample). Positive and neutral tweets constituted the largest percentage of tweets mentioning prevention or protection (20,425/75,393, 27.09% and 6477/25,110, 25.79%, respectively), compared with only 11.5% of negative tweets (5647/48,940; P<.001). Nearly one-half (22,726/48,940, 46.44%) of negative tweets mentioned side effects, compared with only 17.14% (12,921/75,393) of positive tweets and 15.08% of neutral tweets (3787/25,110; P<.001). |
| Massey2018[74]     | Characterise and quantify three types of Twitter messages related to the HPV vaccine: 1) tweets sent by health professionals, 2) tweets intended for a parent audience, and 3) tweets sent by health professionals and intended for a parent audience. | Social media type: Twitter  
Vaccine: HPV  
Country: Global/Not specified  
Period monitored: 1 August 2014 - 31 July 2015 | Search strategy: Automated (Twitter API)  
Sentiment analysis: Automated (negative, neutral, positive) | Of the 193,379 tweets, 20,451 tweets were from health professionals; 16,867 tweets were intended for parents; and 1,233 tweets overlapped both groups. The content of each spike varied per group. The largest spike in tweets from health professionals (n = 851) focused on communicating recently published scientific evidence. Most tweets were positive and were about resources and boys. The largest spike in tweets intended for parents (n = 1,043) centred on a national awareness day and were about resources, personal experiences, boys, and girls. The largest spike in tweets from health professionals to parents (n = 89) was in January and centred on an event hosted on Twitter that focused on cervical cancer awareness month. |
| McNeill2016[76]    | Offer a more detailed and nuanced picture of the opportunities and challenges associated with pandemic health-communication on Twitter. | Social media type: Twitter  
Vaccine: HINI  
Country: UK  
Period monitored: 1 April 2009 - 1 May 2010 | Search strategy: Automated (Gnip)  
Sentiment analysis: n/a | "Network analysis of retweets showed that information from official sources predominated. Analysing the spread of significant messages through Twitter showed that most content was descriptive but there was some criticism of health authorities. A detailed analysis of responses to press releases revealed some scepticism over the economic beneficiaries of vaccination, that served to undermine public trust. Finally, the conversational analysis showed the influence of peers when weighing up the risks and benefits of vaccination." |
| Mitrā2016[77]      | Identify Twitter users who persistently hold pro and anti-attitudes towards vaccination and explore differences in the individual narratives across the user cohorts. | Social media type: Twitter  
Vaccine: Measles  
Country: Global/Not specified  
Period monitored: 1 January 2012 - 30 June 2015 | Search strategy: Automated (Twitter Firehose)  
Sentiment analysis: Automated (anti, pro) | We find that those with long-term anti-vaccination attitudes manifest conspiratorial thinking, mistrust in government, and are resolute and in-group focused in language. New adoptees appear to be predisposed to form anti-vaccination attitudes via similar government distrust and general paranoia, but are more social and less certain than their long-term counterparts. We discuss how this apparent predisposition can interact with social media-fuelled events to bring newcomers into the anti-vaccination movement. |
| Mollema2015[131]   | Compare the number of social media messages with the number of online news articles and with the epidemiological curve (i.e., the number of reported measles cases) and assess the usefulness of social media in tracking factors that might affect vaccination behaviour. | Social media type: Mix: Facebook, Forums, weblogs, Twitter  
Vaccine: Measles  
Country: Netherlands  
Period monitored: 15 April - 11 November 2013 | Search strategy: Automated (Twiqs.nl, Howardishome)  
Sentiment analysis: Manual (concern, frustration, humour/sarcasm, relief) | "There was a stronger correlation between the weekly number of social media messages and the weekly number of online news articles (P<.001 for both tweets and other social media messages) than between the weekly number of social media messages and the weekly number of reported measles cases (P=.003 and P=.048 for tweets and other social media messages, respectively), especially after the summer break. All data sources showed 3 large peaks, possibly triggered by announcements about the measles outbreak by the Dutch National Institute for Public Health and the Environment and statements made by well-known politicians. Most messages informed the public about the measles outbreak (i.e., about the number of measles cases) (93/165, 56.4%) followed by messages about..." |
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Methodology</th>
<th>Results (taken from the article’s abstract)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nawa2016[124]</td>
<td>Categorise questions by conducting detailed qualitative analyses from the clinicians’ viewpoint and to investigate how public concerns regarding influenza vaccinations range over time, particularly in relation to seasonal influenza epidemics.</td>
<td>Social media type: Yahoo! Answers  Vaccine: Influenza  Country: Japan  Period monitored: 1 April 2004 - 7 April 2009</td>
<td>Search strategy: Automated (Yahoo! Answers API (via Python scripts))  Sentiment analysis: n/a</td>
<td>After filtering data, we obtained 1950 questions regarding influenza vaccinations. The three most frequently asked questions were regarding the vaccination schedule, safety, and effectiveness. When we analysed monthly trends in question contents, we noted the emergence of similar questions in the same period every year. Therefore, we classified the time periods of each year into three parts: (1) from April to the commencement of seasonal influenza vaccinations (September), (2) from October until the epidemic period, and (3) the epidemic period. Two interesting results were obtained: concerns regarding effectiveness abruptly increased during the epidemic period and pregnant or breastfeeding women increasingly asked questions regarding feasibility between October and the epidemic period.</td>
</tr>
<tr>
<td>Nicholson2012[119]</td>
<td>Develop an understanding of how epidemiological, scientific and anecdotal evidence interacted with, and shaped, ideas about the MMR vaccine and provide recommendations for strategically responding to future online debates about safe and effective vaccines like MMR.</td>
<td>Social media type: Forums  Vaccine: Measles  Country: Australia  Period monitored: Three hours</td>
<td>Search strategy: Manual  Sentiment analysis: Manual</td>
<td>The analysis of site ages revealed that the battle between the two sides had a long history and is still ongoing. The web scene was polarised with either pro or anti views and little evidence interacted with, and shaped, ideas about the MMR vaccine. The remainder were ambivalent but seeking no information (9%), supportive (14%), or uninterested (15%). Among five author categories, only 4% identified themselves as health professionals. Topics included alleged adverse effects of immunisation (35%); autism spectrum disorders treatment and causes (31%); vaccine ingredients (12%); a conspiracy (9%); immunisation policies (8%); and measles, mumps or rubella (4%). Scientific concepts of evidence failed to compete with lay concepts and personal anecdotes prevailed.</td>
</tr>
<tr>
<td>Ninkov2017[90]</td>
<td>Identify whether webometrics methods are effective in analysing the web presence of vaccine information.</td>
<td>Social media type: Twitter  Vaccine: Any  Country: Global/Not specified  Period monitored: 120 days from 16 May - 13 September 2015</td>
<td>Search strategy: Automated (Topsy)  Sentiment analysis: Manual</td>
<td>The study found far more anti- than pro-vaccine web domains. The anti and pro sides had similar web visibility as measured by the number of links coming from general websites and Tweets. However, the links to the pro domains were of higher quality measured by PageRank scores. The result from the qualitative content analysis confirmed this finding. The analysis of site ages revealed that the battle between the two sides had a long history and is still ongoing. The web scene was polarised with either pro or anti views and little neutral ground.</td>
</tr>
<tr>
<td>Numark2014[78]</td>
<td>Propose a monitoring system with visualisations and analytics of significant vaccine information from Twitter and RSS feeds (VaccineWatch).</td>
<td>Social media type: Twitter  Vaccine: Any  Country: Global/Not specified  Period monitored: 1 April - 20 June 2014</td>
<td>Search strategy: Automated (VaccineWatch)  Sentiment analysis: n/a</td>
<td>The VaccineWatch monitoring system aimed to help identify and extract vaccine-related information from social media data. It provides various visualisations that help users capture both spatial and temporal information between vaccines, diseases, countries/cities, and companies, together with the top 50 tagged terms, messages related to vaccine and disease alerts, and company announcements. The flexible management of data sources and backend processes provides users the extensible and customizable system.</td>
</tr>
</tbody>
</table>
| Orr2016[109]       | Map and describe the role played by social media and mainstream web-based media as platforms for vaccination-related public debates and discussions during the Polio crisis in Israel. | Social media type: Facebook  Vaccine: Polio  Country: Israel  Period monitored: 28 May - 31 October 2013 | Search strategy: Manual  Sentiment analysis: n/a | The traditional media mainly echoed formal voices from the Ministry of Health. The comments on the Facebook vaccination opposition groups could be divided into four groups: comments with individualistic perceptions, comments that expressed concerns about the safety of the OPV, comments that expressed distrust in the Ministry of Health, and comments denying Polio as a disease. In the Facebook group "Parents talk about the Polio vaccination", an active group with various participants, 321 commentators submitted 2289 comments, with 64% of the comments written by women. Most (92%) people involved were parents. The comments were both personal (referring to specific situations) and general in nature (referring to symptoms or wide implications). A few (13%) of the commentators were physicians (n = 44), who were responsible for 90% (40%) of the items in the sample. Half the doctors and 6 % of the non-doctors wrote over 10 items each. This
### Systematic scoping review on social media monitoring methods and interventions relating to vaccine hesitancy

**Reference** | Study aim(s) | Study details | Methodology | Results (taken from the article’s abstract)
---|---|---|---|---
Orr2018[108] | Characterise public engagement with the 2013 polio crisis in Israel in a social media environment. | **Social media type**: Facebook  
**Vaccine**: Polio  
**Country**: Israel  
**Period monitored**: 14 August - 12 November 2013 | **Search strategy**: Manual  
**Sentiment analysis**: n/a | Facebook group formed a unique platform where unmediated debates and discussions between the public and medical experts took place.”  
# results: 40 Facebook conversation threads  
“The qualitative analysis suggested that dialogue became more political than scientific overall, yet the quantitative analysis showed that the discusants did not abandon the scientific nature of the issue at hand.”

Pananos2017[91] | Detect rates of critical slowing down in discussion and uptake of vaccines on Twitter before and after disease outbreaks, and test possibility of building a mathematical model or analytical tools to detect populations at heightened risk of a future episode of widespread vaccine refusal. | **Social media type**: Twitter  
**Vaccine**: Measles  
**Country**: US  
**Period monitored**: 2011-2016 | **Search strategy**: Automated (Twitter API)  
**Sentiment analysis**: Automated (anti-vaccine, other, pro-vaccine) | “We find critical slowing down in the data at the level of California and the United States in the years before and after the 2014–2015 Disneyland, California measles outbreak. Critical slowing down starts growing appreciably several years before the Disneyland outbreak as vaccine uptake declines and the population approaches the tipping point. However, due to the adaptive nature of coupled behaviour–disease systems, the population responds to the outbreak by moving away from the tipping point, causing "critical speeding up" whereby resilience to perturbations increases. A mathematical model of measles transmission and vaccine sentiment predicts the same qualitative patterns in the neighbourhood of a tipping point to greatly reduced vaccine uptake and large epidemics. These results support the hypothesis that population vaccinating behaviour near the disease elimination threshold is a critical phenomenon.”  
# results: 27,906 tweets

Penta2014[117] | Explore HPV vaccine-related conversations posted on discussion forums and provide in-depth insight into people’s perspectives, factors that restricted uptake and particularities of communication about the vaccine. | **Social media type**: Forums  
**Vaccine**: HPV  
**Country**: Romania  
**Period monitored**: 2007-2012 | **Search strategy**: Manual (Google Search)  
**Sentiment analysis**: n/a | “Positive discourses relying on evidence-based arguments or cancer-related experiences battled with negative discourses that focused mostly on pseudo-scientific information and affect-based testimonials. Both camps made use of appeals to authority in order to provide powerful messages. Critics expressed high levels of mistrust in the health system and perceived the vaccine as dangerous, as part of a conspiracy, as unnecessary or as a promoter of promiscuity. By contrast, supporters considered the HPV vaccine to be helpful and criticised the irrationality of opponents. Ambivalence and uncertainty also emerged, along with criticism toward the suboptimal organisation of the vaccination programmes. Findings highlight ways in which views about the vaccine are embedded in broader perspectives about science, the national medical system, society development and economic inequality.”  
# results: 2,240 forum comments

Porat2018[79] | Analyse the most popular tweets in the context of vaccination, documenting the source, topic, tone and sentiment, using the 2015 diphtheria episode in Spain. | **Social media type**: Twitter  
**Vaccine**: Diphtheria  
**Country**: Spain  
**Period monitored**: 1 May - 15 July 2015 | **Search strategy**: Automated (Topsy)  
**Sentiment analysis**: Manual (negative, neutral, positive) | “A total of 722,974 tweets were collected. Prevalence of terms relating to policy and misinformation increased at the onset of the case and after the death of the child. Popular tweets (194) were either pro-vaccination (58%) or neutral, with none classified as anti-vaccination. Popular topics included criticism towards anti-vaccination groups (35%) and effectiveness of immunisation (22%). Popular tweets were informative (47%) or opinions (53%), which mainly expressed frustration (24%) or humour/sarcasm (23%). Popular Twitter accounts were newspaper and TV channels (15%), as well as individual journalists and authors of popular science (13.4%).”  
# results: 722,974 tweets

Radzikowski2016[80] | Study Twitter narrative regarding vaccination in the aftermath of the 2015 measles outbreak, both in terms of its cyber and physical characteristics; contribute to the analysis of the data and present a quantitative interdisciplinary approach to analyse open-source data in the context of health narratives. | **Social media type**: Twitter  
**Vaccine**: Measles  
**Country**: Global/Not specified  
**Period monitored**: 1 February - 9 March 2015 | **Search strategy**: Automated (Twitter API)  
**Sentiment analysis**: n/a | “The data analysis captures the anatomy of the themes and relations that make up the discussion about vaccination in Twitter. The results highlight the higher impact of stories contributed by news organisations compared to direct tweets by health organisations in communicating health-related information. They also capture the structure of the anti-vaccination narrative and its terms of reference. Analysis also revealed the relationship between community engagement in Twitter and state policies regarding child vaccination. Residents of Vermont and Oregon, the two states with the highest rates of non-medical exemption from school-entry vaccines nationwide, are leading the social media discussion in terms of participation.”  
# results: 669,136 tweets

Rivera2016[126] | Examine content, mood and general dynamics of health forum discussions | **Social media type**: Reddit  
**Vaccine**: Any | **Search strategy**: Automated (Reddit API) | “The qualitative analysis suggested that dialogue became more political than scientific overall, yet the quantitative analysis showed that the discusants did not abandon the scientific nature of the issue at hand.”  
# results: 272,862 Reddit comments
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Methodology</th>
<th>Results (taken from the article’s abstract)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skea2006</td>
<td>Measure the spatio-temporal sentiment towards a new vaccine.</td>
<td>Country: Global/Not specified&lt;br&gt;Period monitored: January 2007 - September 2014</td>
<td>Sentiment analysis: Automated, LDA (affirmative, negative)</td>
<td>“Manual annotation resulted in moderate interrater agreement of an average 0.48 Fleiss-Kappa. Despite that, the disposition models for each topic were able to achieve a balanced successful prediction rate of between 68% and 74%, involving considerably better than chance assessment of a commentator’s disposition towards each topic. We observed changes in disposition over time and found areas of disagreement between the supporters and opponents of each topic. Despite the limitations associated with manual annotations, we obtained a wider view on the issues concerning the topics of interest than those offered by previous research.”</td>
</tr>
<tr>
<td>Shapiro2017</td>
<td>Examine discussions about MMR among parents who participated in an online chat forum.</td>
<td>Country: Global/Not specified&lt;br&gt;Period monitored: January 2007 - September 2014</td>
<td>Sentiment analysis: Automated (Twitter API)</td>
<td>Tweets expressing concerns about HPV vaccines made up 14.9% of tweets in Canada, 19.4% in Australia and 22.6% in the UK. The types of concerns expressed were similar across the three countries, with concerns related to ‘perceived barriers’ being the most common. Users expressing concerns about HPV vaccines in each of the three countries had a relatively high proportion of international followers also expressing concerns. “</td>
</tr>
<tr>
<td>Salathé2011[30]</td>
<td>Explore discussion on issues related to vaccination on social media platforms, specifically Twitter and identify the 'influencers' in the conversation.</td>
<td>Country: Global/Not specified&lt;br&gt;Period monitored: January 2007 - September 2014</td>
<td>Search strategy: Automated (NodeXL)</td>
<td>“The findings show that there are six types of influencers that dictate the discourse on vaccination on Twitter which are: celebrity doctor, media organisations, homeopathy promoter, government and government agencies, blogger and renowned medical journal. It also found that some of the influencers have their own circle of audience while some of the influencers are sharing the same crowd.”</td>
</tr>
<tr>
<td>Schmidt2018[110]</td>
<td>Assess whether users' attitudes are polarised on the topic of vaccination on Facebook and how this polarisation develops over time.</td>
<td>Country: Global/Not specified&lt;br&gt;Period monitored: 2009 - 31 May 2017</td>
<td>Search strategy: Automated (Facebook Graph API)</td>
<td>“Our findings show that the consumption of content about vaccines is dominated by the echo chamber effect and that polarisation increased over the years. Well-segregated communities emerge from the users' consumption habits i.e., the majority of users consume information in favour or against vaccines, not both.”</td>
</tr>
<tr>
<td>Sanawi2017[81]</td>
<td>Track whether online postings about the A(H1N1) influenza vaccine were undermining ongoing communications efforts by public health authorities during the fall of 2009 and whether anti-vaccine sentiment escalated after Health Canada's approval of the vaccine.</td>
<td>Country: Global/Not specified&lt;br&gt;Period monitored: 27 October 2009 - 6 April 2010</td>
<td>Search strategy: Automated, NaiveBayes (negative, neutral, positive)</td>
<td>“Websites and blog posts with anti-vaccine sentiment remained popular during the course of the pandemic.”</td>
</tr>
<tr>
<td>Seeman2010[128]</td>
<td>Conduct an international comparison of the proportions of tweets about HPV vaccines that express concerns, the types of concerns expressed and the social connections among users posting about HPV vaccines in Australia, Canada and the UK.</td>
<td>Country: Global/Not specified&lt;br&gt;Period monitored: 2009 - 6 April 2010</td>
<td>Search strategy: Automated (Twitter API)</td>
<td>“Tweets expressing concerns about HPV vaccines made up 14.9% of tweets in Canada, 19.4% in Australia and 22.6% in the UK. The types of concerns expressed were similar across the three countries, with concerns related to ‘perceived barriers’ being the most common. Users expressing concerns about HPV vaccines in each of the three countries had a relatively high proportion of international followers also expressing concerns.”</td>
</tr>
</tbody>
</table>

**Reference:**

- Shapiro2017
- Skea2006
- Salathé2011
- Seeman2010
- Sanawi2017
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Methodology</th>
<th>Results (taken from the article’s abstract)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smith2017a[81]</td>
<td>Detail a preliminary system of real-time geographical monitoring and analysis in the context of the vaccine hesitancy discussion across the US.</td>
<td>Vaccine: Any Country: US Period monitored: 2011-2017</td>
<td>Search strategy: Automated (Twitter API) Sentiment analysis: n/a</td>
<td>In this study, we applied automatic topic modelling on a collection of 943 discussion posts in which vaccine was debated, and six distinct discussion topics were detected by the algorithm. When manually coding the posts ranked as most typical for these six topics, a set of semantically coherent arguments were identified for each extracted topic. This indicates that topic modelling is a useful method for automatically identifying vaccine-related discussion topics and for identifying debate posts where these topics are discussed. This functionality could facilitate manual coding of salient arguments, and thereby form an important component in a system for computer-assisted coding of vaccine-related discussions.</td>
</tr>
<tr>
<td>Smith2017b[111]</td>
<td>Examine the characteristics of and the discourses present around childhood vaccination within six popular anti-vaccination Facebook pages.</td>
<td>Vaccine: Any (childhood vaccines) Country: Mix: Australia, US Period monitored: 14 April 2013 - 14 April 2016</td>
<td>Search strategy: Automated (Facebook API, Social-MediaLab) Sentiment analysis: n/a</td>
<td>We find that present-day discourses centre around moral outrage and structural oppression by institutional government and the media, suggesting a strong logic of ‘conspiracy-style’ beliefs and thinking. Furthermore, anti-vaccination pages on Facebook reflect a highly ‘feminised’ movement – the vast majority of participants are women. Although anti-vaccination networks on Facebook are large and global in scope, the comment activity sub-networks appear to be ‘small world’.</td>
</tr>
<tr>
<td>Sundstrom2018[130]</td>
<td>Investigate online HPV vaccination communication to provide insight to increase vaccine uptake through effective messaging.</td>
<td>Vaccine: HPV Country: US Period monitored: 1 June 2014 - 31 May 2015</td>
<td>Search strategy: Manual Sentiment analysis: n/a</td>
<td>Current messaging in South Carolina emphasised the relative advantage of HPV vaccination as cancer prevention strategy. Two primary misconceptions about the HPV vaccination were identified: concerns about safety and that the vaccine could increase sexual activity among adolescents. The content analysis revealed that health care provider support is needed to normalise HPV vaccination as part of the routine immunisation series. Observing messages from peers served as a vicarious trial experience of the vaccine for adolescents and young adults and showed gaps in vaccine uptake among males and lack of series completion among males and females.</td>
</tr>
<tr>
<td>Suragh2018[12]</td>
<td>Assess the possibility of detecting clusters of anxiety-related adverse events following immunisation, not otherwise reported in traditional peer-reviewed systems.</td>
<td>Vaccine: Any Country: Global/Not specified Period monitored: 2007-2016</td>
<td>Search strategy: Manual Sentiment analysis: Manual (neutral, positive)</td>
<td>We found 39 reports referring to 18 unique cluster events. Some reports were only found based on the geographic location from where the search was performed. The most common vaccine implicated in reports was human papillomavirus (HPV) vaccine (48.7%). The majority of reports (97.4%) involved children and vaccination programs in school settings or as part of national vaccination campaigns. Five vaccination programs were reportedly halted because of these cluster events. In this study, we identified 18 cluster events that were not published in traditional scientific peer-reviewed literature.</td>
</tr>
</tbody>
</table>
| Surian2016[84]  | Evaluate the use of community structure and topic modelling methods as a process for characterising the clustering of opinions about HPV vaccines on Twitter. | Vaccine: HPV Country: Global/Not specified Period monitored: October 2013 - October 2015 | Search strategy: Automated (Twitter API) Sentiment analysis: n/a | We analysed 285,417 Twitter posts (tweets) about HPV vaccines from 101,519 users connected by 4,387,524 social connections. Examining the alignment between the community structure and the topics of tweets, the results indicated that the Louvain community detection algorithm together with DMM produced consistently higher alignment values and that alignments were generally higher when the number of topics was lower. After applying the Louvain method and DMM with 30 topics and grouping semantically similar topics in a hierarchy, we characterised 163,148 (57.16%) tweets as evidence and advocacy, and 6244 (2.19%) tweets describing personal experiences. Among the 4548
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Methodology</th>
<th>Results (taken from the article’s abstract)</th>
</tr>
</thead>
</table>
| Tang2018[85]       | Conduct a semantic network analysis of Twitter content about measles during a measles outbreak in California. | Social media type: Twitter  
Vaccine: Measles  
Country: US  
Period monitored: 1 December 2014 - 30 April 2015  
Sentiment analysis: n/a | Search strategy: Automated (DiscoverText.com)  
Sentiment analysis: n/a | # results: 1,133,656 tweets  
“Four frames were identified based on word frequencies and co-occurrence: news update, public health, vaccination, and political. The prominence of each individual frame changed over the course of the pre-crisis, initial, maintenance, and resolution stages of the outbreak.” |
| Tangherlini2016[121] | Develop an automated and scalable machine-learning method for story aggregation on social media sites dedicated to discussions of parenting. | Social media type: Forums (www.mothering.com and one unnamed)  
Vaccine: Any (childhood vaccines)  
Country: Mix: Canada, US  
Sentiment analysis: n/a | # results: 1.99 million forum posts  
“We discovered that discussions of exemption from vaccination requirements are highly represented. We found a strong narrative framework related to exemption seeking and a culture of distrust of government and medical institutions. Various posts reinforced part of the narrative framework graph in which parents, medical professionals, and religious institutions emerged as key nodes, and exemption seeking emerged as an important edge. In the aggregate story, parents used religion or belief to acquire exemptions to protect their children from vaccines that are required by schools or government institutions, but (allegedly) cause adverse reactions such as autism, pain, compromised immunity, and even death. Although parents joined and left the discussion forums over time, discussions and stories about exemptions were persistent and robust to these membership changes.” |
| Teoh2018[86]      | Quantify personal stories about cervical cancer on Twitter during cervical cancer awareness month and determine the proportion of Twitter messages discussing prevention (vaccination) and evaluate positive or negative sentiment of these messages. | Social media type: Twitter  
Vaccine: HPV  
Country: Global/Not specified  
Period monitored: January 2016 | Search strategy: Manual  
Sentiment analysis: Manual (negative, positive) | # results: 348 top tweets  
“During January 2016, 348 top tweets about cervical cancer were identified. Professional health organisations produced 20.7% of tweets and individuals identifying themselves as healthcare professionals contributed an additional 4%. In addition to the tweet, 45.1% attached a photo or video; 54.6% included links to a larger article. Only 11.2% of tweets included personal stories from cervical cancer patients. Among the top tweets, 70.3% were focused on prevention through screening and/or HPV vaccination, with 97.4% recommending such practices. A substantial proportion of the Twitter traffic (24.7%) referenced the #SmearForSmear campaign by the patient-advocate organisation Jo’s Cervical Cancer Trust, based in the United Kingdom.” |
| Tomeny2017[87]    | Examine variations in anti-vaccine beliefs that link vaccines to autism by geographic distribution and demographics on Twitter. | Social media type: Twitter  
Vaccine: Any  
Country: US  
Period monitored: 1 January 2009 – 21 August 2015  
Sentiment analysis: n/a | Search strategy: Automated (Social Studio’s Radian6 API)  
Sentiment analysis: Automated, Lightside (anti-vaccine, neutral, pro-vaccine) | # results: 549,972 tweets  
“Fifty percent of our sample of 549,972 tweets collected between 2009 and 2015 contained anti-vaccine beliefs. Anti-vaccine tweet volume increased after vaccine-related news coverage. California, Connecticut, Massachusetts, New York, and Pennsylvania had anti-vaccination tweet volume that deviated from the national average. Demographic characteristics explained 67% of variance in geographic clustering of anti-vaccine tweets, which were associated with a larger population and higher concentrations of women who recently gave birth, households with high income levels, men aged 40 to 44, and men with minimal college education.” |
| Tuedl2015[102]    | Identify the characteristics of YouTube videos in Spanish about HPV vaccination. | Social media type: YouTube  
Vaccine: HPV  
Country: Global/Not specified  
Sentiment analysis: Manual (negative, positive) | # results: 170 videos  
“A total of 170 videos were classified like: local news (n=39; 37 favourable; 2:06:29; 42972 visits), national news (n=32; 30/2; 1:49:27; 50138 visits), created by YouTube subscribers (n=21; 21/1; 1:44:39; 10991 visits), advertisements (n=21; 19/2; 0:27:05; 28435 visits), conferences (n=17; 15/2; 3:25:39; 27206 visits), documentaries (n=16; 12/4; 2:11:31; 30629 visits). From all of the 20 most viewed YouTube videos predominated those which were favourable to the vaccination (n=12; 0:43:43; 167189 visits) against the unfavourable (n=8; 2:44:14; 86583 visits).” |
| Tustin2018[113]    | Qualitatively analyse and quantify the content of users’ posts to describe the main vaccination sentiments and themes of an online immunisation debate of Facebook users who commented on posted advertisements, in order to better understand users who posted experiential tweets, 3449 users (75.84%) were found in communities where the majority of tweets were about evidence and advocacy.” | Social media type: Facebook  
Vaccine: Any  
Country: Canada  
Period monitored: 12 December 2013 - 11 January 2014  
Sentiment analysis: Manual (ambiguous, hesitant, negative, positive) | Search strategy: Manual  
Sentiment analysis: Manual (ambiguous, hesitant, negative, positive) | # results: 117 Facebook comments  
“Of 117 comments, 85 were posted by unique commentators, with most being female (65/85, 77%). The largest proportion of the immunisation comments were positive (51/117, 43.6%), followed by negative (41/117, 35.0%), ambiguous (20/117, 17.1%), and hesitant (5/117, 4.3%). Inaccurate knowledge (27/130, 20.8%) and misperceptions of risk (23/130, 17.7%) were most prevalent in the 130 non-positive comments. Other claims included..."
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Methodology</th>
<th>Results (taken from the article’s abstract)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vayreda2011[114]</td>
<td>Understand the vaccination debate and to identify underlying themes.</td>
<td>Social media type: Forums Vaccine: H1N1 Country: Spain Period monitored: n/a</td>
<td>Search strategy: Manual Sentiment analysis: Manual (sceptical, pro-vaccination)</td>
<td>“We identify the discursive practices that contributors use to valorise certain elements in the debate (what they cast as science, rationality, and ‘proper’ scepticism) over others (especially commercial interests, ‘charlatanism’, and ‘profiteering’). A forum participant can be disqualified on the basis of their alleged partiality and interest, if they can be accused of having a commercial stake in the matter. But no such opprobrium results if they have a ‘scientific’ interest.”</td>
</tr>
<tr>
<td>Venkatraman2015[103]</td>
<td>Identify how viewpoints vary with the degree of freedom of speech offered.</td>
<td>Social media type: YouTube Vaccine: Any Country: Global/Not specified Period monitored: 20-27 November 2013</td>
<td>Search strategy: Manual Sentiment analysis: Manual (anti-vaccine, pro-vaccination)</td>
<td>“Support for a link between vaccines and autism is most prominent on YouTube, followed by Google search results. It is far lower on Wikipedia and PubMed. Anti-vaccine activists use scientific arguments, certified physicians and official-sounding titles to gain credibility, while also leaning on celebrity endorsement and personalised stories.”</td>
</tr>
<tr>
<td>Yuan2018[88]</td>
<td>Investigate the communicative patterns of anti-vaccine and pro-vaccine users in Twitter by studying the retweet network related to MMR vaccine published by users after the 2015 California Disneyland measles outbreak.</td>
<td>Social media type: Twitter Vaccine: Measles Country: US Period monitored: 1 February - 9 March 2015</td>
<td>Search strategy: Automated (Geosocial gauge) Sentiment analysis: Automated (anti-vaccination, neutral, pro-vaccination)</td>
<td>“Using supervised learning, we classified the users into anti-vaccination, neutral to vaccination, and pro-vaccination groups. Using a combination of opinion groups and retweet network structural community detection, we discovered that pro- and anti-vaccine users retweet predominantly from their own opinion group, while users with neutral opinions are distributed across communities. For most cross-group communication, it was found that more pro-vaccination users were retweeting anti-vaccination users than vice-versa.”</td>
</tr>
<tr>
<td>Zhou2015[92]</td>
<td>Determine if information about social connections could be used to improve the performance of classifiers intended for ongoing use in public health surveillance.</td>
<td>Social media type: Twitter Vaccine: HPV Country: Global/Not specified Period monitored: 1 October 2013 - 31 March 2014</td>
<td>Search strategy: Automated (Twitter API) Sentiment analysis: Automated (anti-vaccine)</td>
<td>“From 42,533 tweets posted between October 2013 and March 2014, 2,098 were sampled at random and two investigators independently identified anti-vaccine opinions. Machine learning methods were used to train classifiers using the first three months of data, including content (8,261 text fragments) and social connections (10,758 relationships). Connection-based classifiers performed similarly to content-based classifiers on the first three months of training data, and performed more consistently than content-based classifiers on test data from the subsequent three months. The most accurate classifier achieved an accuracy of 88.6% on the test data set, and used only social connection features. Information about how people are connected, rather than what they write, may be useful for improving public health surveillance methods on Twitter.”</td>
</tr>
</tbody>
</table>
## Annex 4.

### List of commercial software to monitor social media included in the studies

<table>
<thead>
<tr>
<th>Commercial software included in studies</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Topsy[70,73,79,90]</td>
<td>Topsy was an automated tool used for social media analytics and deep Twitter searches, which was purchased by Apple in 2013, and ceased operating in 2015[190]. A deep Twitter search can be classified as an advanced search via the Twitter API so that one can get more detailed information beyond a simple keyword search using the Twitter web browser or app search function. This advanced &quot;deep&quot; search may be constructed using specified Boolean search formats that have a mixture of inclusion and exclusion criteria. For example, the following search, would get all tweets that mention any variation of the term &quot;vaccine&quot;, &quot;vaccination&quot; or &quot;vaccinated&quot;, but not tweets related to non-human (e.g. animal) vaccines: (&quot;vaccin*&quot;) NOT (&quot;a vet&quot; or veterinary OR dog* OR cat* OR horse* OR mouse* OR pig* OR cow*). Because the Twitter API only gives a random sample, and limited percentage of tweets depending on the type of access (free/commercial) – making sure one's search term is specific when utilizing the API is key for getting access to a better quality data sample within the limitations of the API[191].</td>
</tr>
<tr>
<td>Crimson Hexagon[52,129,132]</td>
<td>Crimson Hexagon is an AI (Artificial Intelligence)-powered consumer insights company that has a powerful social media analytics tool. It gives access to the company's online data library, which consists of over 1 trillion posts, and includes documents from social networks such as Twitter, Instagram and Facebook as well as blogs, forums, and news sites. The company's ForSight platform is a Twitter certified product[192].</td>
</tr>
<tr>
<td>Gnip[56,76,77]</td>
<td>Gnip, Inc. was a social media API aggregation company, which provided full historical and current data from many different social media platforms via a single API. Twitter purchased Gnip in April 2014, and is now part of Twitter's enterprise API platform, which delivers real-time and historical social data for research and business purposes[193].</td>
</tr>
<tr>
<td>NodeXL[72,81]</td>
<td>An open-source network analysis and visualisation software package for Microsoft Excel, that includes access to social media network data importers, advanced network metrics, and automation[194].</td>
</tr>
<tr>
<td>HealthMap[53]</td>
<td>A website that delivers real-time intelligence on a broad range of emerging infectious diseases via disparate data sources, including online news aggregators, eyewitness reports, and expert-curated discussions and validated official reports, to achieve a unified and comprehensive view of the current global state of infectious diseases and their effect on human and animal health. Through an automated process, the system monitors, organises, integrates, filters, visualises and disseminates information from international online news and health information sources about emerging diseases in nine languages, facilitating early detection of global public health threats. Results are available on a platform called the Vaccine Sentimeter. However, the study found that a limitation of HealthMap and the vaccine sentiment analysed with it is that data sources are not exhaustive; they only use a small selection of news and public health data and are limited to publicly available data.</td>
</tr>
<tr>
<td>ChatterGrabber[68]</td>
<td>An open source, natural language processing based toolset for public health social media surveillance[196].</td>
</tr>
<tr>
<td>Social Studio's Radian6 API[87]</td>
<td>A web service for retrieving, analysing, and modifying social media data[197].</td>
</tr>
<tr>
<td>Twiqs.nl and HowardsHome[131]</td>
<td>Twiqs.nl is a free analytic Dutch tool for tweets[198], and HowardsHome is a Dutch online monitoring service, which specialises in collecting news and content for content marketing, content curation and knowledge sharing[199].</td>
</tr>
<tr>
<td>Twitter Zombie and Microsoft Research[75]</td>
<td>Twitter Zombie is a monitoring tool for capturing, socially transforming and analysing Twitter[200]. The Microsoft Research Open Data project has a collection of Social Media Conversation Corpus', that contain collections of tweets, which are open to researchers for analysis[201].</td>
</tr>
<tr>
<td>Clipit[134]</td>
<td>A Dutch online media monitoring programme that can be used to search online and social media, print media, radio &amp; TV and international online media for preselected terms[202].</td>
</tr>
<tr>
<td>Geosocial gauge[88]</td>
<td>A social analytics tool that brings together social media and geographical analysis to monitor and explore people's views, reactions, and interactions through space and time[203].</td>
</tr>
<tr>
<td>VaccineWatch[78]</td>
<td>An online monitoring system with visualisations and analytics of significant vaccine information from Twitter[78].</td>
</tr>
</tbody>
</table>
### Annex 5

**List of identified keywords used in social media monitoring articles**

<table>
<thead>
<tr>
<th>Platform</th>
<th><strong>Vaccination in general:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Facebook</strong></td>
<td>Vaccine[104]</td>
</tr>
<tr>
<td></td>
<td>Vaccine, vaccines or vaccination[110]</td>
</tr>
<tr>
<td></td>
<td>Vaccine concern, vaccine choice, vaccines and autism, and anti-vaccination[111]</td>
</tr>
<tr>
<td><strong>Vaccine specific:</strong></td>
<td>Cervarix, Gardasil, HPV vaccine, and human papillomavirus vaccine[45]</td>
</tr>
<tr>
<td></td>
<td>Polio[109]</td>
</tr>
<tr>
<td><strong>Issue specific:</strong></td>
<td>Mass hysteria after vaccine, mystery illness after vaccine, fainting in school children after vaccine, mass fainting after vaccine[112]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Forums</strong></th>
<th><strong>Vaccination in general:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Vaccination and forum (to identify forums) and Vaccin* (to identify threads)[118]</td>
</tr>
<tr>
<td><strong>Vaccine specific:</strong></td>
<td>Discussion forum, HPV vaccine and cervical cancer vaccine[117]</td>
</tr>
<tr>
<td></td>
<td>MMR[116]</td>
</tr>
<tr>
<td></td>
<td>Rotavirus vaccine and autumn diarrhoea vaccine[115]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Pinterest</strong></th>
<th><strong>Vaccination in general:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Vaccination, vaccine, vaccines and vaccinate[125]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Reddit</strong></th>
<th><strong>Vaccination in general:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Vaccines, vaccination, vaxxer[126]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Twitter</strong></th>
<th><strong>Vaccination in general:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>#vaccine (study A) and #vaccineswork (study B)[56]</td>
</tr>
<tr>
<td></td>
<td>&quot;The vaccine stream&quot;[57]</td>
</tr>
<tr>
<td></td>
<td>Vaccine, vaccination, immunization[72]</td>
</tr>
<tr>
<td></td>
<td>Vaccine, vaccines, mmr, tdap, flushot, hpv, polo, rotavirus, chickenpox, smallpox, hepatitis, hepa, heb, dtap, meningitis, shingles, vaccinated, vaccinated, vaccine, vaccines, vaccine, vaccines, tetanus, dipheria, pertussis, whooping cough, dtp, dhpv, chickenpox, measles, mumps, rubella, varicella, dipheria, haemophilus, papillomavirus, meningococcal, pneumooccocal, rabies, tuberculosis, typhoid, yellow fever, immunizations, immunization, immunization, immune, imune, cholaera, globulin, encephalitis, lyme, zika[59]</td>
</tr>
<tr>
<td>**Vaccines, vaccinations, trivalent, vaccination cocktail, mercury, vaaxed, big pharma (Vaccination keywords examples); autism, adverse event (claimed side effects keywords examples); meningitis, measles, rubella, mumps, varicella (vaccine-preventable diseases keywords examples)[89]</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Vaccines conspiracy; vaccination coverage; vaccine(s); big pharma; vaccine risk(s); vaaxed; trivalent; hexavalent; vaccine; quadrivalent; vaccination(s); vaccination freedom; vaccination objection; vaccination age; vaccination cocktail; vaccine contraindications (Vaccination keywords); flaccid paralysis; autism; autoimmune diseases; adverse event(s) (claimed side effects keywords); meningitis, measles; rubella; mumps; whooping cough; polo; varicella; MMR (vaccine-preventable diseases keywords examples), #novacino (hashtag for &quot;no vaccine&quot;); #ovaccino (hashtag for &quot;I vaccinate&quot;); #libertadisella (hashtag for &quot;freedom of choice&quot;)[56]</td>
</tr>
<tr>
<td></td>
<td>Outbreak, vaccination, Influenza, H7N9, H5N1, Japanese encephalitis (examples)[78]</td>
</tr>
<tr>
<td></td>
<td>Vaccine, Vaccinate, Vaccine, Vaccinate, MMR, Antivac (conditions keywords); Autism, Autistic, Conspiracy, Give me, Give me, Oprah, Aspergers, Poison, Jenny mccharly, Kristin cavallari, Conspiracy, Mercury, Aluminum, Truther, Bravo, Anti, Manufacturers, Have known, Vaccine choice, Your child, Your right, Cancer, Fertility, Constitution, Risks, Dangerous (qualifier keywords)[68]</td>
</tr>
<tr>
<td></td>
<td>Vaccine, vaccinated, immunization, mmr vaccine, mmrvaccine, #b1less, #hearsus, heavy metals, leaky gut, mercury, ethylmercury, methylmercury, thimerosal, preservative, dpt, diphereria-pertussistemutanus, pharmaceutical companies, big pharma, autism, autistic, Asperger, vacinne, vacine, anti vax, aspie, asberger, asberger, and, #cdcwhistleblower, #cdwhistleblower, #db277[87]</td>
</tr>
<tr>
<td></td>
<td>Vaccine, vaccines, #vaccine or #vaccines[55]</td>
</tr>
<tr>
<td><strong>Vaccine specific:</strong></td>
<td>#HPV and #Gardasil[70]</td>
</tr>
<tr>
<td></td>
<td>Cervical cancer, #gyncom[86]</td>
</tr>
<tr>
<td></td>
<td>Dipherthia, Olot (the town where the case occurred), anti-vaccination and vaccination/vaccine[*79]</td>
</tr>
<tr>
<td></td>
<td>Flu shot and flu vaccine, influenza vaccine, flu vaccine, influenza vaccination, flu vaccination[71]</td>
</tr>
<tr>
<td></td>
<td>Gardasil, Cervarix, hpv AND vaccin* and cervical AND vaccin*[66,82]</td>
</tr>
<tr>
<td></td>
<td>(H1N1 OR &quot;swine flu&quot; OR swineflu OR pigflu OR &quot;pig flu&quot; OR &quot;pandemic&quot; OR influenza OR flu) AND (vaccin OR antiviral OR jab OR vac OR vaccines OR injection OR shot OR Tamiflu) OR (Tamivir OR Relenza OR Pandemrix OR Celvapan)[76]</td>
</tr>
<tr>
<td></td>
<td>&quot;HPV AND vaccination&quot; (relevant keywords example); &quot;HPV OR vaccination&quot; (semi-relevant keywords example); words related to other types of injections, e.g. blood tests, travel vaccinations, and other meanings of the search keywords, e.g. the Dutch translation of stinging eyes (&quot;prikkende ogen&quot;) contains the word injection(&quot;prik&quot;) (non relevant keywords example)[69]</td>
</tr>
<tr>
<td></td>
<td>HPV and vaccine, HPV and vaccination, gardasil, cervical and vaccination, cervical and vaccine, cervarix[84]</td>
</tr>
<tr>
<td></td>
<td>HPV, HPV vaccine, HPV shot, Gardasil, and Cervarix (as well as the 5 corresponding hashtags)[74,75]</td>
</tr>
<tr>
<td></td>
<td>HPV, human papillomavirus, Gardasil, and Cervarix[63,64]</td>
</tr>
</tbody>
</table>
Systematic scoping review on social media monitoring methods and interventions relating to vaccine hesitancy

**Vaccination OR vaccine OR vaccination OR vaccines OR vaccine OR alive OR immunized OR immunize OR immunization OR immunizing**[30]

**Vaccination, vaccine, vacines, vacine, and vaxx (examples)**[80]

(('Vaccinations' OR 'vaccination' OR 'vaccines' OR 'vaccine' OR 'measles-mumps-rubella' OR "MMR" OR "mrr" OR "#MMR") AND ("autism" OR "autistic disorder") AND NOT "RT:"[52])

((vaccin* OR immuni*) AND (ingredient* OR risk* OR lies OR disease* OR exemption* OR safe* OR unsafe OR killing* OR conspiracy OR scandal* OR whistleblower* OR pharmaceutical OR CDC OR documentary OR truth* OR theory OR health OR infant* OR baby OR babies OR newbon* OR school* OR aluminum OR death* OR dead OR children OR kid* OR child* OR poison* OR toxic OR mercury OR injur* OR harm* OR brain OR paraly* OR scar* OR fear* OR autism OR IBS OR autistic OR "irritable bowel syndrome") OR measles OR mrr OR "andrew wakefield"[91]

**Vaccine autism, vaccines autism, vaccine measles autism, vaccine measles mumps rubella autism, MMR autism**[133]

**Vaccine, vaccines, shot, mrr, tdap, flushot, hpv, polio, rotavirus, chickenpox, smallpox, hepatitis, hep a, hep b, dta, meningitis, shingles, vaccine, vaccinated, vaccine, vaccines, vacine, vacines, tetanus, diptheria, pertussis, whooping cough, dtp, dtvp, chickenpox, measles, mumps, rubella, varicella, diphertheria, haemophilus, papillomavirus, meningococcal, pneumococcal, rabies, tuberculosis, typhoid, yellowfever, immunizations, immunization, imune, imune, cholera, globulin, encephalitis, lyne[83]

**Vaccine specific:**

**Hepatitis B vaccine**[127]

**Influenza vaccine**[124]


**Vaccination in general:**

Autism and vaccine, autism and vaccines, autism and vaccination, autism and vaccinations*[98]

Vaccination and immunization[101]

Vaccinations[32]

"Vaccine safety" and "vaccines and children"[95]

Vaccine, vaccines, anti-vaccine and non-vaccine[97]

Vaccines autism[103]

**Vaccine specific:**

Gardasil, cervical cancer vaccination, HPV vaccination[93]

HPV and "human papillomavirus"[94]

"HPV vaccine", "cervical cancer vaccine", "should I get the HPV vaccine", "what can go wrong with the HPV vaccine", "HPV vaccine side effects", and Gardasil[99]

HPV vaccine, HPV vaccination, HPV immunization, human papilloma virus vaccine, human papilloma virus immunization, Gardasil, and Cervarix[96]

"Human papilloma virus vaccine", "HPV vaccine", "Gardasil vaccine", "Cervarix vaccine"[102]

Meningitis B vaccine, Bexsero®, and Bexsero® vaccine*[100]

**Vaccination in general:**

Vaccine OR vaccines OR MMR (search for media attention to vaccines), (vaccine OR vaccines OR MMR) and autism (search for media attention to vaccine-autism link)[132]

**Vaccine specific:**

(autism OR mercury OR thimerosal OR wakefield OR mccarthy OR immigrant OR obama OR #vax) AND (vaccine OR measles OR MMR vaccine OR sb40 OR polio OR chickenpox OR hepatitis OR "mmr shot") AND -$ AND -http AND -RT[129]

HPV, Human Papillomavirus, HPV vaccine, HPV vaccination, Gardasil, Gardasil9, and Cervarix[130]

Influenza, vaccination, vaccine and epidemic[134]

Measles*[131]
## Annex 6.

### Social media as an intervention tool in relation to vaccination

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Description of intervention</th>
<th>Outcome and Results about social media</th>
</tr>
</thead>
</table>
| Finnegan 2018[139] | Assess what works in online communication about vaccines and offer proposals for improving the impact of online vaccine advocacy. | **Social media type:** Instagram, Facebook, Twitter, YouTube  
**Vaccine:** Any vaccine  
**Country:** Worldwide  
**Target population:** online users | Online platform (Vaccines Today) for discussing vaccines and vaccination to improve vaccine uptake by providing factual information about vaccination. Project features a website and several social media channels targeting the general public, launched in March 2011. In social media interactions, replies are made with information that would be of value to observers who are making decisions about vaccination. | The article found that two categories of content were the most popular: storytelling approaches and answers to questions posed by readers. The most popular content of the website was published on Facebook: "How measles can change a life" was written by a parent whose son developed subacute sclerosing panencephalitis several years after measles infection in his first year. The article – which is relatively long compared with other content on the site – was read for more than seven minutes, which is long enough to digest the article in full (07:16, 233,996 views). The authors considered that articles widely read were more successful. The most-viewed video on YouTube was an animation showing how herd immunity works (33,000 views). |
| Haase 2015[140] | Assess the potential moderating effect of statistic and narrative source credibility on the biasing effect of narrative information regarding the perception of vaccination risks. | **Social media type:** Online forum  
**Vaccine:** Any vaccine  
**Country:** Germany  
**Target population:** online users | Researchers aimed to understand if the credibility of the source of a forum post influenced the readers’ perception of vaccination risk. They did this by presenting identical narratives, but with different introductory texts (one from a neutral online health forum and the other from a known anti-vaccination website). | Researchers found that narratives discussing vaccine adverse events decreased intentions to get vaccinated and increased perceptions of vaccination risk. This bias occurred irrespective of whether the post was read on the neutral online health forum or the anti-vaccination website. |
| La Torre 2014[141] | Pilot a project with the aim of informing healthcare workers and the general population about vaccination through Facebook and present results of one year of activity. | **Social media type:** Facebook  
**Vaccine:** Any vaccine  
**Country:** Italy  
**Target population:** online users | Facebook messages developed to share information about vaccination. Information materials chosen by health professionals and scientific communication experts published three times a week. Short and regular messages with breaks of one day approximately between publications. News with images were chosen more often. | Likes: Events were the most popular type of news, followed by press releases, and scientific publications. Institutional Videos and documents are forms of communication less considered or appreciated by users. The day of the week in which users were most likely to be attracted by the contents of the links was Friday.  
Shares: Press releases were the communication form most shared by Facebook users, followed by scientific publications and institutional documents. No sharing of video links. Users shared more links on Fridays. |
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Description of intervention</th>
<th>Outcome and Results about social media</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lee 2017[142]</td>
<td>Investigate whether using different message framing and media influences the public’s perceived severity, benefits, barriers and willingness to get vaccinated.</td>
<td><strong>Social media type:</strong> Facebook <strong>Vaccine:</strong> HPV <strong>Country:</strong> United States <strong>Target population:</strong> 142 college students</td>
<td>Participants exposed to four scenarios: 1- a gain-framed message on a fake look-alike Facebook page, 2- a loss-framed message on a fake look-alike Facebook page; or 3- a gain-framed message on a fake look-alike New York Times website or a 4- loss-framed message on a fake look-alike New York Times website. Gain-framed message: health benefits from getting the HPV vaccine (e.g. prevention of cervical cancer or genital warts) Loss-framed message: negative consequences of not getting the HPV vaccine (e.g. getting cervical cancer or genital warts).</td>
<td><strong>Perceived severity of HPV:</strong> Participants who viewed the Facebook page perceived a lower severity than those who saw the online newspaper (p&lt;0.05). <strong>Perceived benefits of getting vaccinated:</strong> No statistically significant medium effect between newspaper and Facebook (p=.94). <strong>Perceived barriers to getting vaccinated:</strong> Participants who viewed the Facebook page perceived lower barriers than those who saw the newspaper (p&lt;.05). <strong>Willingness to get vaccinated:</strong> Participants who viewed the loss-framed message on Facebook mostly exhibited a higher level of behavioural intention to get vaccinated than those in the gain-framing condition (p&lt;.05).</td>
</tr>
<tr>
<td>Mohanty 2018[143]</td>
<td>Assess the campaign reach, engagement, and HPV vaccine uptake among Philadelphia adolescents through the 3forME campaign.</td>
<td><strong>Social media type:</strong> Facebook <strong>Vaccine:</strong> HPV <strong>Country:</strong> United States <strong>Target population:</strong> 155,110 adolescents (13-18) reached</td>
<td>Advertisements from 3forME displayed on the right side of the Facebook login page with varied themes, images and text. Link provided to the 3forME Facebook page and website. Messages addressed perceived susceptibility of HPV disease, severity of HPV infection, and benefits of getting vaccinated. The pages were designed as cues to actions to motivate adolescents to seek the HPV vaccine.</td>
<td><strong>Uptake of HPV vaccination:</strong> On average, each advertising campaign reached 155,110 adolescents and engaged 2106 adolescents. The advertising campaigns that focused on HPV disease risk and local resources were the most successful in engaging adolescents. Overall, 3400 adolescents became fans of the campaign and 176 doses of HPV vaccine were administered to 152 adolescents, out of which 63 received the three doses.</td>
</tr>
<tr>
<td>Ortiz 2018[144]</td>
<td>Describe the formative research, execution, and evaluation of a social media health intervention to improve adolescents’ knowledge about and vaccination against HPV.</td>
<td><strong>Social media type:</strong> Facebook <strong>Vaccine:</strong> HPV <strong>Country:</strong> United States <strong>Target population:</strong> 108 adolescents (13-18)</td>
<td>A Facebook page, “About your Health”, with information about HPV vaccination and notifications received each time a new message was posted on the page. Maintained by local healthcare providers. 24 health facts (11 about HPV) were posted throughout a three-month period (with images and links to credible websites). Topics included virus susceptibility, virus severity, vaccine benefits, vaccine barriers and self-efficacy.</td>
<td><strong>Knowledge:</strong> Participants who reported receiving notifications for each new Facebook post were significantly more likely to have an increase in their HPV and vaccine knowledge but not in their vaccination rates.</td>
</tr>
<tr>
<td>Peter 2014[145]</td>
<td>Investigate the potential of online discussions on social network sites to convey health messages and to affect people’s judgements regarding health issues.</td>
<td><strong>Social media type:</strong> Facebook <strong>Vaccine:</strong> Influenza <strong>Country:</strong> Germany <strong>Target population:</strong> 577 adults</td>
<td>Facebook page that featured a fictitious person who posted an article from an online magazine about influenza vaccination. The post was followed by five comments about this issue. In one version (pro vaccination version), four of the five comments stated a positive attitude toward flu vaccination, and one comment represented a negative attitude. In the other version (contra vaccination version), this relationship was reversed (four negative and one positive comment). Furthermore, in one version, one of the comments that represented the opinion of the majority (e.g., a positive comment in the pro vaccination version) was also liked by five other users. In the second version, the single minority comment was liked by five other users. In the third version, no comment was liked. Finally, the post itself was liked by 24 users.</td>
<td><strong>Perceived flu vaccination rate:</strong> No effect found from being exposed to user comments in favour of flu vaccination. No significant interaction of comment likes or post likes. <strong>Risk perception:</strong> Significant effect of the interaction effect between the exemplars and the evaluation of the stimulus: with a positive stimulus evaluation, the readers of a version with comments supporting vaccination expressed a marginally lower perception of risk than readers of comments opposing vaccination. For participants with a negative stimulus evaluation, the exact opposite was found. <strong>Perceived flu vaccination rate:</strong> No effect found from being exposed to user comments in favour of flu vaccination. No significant interaction of comment likes or post likes. <strong>Perceived flu vaccination rate:</strong> No effect found from being exposed to user comments in favour of flu vaccination. No significant interaction of comment likes or post likes. <strong>Risk perception:</strong> Significant effect of the interaction effect between the exemplars and the evaluation of the stimulus: with a positive stimulus evaluation, the readers of a version with comments supporting vaccination expressed a marginally lower perception of risk than readers of comments opposing vaccination. For participants with a negative stimulus evaluation, the exact opposite was found. <strong>Perceived flu vaccination rate:</strong> No effect found from being exposed to user comments in favour of flu vaccination. No significant interaction of comment likes or post likes. <strong>Risk perception:</strong> Significant effect of the interaction effect between the exemplars and the evaluation of the stimulus: with a positive stimulus evaluation, the readers of a version with comments supporting vaccination expressed a marginally lower perception of risk than readers of comments opposing vaccination. For participants with a negative stimulus evaluation, the exact opposite was found.</td>
</tr>
<tr>
<td>Reference</td>
<td>Study aim(s)</td>
<td>Study details</td>
<td>Description of intervention</td>
<td>Outcome and Results about social media</td>
</tr>
<tr>
<td>-----------------</td>
<td>------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Piedimonte 2018[146] | Determine the level of knowledge related to HPV and cervical cancer among university students and develop a targeted education and vaccination campaign to increase uptake. | Social media type: Facebook and Instagram  
Vaccine: HPV  
Country: Canada  
Target population: 151 | This project aimed to use an education campaign on HPV and cervical cancer to increase HPV vaccine uptake at two university campuses in Canada. Phase II of the project included the education campaign through social media, email communication, information booths and individual solicitation. The precise use of social media in the education campaign is unclear. | A Facebook event had 535 invitations, 23 attendees, and 6 shares. Four people posted pictures on Facebook that generated 106 likes. One picture on Instagram generated 45 likes. |
| Robichaud 2012[43] | Examine the prior attitudes of first year medical students to seasonal influenza immunisation (their risk-benefit calculation, their sense of vulnerability to seasonal influenza, their overall attitudes towards immunisation and their immunisation history) and assess the impact of the most popular vaccine-critical YouTube videos on their attitudes towards seasonal influenza vaccine. | Social media type: YouTube  
Vaccine: Influenza  
Country: Canada  
Target population: 41 medical students | This study randomly assigned medical students to watch one of two YouTube videos with different rhetorical styles (evidence-based versus anecdotal) and measured any change in attitudes and behaviours before and after watching the video. | The study did not find a significant difference in the responses to the questions asked before and after watching the videos. |
| Sundstrom 2018[147] | Describe the development, implementation and evaluation of a theory-based cervical cancer prevention communication campaign for college-age women. | Social media type: Facebook, Twitter, and Vine  
Vaccine: HPV  
Country: United States  
Target population: 18 university female students | Messages communicated about perceived threats, benefits and safety of HPV vaccine. The main campaign message, "It's my time", encouraged the consideration of HPV vaccination and regular screening, and reminded individuals that it is not too late to receive the HPV vaccine. Messages were delivered through mass media and social media (Facebook, Twitter and Vine). Twitter and Facebook were updated daily with relevant news articles, pictures and facts and messages included the hashtag #MyTime. A video contest was also prepared on Vine, where participants had to submit a video that finished the sentence: "I received the HPV vaccine so that I have time to...". | Uptake of HPV vaccination: Despite widespread coverage in the media, the messaging does not seem to have effectively changed behaviour given the limited knowledge seen in focus groups.  
Among participants, 63% had heard of the campaign. Following the campaign, 93% had heard of the HPV vaccine and 74% believed the HPV vaccine was successful at preventing cervical cancer. |

**Online group discussions**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Description of intervention</th>
<th>Outcome and Results about social media</th>
</tr>
</thead>
</table>
| Kimmerle 2014[150] | Examine in what way the particular type of contribution (i.e. factual information vs personal experiences) has an impact on the subsequent communication in health-related Internet forums. | Social media type: Internet Forum  
Vaccine: Measles  
Country: Germany (although unclear whether the forums are German)  
Target population: The users of 28 various Internet forums | This study compared the differences between using factual information versus personal experience in a post on health-related Internet forums. The researchers observed how each condition of the initial post affected subsequent communication on the forum. They considered the number of responses each post received and how emotional the language/content of the posts were. | There was no statistically significant increase in the number of responses on the personal experience posts as compared to the factual post. However, responses to the personal experience post were significantly more emotional than responses to the factual information post. |
| Lai 2015[148]    | Identify the effectiveness of a Facebook-assisted teaching method for school-based CCPE | Social media type: Facebook  
Vaccine: HPV  
Country: Taiwan | Cervical cancer prevention education (CCPE) programme based on the health belief model, developed by Ministry of Health to assist teens in understanding cervical cancer, Pap Smear | Knowledge, personal attitude and behavioural intention: Under the condition of the vaccine being an out-of-pocket expense, students receiving a Facebook-assisted teaching method were 1,810 (measured |
## Interactive websites

**Daley 2018**

Test the impact of a website with a social media component on vaccine attitudes and beliefs.

**Social media type:** Website with built-in interactive component

**Vaccine:** Non-specific

**Country:** United States

**Target population:** 1,052 parents (during pregnancy and early childhood).

**Description of intervention:** Internet-based platform with vaccine information and interactive social media components

3 arms: 1- vaccine social media (VSM) arm, access to website with vaccine information and interactive social media components; 2 Vaccine information (VI) arm (website without social media), and 3- usual care (UC) arm

To reflect how a Web-based resource would be used in practice, individuals in the VSM and VI arms were given access to the Web site but were not required to visit it. Social media format: blog, discussion forum, chat room. New blogs posts added by the research team every month covering timely or controversial issues such as new vaccine safety research, recent vaccine-preventable disease outbreaks, changes in policies (either text or audio). Ask a question portal available as well to direct questions to experts (vaccine safety researcher, paediatric infectious diseases specialist, general paediatrician, risk communication specialist) - responses provided within 2 days. Online chat sessions held each month to engage in conversations with vaccine experts and between participants. Monthly newsletters to encourage website use.

**Outcome and Results about social media**

Among 542 participants in the VSM study arm, 189 (35%) visited the study website at least once, with a mean of 1.9 visits (SD = 1.8) and a range of one to 15 visits.

**Personal attitude and behavioural intention:** Interventions were associated with significant improvements in attitudes regarding vaccination benefits compared to usual care among vaccine-hesitant parents. Interventions were associated with significant reductions in parental concerns about vaccination risks compared to usual care among hesitant parents.

**Perceived self-efficacy also improved, although a significant change was only observed when comparing VI. No significant differences were observed when comparing the VSM versus VI study arms.** Change in attitudes over time among parents who were not vaccine hesitant at baseline: The VSM and VI interventions were not associated with any significant changes in vaccine-related attitudes compared to usual care.

---

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study aim(s)</th>
<th>Study details</th>
<th>Description of intervention</th>
<th>Outcome and Results about social media</th>
</tr>
</thead>
<tbody>
<tr>
<td>on knowledge and attitudes about cervical cancer prevention and on HPV vaccination intention among female students in a senior high school in Taiwan.</td>
<td><strong>Target population:</strong> 1,200 female students (15-17)</td>
<td>screening and HPV vaccination and cervical cancer prevention The lecturer, a nursing teacher, initiated the discussion with the question: What is an HPV vaccine? This was followed by a brief introduction of the HPV vaccine and the CCPE lecture commenced. The lecture concluded with a brief summary and discussion, reflecting on the importance of cervical cancer prevention. Six-hour discussion sessions were offered either with Facebook-assisted or in-person discussions after class.</td>
<td>Two weeks after the Facebook teaching method and 1.847 (measured eight weeks after the Facebook teaching method) times more likely to have the intention to be vaccinated compared with students who received traditional teaching instruction. Under the condition of receiving the vaccine free of charge, this figure was 2.531 times higher. A comparison of change across groups indicates that knowledge improvement scores in the experimental group were 2.942 points greater than those in the control group. Attitude improvement scores in the experimental group were 3.888 points greater than those in the control group. Under the condition of the vaccine being an out-of-pocket expense, the experimental group’s improvement scores were 2.284 times greater than those in the control group.</td>
<td></td>
</tr>
<tr>
<td>Reference</td>
<td>Study aim(s)</td>
<td>Study details</td>
<td>Description of intervention</td>
<td>Outcome and Results about social media</td>
</tr>
<tr>
<td>-----------------</td>
<td>------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Glanz 2017[152]| Test the impact of a website with a social media component on vaccine uptake.| Social media type: Website with built-in interactive component  
Vaccine: Hepatitis B, rotavirus, diphtheria-tetanus-acellular pertussis, Haemophilus influenzae type B, pneumococcal conjugate vaccine, polio, MMR  
Country: United States  
Target population: 1,052 parents (during pregnancy and early childhood) | Same as above (Daley2018)                                                                                           | Vaccine acceptance: Mean ranks for days undervaccinated were 438.5, 443.0, and 465.4 for the VSM, VI, and UC arms, respectively. Infants in the VSM arm had a lower mean rank for days undervaccinated than infants in the UC arm (p=.02). Mean ranks did not differ significantly between the VI and UC arms or the VSM and VI arms. The proportion of infants up-to-date at the end of follow-up were 92.5, 91.3, and 86.6 for the VSM, VI, and UC arms, respectively. Infants in the VSM arm were more likely to be up-to-date at age 200 days than infants in the UC arm (OR 1.92; 95% CI, 1.07–3.47). Up-to-date status did not differ significantly between the VI and UC arms or the VSM and VI arms. For the MMR sub-analysis, there were 71% of infants with at least 489 days of continuous follow-up. The proportion of infants who received MMR by the end of follow-up were 95.6, 95.5, and 91.8 for the VSM, VI, and UC arms, respectively. Although none of the study arm comparisons were statistically significant, infants in the VSM and VI arms were 2 times more likely to have received MMR than infants in the UC arm. |
| Ferro 2014[153]| Evaluate the activity of the Societa Italiana di Igiene’s web project to address misinformation online regarding vaccination. | Social media type: Website with built-in interactive component  
Vaccine: Non-specific  
Country: Italy  
Target population: Online users | The Societa Italiana di Igiene (Italian Society of Hygiene) created a web project to address misinformation online regarding vaccination, particularly among healthcare professionals. This comprises of a series of information tools including scientific articles, educational information, video and multimedia presentations, a forum, a periodic letter and a Twitter account. A website (www.vaccinarsi.org) was developed specifically to counterbalance, with credible and proved information, the diffuse misinformation about vaccines online. The exhibition and structuring of the website contains a first level with easy, accessible information and a second level, exposing information with more depth. A third level comprises of user’s direct interaction with the website. The website content comprises of multimedia presentations, informative videos, informational support and scientific articles. | The website was visited 27,173 times. From those, 25% returned to the website. The average visit to the website is 10,000 hits per month. Most visits are from Italy, with 6000 visits from Milan and 5000 visits from Rome. Other than desktops, smartphones and tablets are the most common devices to access the webpage. Different sections of the website have different access rates, and the initial pages had 9000 hits, and page ‘against misinformation’ had 1460 visits. The website had, since the first month, a considerable number of visit and this can be due to Search Engine Optimizer (SEO) and an advertising campaign online. The fact that the website remains as one of the first search results on Google means it is a very sought for website. The results from first month are encouraging and denote the importance of similar initiatives. |
| Shoup 2015[154]| Describe a process for designing, building, and evaluating a theory-driven social media intervention tool to help reduce parental concerns about vaccination. | Social media type: Website with built-in interactive component  
Vaccine: Non-specific  
Country: United States  
Target population: 443 pregnant mothers and parents of children younger than 4 years | The objective was to create a web-based tool that provides evidence-based information in an interactive environment where parents can contribute content and discuss concerns with other parents and vaccine experts. To gauge interest from target population of parents, authors developed, pilot-tested, and mailed a survey to assess their hypothetical trust in and use of a social media web-based tool for vaccine and health information. A manual medical record review was then conducted on the children to determine if parents had delayed or refused vaccination for personal, nonmedical reasons. Surveys were subsequently sent by mail to a random sample of parents who accepted vaccines (n = 500), all parents who delayed vaccines (n = 227), and all parents who refused vaccines (n = 127). Parents who delay vaccines, in particular, are the primary target population for the intervention. | Approximately 50% of parents in all three vaccine behaviour groups reported that they would use the web-based tool often. More than 60% of parents who delay or accept vaccines reported that they would trust the information about vaccines presented on the tool. Regardless of their vaccine decisions, a high proportion of parents reported that they would use the tool to ask questions, to receive current vaccine information, and to review the childhood vaccination schedule. Approximately 50% of parents who delay vaccines also said they would discuss their experiences and vaccine concerns using the web-based tool. In the sub-analysis comparing survey responders to non-responders, there were no significant differences in age, income, or home clinic. Overall, these results suggested that websites with built-in interactive components may represent an effective intervention tool to help parents make informed vaccination decisions for their children. |
ECDC is committed to ensuring the transparency and independence of its work

In accordance with the Staff Regulations for Officials and Conditions of Employment of Other Servants of the European Union and the ECDC Independence Policy, ECDC staff members shall not, in the performance of their duties, deal with matters in which they may, directly or indirectly, have a personal interest that could impair their independence. Declarations of interest must be received from any prospective contractor before a contract can be awarded.