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Opportunities and challenges of Web 2.0 for vaccination decisions☆

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A B S T R A C T

A growing number of people use the Internet to obtain health information, including information about vaccines. Websites that allow and promote interaction among users are an increasingly popular source of health information. Users of such so-called Web 2.0 applications (e.g. social media), while still in the minority, represent a growing proportion of online communicators, including vocal and active anti-vaccination groups as well as public health communicators. In this paper, the authors: define Web 2.0 and examine how it may influence vaccination decisions; discuss how anti-vaccination movements use Web 2.0 as well as the challenges Web 2.0 holds for public health communicators; describe the types of information used in these different settings; introduce the theoretical background that can be used to design effective vaccination communication in a Web 2.0 environment; make recommendations for practice and pose open questions for future research. The authors conclude that, as a result of the Internet and Web 2.0, private and public concerns surrounding vaccinations have the potential to virally spread across the globe in a quick, efficient and vivid manner. Web 2.0 may influence vaccination decisions by delivering information that alters the perceived personal risk of vaccine-preventable diseases or vaccination side-effects. It appears useful for public health officials to put effort into increasing the effectiveness of existing communication by implementing interactive, customized communication. A key step to providing successful public health communication is to identify those who are particularly vulnerable to finding and using unreliable and misleading information. Thus, it appears worthwhile that public health websites strive to be easy to find, easy to use, attractive in its presentation and readily provide the information, support and advice that the searcher is looking for. This holds especially when less knowledgeable individuals are in need of reliable information about vaccination risks and benefits.

Keywords:
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A growing number of people use the Internet to obtain health information, including information about vaccines [1–4] obtained from different sources: both public health communicators as well as organized anti-vaccination groups disseminate information related to vaccinations [5]. Furthermore, websites that allow and promote interaction among users are a source of health information that is growing in popularity. Users of such so-called Web 2.0 applications (e.g. social media), while still in the minority, represent a growing proportion of online communicators, including vocal and active anti-vaccination groups.

☆ *Disclaimer*: The statements are the personal views of the authors and do not necessarily conform to the views of the authors' organizations.

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In this paper, we[1]: define Web 2.0; examine how Web 2.0 may influence vaccination decisions; discuss how anti-vaccination movements use Web 2.0 as well as the challenges Web 2.0 holds for public health communicators; describe the types of information used in different settings; introduce a theoretical background that can aid designing vaccination communication in a Web 2.0 environment; make recommendations for practice; and pose open questions for future research.

1. Defining Web 2.0

We define Web 2.0 as Internet applications that enable users to create and upload new content, comment on existing content and share content with other users [6], e.g. discussion boards, web blogs and social media websites such as Facebook, Twitter, Wikipedia, LinkedIn and YouTube. That is, while 'Web 1.0' Internet websites typically allowed for one-way communication from the creator of the site to the user (e.g. static health portals), Web 2.0 enables two-way and multi-way communication [6–8]. Web 2.0 applications reduce major technical barriers to facilitate interactions with other users. Social media, for example, provide opportunities to publicly express support for an issue and forward information to friends without great effort (e.g. 'like' button in Facebook, 'retweeting' in Twitter). Existing information can be re-used, modified and added to growing databases of crowd-sourced knowledge [7]. This technological progress blurs the lines between the reception and production of media content [8,9].

Meta-analyses show that mass-mediated health and risk messages can raise awareness regarding health issues as well as, to a more limited extent, influence individuals' perceptions, attitudes, behavior intentions and behavior [10,11]. For the purpose of health promotion, health scholars see great potential in the use of online communication and, to a growing extent, also Web 2.0-applications for several reasons [12]. Due to their hybrid character, social media combine the reach of traditional mass media with the interactivity and dynamism of interpersonal communication, thus potentially increasing their effectiveness [12–14]. By actively creating and disseminating information, users become more involved, which is assumed to amplify potential effects of information on perceptions, attitudes and behavior [15–17]. Web 2.0 health messages also have the potential to reach a large audience through rapid electronic word-of-mouth, which can grow exponentially (viral marketing [18]). Importantly, such messages are disseminated by individuals who users like, trust, and/or know. For example, Twitter followers may admire those whom they follow or view them as opinion leaders [19,20]. Known and trusted sources are more likely to shape beliefs, attitudes, and behavior [19,20]. Finally, the Internet provides a good platform for tailored health communication [21]: When users enter a tailored website, they first complete a questionnaire assessing central personal characteristics relevant to specific health behaviors. Then, users receive messages specifically tailored to their personal needs. Evaluations indicate that tailored health communication has a small but reliable effect on user health behavior [22].

In this paper, we focus on three different actors in Web 2.0: 1) the decision maker (referred to as the user) as the receiver of information obtained on the Internet; 2) health-communicators who use Web 2.0 to disseminate evidence-based facts about vaccination as well as messages providing support for recommended vaccinations, e.g. via social media (such as the Centers for Disease Prevention and Control (CDC)); and 3) anti-vaccination activists who use Web 2.0 to disseminate messages, facts and beliefs that oppose some or all recommended vaccinations [23–28].

2. How may Web 2.0 influence vaccination decisions?

Vaccination decisions are made on a complex array of factors including doctor's recommendation, social norms, previous experiences, trust in individuals and organizations and other cognitions. These factors mostly work in favor of vaccinating. However, there are concerns that worries about vaccines may be growing [29]. Hence, understanding decision processes is important. These can be described as occurring in three stages [30]. In the *pre-decisional phase*, individuals consider their options, usually to either vaccinate within the recommended time frame, with delay or not at all. While most individuals trust the official vaccination recommendations [31,32], individuals may still seek additional information during this phase, e.g. by consulting the easily accessible Internet [4,33].

Individuals in the *decisional phase* then evaluate potential outcomes of alternative actions (such as vaccinating or not) based on the obtained information. Current theories of health behavior assume that individuals must first perceive themselves as being at risk before they will take protective action [34,35]. Thus, the perceived risk of contracting the vaccine-preventable disease as well as the perceived risk of vaccine adverse events represent core predictors of vaccination intentions [28,36–40]. Risk perception has been conceptualized as a combination of one's beliefs about the likelihood of being affected by a negative event (e.g., contracting HPV) and the severity of the negative event (e.g., cervical cancer can be lethal [41]). This 'risk as analysis' view has been complemented with the intuitive sensing of risk: the 'risk as feeling' perspective ([42] or 'affect heuristic' [43]) holds that risk perception is based on affective stimulus evaluations [44,45], which form the basis of authentic experiences of risk as opposed to cognitive inferences. Thus, any information obtained during pre-decisional online research that alters either type of perceived personal risk should affect vaccination intentions in the decisional phase.

Initially, individuals may perceive themselves to have a low risk of contracting a vaccine-preventable disease, as the incidence rates of vaccine-preventable diseases are low due to the success of vaccinations. As few individuals have first or second-hand experience with vaccine-preventable diseases, they lack vivid representations of disease risk. In addition, the benefits of vaccination arise in the future and are thus typically intangible to individuals at the time of the decision, especially since they refer to an event that will not occur, i.e. not contracting a disease. Further, individuals also benefit when others get vaccinated and herd-immunity increases, which makes free-riding attractive [46]. Contrary to the societal benefit, the individual benefit becomes smaller as more people get vaccinated. Vaccinations may also be followed by adverse events that are either correctly or falsely attributed to them (e.g., causally established outcomes such as anaphylaxis or disproven outcomes such as autism [47,48]. Individuals may find it easier to visualize that vaccinations are harmful, especially since such links are suggested by vivid anti-vaccination messages and possess face-value biological plausibility [49]. Given that anti-vaccination websites and the emotion-eliciting materials they host are readily available (see below), individuals may perceive a greater risk of suffering from vaccination side-effects than of contracting a vaccine-preventable disease.

In the *post-decisional phase*, individuals again receive imbalanced feedback regarding their decision: while vaccination costs such as pain, time, money and potential adverse events are

[1] The questions were discussed during the 2½-day conference "Risk 2.0 – Risk perception and communication regarding vaccination decisions in the age of Web 2.0" in Erfurt, Germany in May 2011. All authors of this paper participated in the meeting. This publication outlines the discussion and the consensus that was reached during the meeting.

immediate and tangible, the benefits are typically delayed or less tangible. As with all types of prevention, the difficulty with vaccinations is that individuals can never know whether they would have contracted the disease had they not been vaccinated – the prevention is unobservable. In contrast, adverse events are easily connected to the vaccination, even those that are actually unrelated and would have occurred anyway [47,50]. Vaccination experiences might be eventually published by individuals on the Internet (e.g. as advice to other users or in the form of stories about (alleged) side effects), thus making the user a producer of vaccination information, as well.

3. Online vaccination information in the era of Web 2.0

As many as 72% of American users trust health information they obtain on the Internet [51]. Also, around 75% of American users evaluate the source and status of online health information only sometimes, hardly ever or never [52]. Information available on the World Wide Web can be more reliable, accurate and up-to-date than that found in printed brochures or printed encyclopaedias, e.g. because public health agencies increasingly invest in online publications or due to the so-called *wisdom of the crowd* phenomenon (i.e. heterogeneous contributors collaboratively produce high quality content in an open environment, such as Wikipedia; [53,54]). However, substantial misinformation is also widely available, especially on anti-vaccination websites [24,55,56]. Further, lots of important information is missing when individuals conduct web searches: A recent study showed that approximately one third of websites obtained in a Google search on the relation between autism and the MMR vaccination do not contain key information regarding the absence of a link between autism and vaccinations and about a quarter of websites contain inaccurate information [57]. In another study, websites provided correct information regarding the questions of whether the doses of vaccine additives were dangerous, whether chronic diseases are triggered by vaccines and whether vaccines promote allergies in only 58%, 53% and 34% of the websites, respectively [58].

Recent research has identified characteristics that could increase users' vulnerability to obtain non-reliable information in Internet searches: lower socioeconomic status [59,60], lower cognitive ability and older age [61], lower literacy or health literacy (the ability to read and understand written or verbal (health) information [62]), less understanding of how to search the Internet (i.e., digital literacy [63,64]), less knowledge about vaccination [65] and lower numeracy (the ability to understand and use numbers [66]). Thus, while trust in online information appears to be high, retrieval of reliable information depends on the accessed sources and individual factors. The remainder of this section discusses two different sources of vaccine information: anti-vaccination activists with a focus on their efforts in Web 2.0 utilization; and public health communicators and the challenges they face.

3.1. Anti-vaccination activists' Web 2.0 efforts

Opposition to vaccination has existed since the practice first began [67–69]. In recent years, the Internet has provided well-organized anti-vaccination groups with a rapidly growing international forum for communicating, networking and coordinating lobbying efforts. Many such groups have websites that place enormous weight on adverse events–both established and alleged side effects [23,24,70]. Larger anti-vaccination groups (e.g. National Vaccine Information Center, Australian Vaccination Network) also actively use Web 2.0 by coordinating their presence in online polls and on parenting discussion boards, Twitter, Facebook and YouTube [25,71,72]. This increases the availability of material opposing vaccination that is often vivid, emotionally arousing and personal. As cohorts of well-connected digital natives (individuals who grew up with digital technology [4,73]) become parents, anti-vaccination information may reach audiences more rapidly and in an even greater volume.

Hobson-West described two distinct interest groups: *reformists* who are critical of vaccines but likely to provide at least partial support to vaccination; and *radicals* who follow alternative notions of health and question all vaccines [74]. Such lobbying groups are typically formed by parents [75] because the majority of vaccines are received in childhood and adolescence. Some parents base their allegiance on an existing interest in alternative therapies and natural health practices with an antipathy to medical intervention. Others previously supported immunization before their child suffered a frightening yet temporary adverse reaction, such as prolonged crying. These parents speak of dissatisfaction with the response of health professionals to such incidents and then embark on phases of questioning and ultimately rejection of vaccinations [76,77]. A final group includes parents whose children are disabled or suffer from chronic, permanent and typically unexplained medical conditions that they believe to be a result of vaccination.

In addition, country-specific and other contextual issues influence public questioning [77]. Policy choices or recommendations, such as the decision in France to withdraw the hepatitis B vaccination program from schools and the European Medicines Agency's recommendation to limit the use of a certain vaccine to persons over the age of 20 [78], also prompt individuals to question vaccine safety [79,80]. Public questioning may also emerge following the publication of new research, such as Andrew Wakefield's now discredited research on the MMR vaccine [81,82]. Finally, political and socio-cultural reasons or beliefs that lead to suspicion and conspiracy theories, such as concerns surrounding the polio vaccination in India and northern Nigeria [83] or the controversy about the safety of the HPV vaccine (e.g. India [84]), may also lead to the public questioning of vaccination.

Vaccine-critical Web 1.0 websites have been repeatedly evaluated regarding their content [23,24,85]. These sites typically argue that vaccines cause illnesses of unknown origin (such as multiple sclerosis, autism, asthma and sudden infant death syndrome), erode immunity, contain ingredients that endanger health and overwhelm children's immune systems, especially when administered in combination[2]. Narratives, i.e. reports of individuals allegedly harmed by vaccines, are used on the majority of such websites [24] (see next paragraph for extended discussion).

3.2. Information that alters risk perceptions and vaccination intentions: the power of narratives

While scholars are reluctant to recommend the inclusion of narratives in decision aids [86,87], online debates about vaccination are filled with personal stories of patients and parents who describe in vivid language the health problems they believe (correctly or incorrectly) to be the result of vaccination. As previous analyses (such as [24]) explicitly exclude Web 2.0 sites, the actual amount of available narrative information is probably even larger than has been documented to date. The person-centered technique of Web 2.0's information creation is particularly well suited for collecting and disseminating personal stories in anti-vaccination messages. Hence, while narrative reports have always been part of

[2] Public health organizations (e.g. the German Robert Koch Institute with the Paul-Ehrlich Institute [56] and the Australian Government [125]) have published online-documents that document these myths and give easy to understand scientific evidence against them.

anti-vaccination messages, their dissemination has grown via these media.

Narratives have inherent advantages over other communication formats [88]. Narratives of purported vaccination injuries include all of the key elements of memorable messages: They are easy to understand, concrete, credible in the way in which a first-person story of victimization is always credible ("I was there!") and highly emotional. These qualities make this type of information compelling; in risky situations, individuals prefer to know *how* consequences might be if they do occur, rather than *how likely* a consequence is to occur [89]. Moreover, when parents already perceive high vaccination risks, they are more inclined to search for narrative reports by other parents on the Internet [90]. Whether or not these stories represent verifiable vaccination risks is immaterial. The existence of narratives about adverse events on websites increases the perceived risk of adverse events, especially via the elicitation of emotional reactions [28]. Further, lab experiments showed that the greater the number of narratives that people read, the higher the perception of risk was, regardless of the information contained in simultaneously presented statistical information [91].

In addition to being individually persuasive, the broad distribution of stories of perceived vaccine-related negative outcomes via the Internet distorts users' perceptions of the actual likelihood of such events. Individuals consider how often they see such narratives in order to estimate how often different events will occur in real life. Thus, if individuals observe two positive and two negative narratives, many will assume that positive and negative events are equally likely in the real world [92]. Currently, however, negative narratives about vaccinations are much more widespread on the Internet than positive narratives. Thus, when individuals sample stories available online, they are typically likely to perceive that the weight of experiential evidence is against vaccination, even though negative narratives do not represent the experience of a large number of people. Additionally, as outlined earlier, narratives may elicit affect and emotions as well as impact risk perceptions via the direct 'risk as feelings' link [28,42]. This, in turn, may decrease individuals' intentions to vaccinate [91].

3.3. Web 2.0 challenges for (Public)health communicators

Public health agencies have the goal of disseminating disease-related news, risk assessments, epidemiological updates and scientific publications. Public health communicators, therefore, provide information that is reliable and correct; however, it is usually also more complex, so that it may require individuals' substantial motivation and effort to be understandable [88]. Scholars agree that efficient risk communication should be carefully designed following evidence-based principles (such as outlined in [93]).

As public health agencies increasingly complement their traditional media offers with Web 2.0 tools (Twitter, Facebook, YouTube, Wikipedia, LinkedIn), efficient risk communication is faced with several new challenges. One communication objective is to take advantage of social media's real-time and rapid dissemination features during crises (e.g. pandemic outbreaks [94] or epidemics of infectious diseases such as measles, *E. coli*). One challenge that public health agencies encounter when using social media is to keep up with and react to this fast moving medium. This challenge requires clear communication strategies and guidelines (such as who is allowed to communicate official messages and what they are permitted to say). Language barriers represent another challenge, not only between countries but also in terms of the difficulty of communicating complicated scientific terms and findings quickly in comprehensible (and still evidence-based) messages to the public – in some cases even in less than 140 characters (e.g. Twitter).

Adequate health messages contain the information that users need, connect users with that information, and are understood by users [95]. Health messages that have a chance to go viral [18] must be memorable and interesting; and there must be a number of well connected people (social hubs) that is initially large enough to spread the message to large groups of other people. Thus, the quandary lies in rapidly creating adequate and effective messages that are evidence-based, both regarding content and design of the message.

3.4. The difficulty with numbers

How should online information be presented? Ideally, medical information should be based on the best available clinical evidence and transparently present statistical information about the benefits and risks [96,97]. However, statistical information that numerically documents the rarity of side effects is usually less engaging than a personal story, e.g. of someone who suffered a presumed side effect [91]. Furthermore, statistical information can also be more difficult to understand. Large proportions of the population have low numeracy [66], including otherwise well-educated individuals and experts. Furthermore, individuals with lower numeracy have distorted perceptions of the risks and benefits of treatments and are more vulnerable to framing effects (see [66] for a recent review). As a consequence, such individuals are more likely to ignore numerical information and instead focus on narratives [98].

Various research findings show that, for most individuals, numbers (demonstrating risk) are often perceived as rather abstract information with only limited vividness and experiential value [99,100]. In order to become relevant for protective behavior, abstract numbers must elicit perceived threat, worry and concern [40,101], i.e. abstract numbers must become 'visceral motivation' [99,102,103].

Research has identified ways in which numbers can be made to matter to people. There are, for instance, basic principles for how numbers must be presented in order to be intuitively understandable [88,97,104,105]. Additionally, graphical representations are promising tools with which to understandably convey numbers [106–112], in particular to individuals with low numeracy [113]. Some of these methods have been used in the vaccination context [114], e.g. in decision aids [115,116], but their use could be greatly expanded [117]. One must be aware, however, that graphical displays are not a silver bullet. Past research suggests that some graphical representations, for example, might work only for individuals with high numeracy [118,119].

4. Communicating gist

As described above, public health communicators are faced with recipients who have diverse prior knowledge, needs and abilities. Internet searches lead to public health and anti-vaccination websites with about equal likelihood (10 vs. 11%; [58]), thus making powerful anti-vaccination information as equally available as scientific evidence that is reliable yet more difficult to understand. How can vaccination communication be improved in such a situation? How can risk perceptions be directly addressed by professional vaccination communication?

To ensure the effectiveness of health messages, the user must understand the message in a way that allows for both retention in memory and the availability of the knowledge at the time of behavior implementation [120]. Most recently, a dual-process theory was applied to risk perception, communication, and decision making: *fuzzy-trace theory* [88,120–123]. According to this theory, individuals integrate information into memory in two ways: Verbatim memories include all precise details, whereas gist memories

contain only the basic meaning. Decisions tend to be based on gist memories – or the basic meaning – not verbatim facts. According to this theory, therefore, websites that produce more coherent and meaningful gist will be more influential. As a recent study showed, anti-vaccination websites were perceived as more coherent than websites from the Centers for Disease Control [65]. This may facilitate retention of the information in memory and foster the use of anti-vaccination information in personal decision making. Thus, in order to increase the effectiveness of health messages, communicators should strive to make the gist of the message memorable.

5. Open questions

Vaccine narratives do not have to be negative. Emotionally powerful stories could be told about a parents' relief at knowing their children are protected during an outbreak. Alternatively, narratives could show the pain of someone who lost a loved one through a preventable disease. While no studies have enumerated the representation of such information on the Internet, a study of the Australian print media found that such narratives were often used as moral tales about the effects of non-vaccination [124]. However, we lack studies comparing the effect of pro- and anti-vaccination narratives on vaccination intentions. Pro-vaccination messages should be analyzed regarding their effects on risk perception and vaccination intention. More evidence is needed on how narratives could be used to report the positive effects of recommended vaccinations. What factors influence the effectiveness of narratives (e.g. message valence, sender credibility, personal contact)? In line with the posed questions, a recent literature review on the effect of narratives in medical decision aids concludes that "until evidence is provided on why and how narratives influence decision making, the use of narratives in interventions to facilitate medical decision making should be treated cautiously" [86]. Thus, the manner in which risk communication is most effective (e.g. a certain combination of narratives and statistical evidence) will be subject of future research.

There is good reason to assume that Web 2.0 can be fruitfully used by public health authorities. However, research is needed that directly investigates the effectiveness of the Web 2.0 activities of public health communicators. The central question will concern how complex scientific information can be condensed into brief and effective messages.

For successful Internet communication activities, it is not only necessary to thoughtfully create content but also post the messages on websites that are likely to be accessed by the intended audience. More research is needed on how users find their way through the Internet as well as under which conditions they use the provided information rather than simply continuing their search.

6. Recommendations for practice

The following recommendations for practice are "informed inferences" rather than evidence-based recommendations. We encourage researchers to further expand the evidence base. Public health communicators are nevertheless encouraged to use and evaluate these communication guidelines.

We assume that social media is a widely used tool that public health communication can harness. In the social media environment, public health communicators should actively strive to establish an online-reputation as experts who are worth following or as sources on websites worth visiting. The opportunities held by recent and advancing technological developments should be used for interpersonal communication and interactivity (e.g. Twitter, social networks). Effective communication about vaccinations may not be about "controlling what is available but rather it is about responding and participating in an interactive, user-responsive environment" [8]. Thus, in addition to fast responding, it is necessary to proactively prepare communication plans rather than simply wait until new scares arrive [29].

Based on the considerations above, communication in this context may profit from the following principles:

Decide what the gist is and then communicate it clearly. The gist that people extract from information answers the question "What does this information *mean* to me?" Even when people accurately remember verbatim facts from a health message, their judgments and decisions reflect how they understand the gist. In order to increase the effectiveness of health messages, communicators should therefore strive to make the gist memorable.

Understand your audience's needs and abilities and provide messages appropriate to your audience. To appropriately target information, communicators must know their audience. Targeting should therefore consider not only the recipients' prior knowledge but also their capacity to process the information, such as numeracy and health literacy, as well as their preferences for how information is presented [92].

7. Conclusion

Given that the benefits of vaccination are intangible while the costs are tangible, the probability of Internet users to share negative (vs. positive) vaccination experiences via Web 2.0 tools is potentially higher. As a result of the Internet and Web 2.0, private and public concerns about vaccines have the potential to virally spread across the globe in a quick, efficient and vivid manner. Web 2.0 may influence vaccination decisions by delivering information that alters the perceived personal risk of vaccine-preventable diseases or vaccination side-effects. It appears useful for public health actors to place effort into increasing the effectiveness of the existent communication by using the opportunity of interactive, customized communication; this may be facilitated by clearly providing the gist of the intended message. One key to successful public health communication is to identify those who are particularly vulnerable to finding and using unreliable and misleading information. It seems worthwhile that public health websites strive to be easy to find by means of search engine optimization, especially when less knowledgeable individuals are in need of reliable information about the risks and benefits of vaccination.

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