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Identifying HPV vaccine narrative communication needs among parents on social media

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ABSTRACT

Sharing personal experiences is an important communication strategy in public health, including vaccination. This study sought to understand if parents would be receptive to learning about the HPV vaccine from other parent experiences, and what format this information should take on social media. In May 2020, we conducted a qualitative study of six online focus groups across the U.S. with parents (n = 48) of children ages 9–14. Using a text-based discussion format, we discussed their experiences getting information about the HPV vaccine and using Twitter to learn about health topics. Four coders structured qualitative findings by themes including content, delivery, and source of information. An accompanying survey was used to describe participant Twitter use and HPV vaccine knowledge and attitudes. The average participant age was 44.6 years old, 63% were mothers, and the majority had high HPV vaccine knowledge. Parents indicated that they want to hear from other parents about their experiences with the HPV vaccine. However, it was hard to know where to find this information. When experiences are shared on social media, the negative ones are more memorable and more personal. Parents thought Twitter could be an important space to communicate about the HPV vaccine if it was done in a credible, verifiable, and authentic way. Parents want to learn about the HPV vaccine through other parent experiences, especially when this aligns with science supporting the vaccine. Public health and medical communities must embrace this mix of evidence and lived experiences to deliver and discuss health information.

1. Introduction

The Advisory Committee on Immunization Practices (ACIP) recommends that children ages 11–12 receive vaccines to protect against human papillomavirus (HPV)-associated cancers, meningococcal disease, and pertussis (Centers for Disease Control and Prevention (CDC), 2020a). In 2018, while vaccine coverage to protect against pertussis (Tdap vaccine) and meningococcal (MenACWY vaccine) were both above 85% nationally, coverage for the HPV vaccine remained lower at around 65% (Walker et al., 2020). The HPV vaccine can prevent more than 32,000 HPV-associated cancers annually, in both men and women (Centers for Disease Control and Prevention (CDC), 2020b), and is an important tool in cancer prevention. Multilevel interventions and communication campaigns will be necessary to increase HPV vaccine coverage (Reiter et al., 2018).

Promising strategies to increase HPV vaccine uptake have focused on parent-provider communication, as this is an important determinant of vaccine uptake (Walker et al., 2020). HPV vaccine messaging research has produced important insights on how providers should communicate with parents (Brewer et al., 2017; Sturm et al., 2017), on what types of national messages should reach parents (Gilkey et al., 2018; Malo et al., 2016), and how to address parent concerns and vaccine hesitancy (Reno et al., 2018; Shah et al., 2019). While the study of parent-provider communication has produced in-depth, practical guidelines and tools to strengthen vaccine uptake, more is needed to understand how these messages resonate with parents, particularly on social media (Reiter et al., 2018). Moreover, strategies to strengthen parent-to-parent communication, be it in person or on social media, remain underdeveloped (Perkins et al., 2019).

With parents turning to social media to learn more about topics

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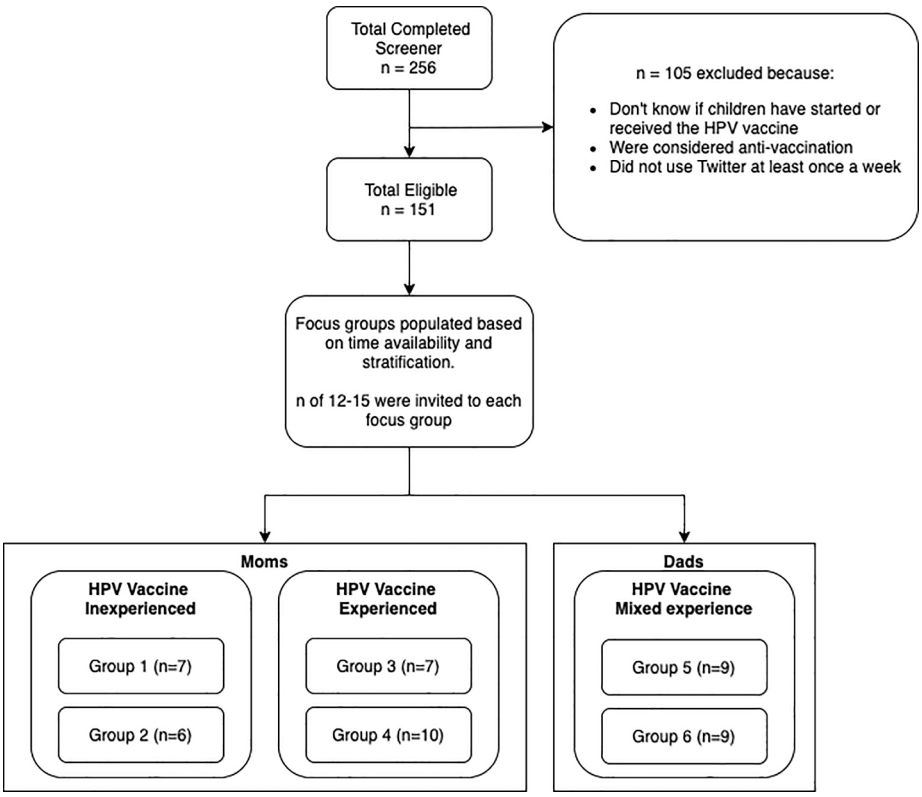

Fig. 1. Study Flow Diagram and Focus Group Recruitment, May 2020.

relevant to their child's health (Duggan et al., 2015), and to communicate with others (i.e., other parents) about their experiences, social media is an important place to share information about the vaccine through stories and experiences. Research examining social media messages and its impact on parents' decision to vaccinate has produced mixed results. While positive messages about the vaccine may outnumber negative messages online (Massey et al., 2016; Surian et al., 2016), stories that discuss vaccine harms have more impact on vaccination behaviors compared to information about prevention and protection (Kearney et al., 2019; Margolis et al., 2019). This may be linked to the fact that sharing information and personal experiences among parents has been a successful strategy in the anti-vaccine world. It is now being recognized as an important communication strategy among pro-vaccine groups (Ernst and Shelby, 2018; Hoffman, 2019; Perkins et al., 2019). The medical and public health communities must support this by providing parents with information and stories about vaccinating their children to protect against HPV that they can relate to. Parents learning from and sharing information with other parents, specifically concerning the HPV vaccine on social media, is an important avenue for future work (Cartmell et al., 2019).

Social media platforms span a wide range, including Facebook, Twitter, Instagram, and TikTok, to name a few. Each platform represents different types of communities and norms, and as such, requires separate and deliberate strategies for research and investigation. For this study, we focus on Twitter, and while it is not the most utilized social media platform, it is used by tens of millions of people and presents an opportunity for population-level health education and promotion. Millions of parents use Twitter to share and look for parenting information, including health information (Duggan et al., 2015). Since 2013, the largest growing age group of Twitter users has been 30–49 year-olds (23% of total users) (Pew Research Center, 2016); this age range represents adults who are most likely to have children who are age-eligible for HPV vaccination. More than 60% of parent users indicated using Twitter at least weekly if not daily (Duggan et al., 2015). Finally, Twitter use transcends urbanicity as urban (22%), suburban (21%), and rural (19%) residents all represent sizeable user groups (Pew Research Center, 2019).

The purpose of this study was to identify salient topics and message strategies to be used in a social media intervention with parents of children who are eligible for the HPV vaccine. Specifically, we sought to understand if parents would be receptive to learning about the HPV vaccine from other parents, if facts and stories are important pieces of evidence to support HPV vaccination, and what format this information should take on Twitter.

2. Methods

2.1. Study setting and recruitment

We contracted with Ipsos, a market research firm, to assemble nationally representative online focus groups from a panel of more than 10,000 U.S. adults (Ipsos, 2020). A total of 256 parents completed the online study screener administered by Ipsos. To be eligible for this study, parents must have 1) had child (ren) ages 9–14 (corresponding to the CDC-recommend age to receive the 2-dose HPV vaccine) (Centers for Disease Control and Prevention (CDC), 2020a), 2) used Twitter at least once a week, 3) not held strong vaccine hesitant views (based on items from the Carolina HPV Immunization Attitudes and Beliefs Scale) (McRee et al., 2010), and 4) spoken English. Of the 256 parents approached, 105 were excluded because they did not meet eligibility criteria. The remaining 151 parents were invited to participate and focus groups were populated based on scheduling availability and mother/father stratification. In total, six focus groups were held with 48 parents across the U.S. between May 8th, 2020 and May 12th, 2020. To ensure homogeneity within each focus group, we stratified participants based on the parent's gender. For mothers, groups were further stratified based on if their child had already received the HPV vaccine (i.e., experienced versus inexperienced); for fathers, groups were mixed due to the number

of eligible and available participants. This study was reviewed and approved by Drexel University Institutional Review Board. Fig. 1 depicts the study flow.

2.2. Study procedures

Prior to participating in focus groups, each participant completed a 31-item online questionnaire administered by Ipsos. The questionnaire included four sections: Twitter use, including typical behaviors and interactions on the platform; HPV knowledge; HPV immunization attitudes and beliefs; and HPV vaccine information needs. Ipsos provided demographic information on all participants as they were part of the existing national panel.

Two members of the study team moderated the text-based focus group on an online platform provided by Ipsos. The platform allowed participants to see the moderator's questions on-screen, as well as hear the moderator speak to facilitate the group chat. Participants were not able to speak, and rather typed their responses and could also comment on the typed responses of other participants, producing a text-based transcript of the discussion. Each focus group lasted approximately one hour. The focus group discussion guide was developed by drawing from prior social media surveillance research by the study team, specifically on how informational and narrative social media posts lead to different levels of engagement (Kearney et al., 2019; Massey et al., 2016), literature on types of messages and the impact of provider recommendations on HPV vaccine uptake (Gilkey et al., 2018; Malo et al., 2016), and research on narrative engagement theory (Murphy et al., 2013). Sections in the discussion guide included decision-making about HPV vaccination, experiences getting information from health care providers and other parents, perceptions about social media platforms, and experiences using Twitter for health information. We also visually presented four Twitter posts on HPV vaccination for group discussion, and compared posts selected from both individuals and organizations, and messages including facts compared to stories (see Appendix A). Participants received $40 dollars for their participation.

2.3. Analysis plan

Upon completion of the focus groups, the transcripts were updated by inserting moderator questions for clarity. A codebook was developed using a mix of a priori codes based on the focus group guide along with themes that emerged from each focus group that were relevant to our research question (Braun and Clarke, 2006). Four members of the research team used NVivo 12 to conduct qualitative analysis for the focus groups. Inter-rater reliability (IRR) was calculated directly in NVivo 12 using Cohen's kappa metric. Using one transcript, the first round of coding yielded an IRR of 0.64. Following the first round of coding, discrepancies were discussed and addressed, and the codebook was updated. A second round of coding with the next transcript produced an IRR of 0.65. While the difference in IRR between the first and second round of coding was small, the IRR remained in a range characterized as substantial with a kappa between 0.61 and 0.80 (McHugh, 2012). Another consensus meeting was held, and the remaining 4 transcripts were assigned for individual coding. Once coding was complete, we structured the presentation of results by themes including the content, delivery, and source of HPV vaccine information.

3. Results

3.1. Sample characteristics

Table 1 presents the overall characteristics of the focus group participants. The sample (n = 48) was on average 44.6 years old. They were primarily mothers (63%), non-Hispanic white (73%), with a bachelor's degree or higher (81%), employed (90%), and married (88%). The majority of parents were highly knowledgeable about the HPV vaccine, with 96% knowing that the vaccine prevents cervical cancer, 83% knowing that 16–17 is *not* the recommended age to vaccinate, and 90% knowing that HPV is a common sexually transmitted infection. Additionally, 84% of participants agreed that if their doctor recommended the HPV vaccine, they would get it for their child, and most knew where to get the vaccine (94%). Parents indicated the importance of scientific evidence (85%) and a doctor's recommendation (81%) for informational needs, and one in three participants wanted to hear from other parents' experiences (35%) and personal stories (31%).

Table 2 provides information on participants' Twitter usage. The majority of participants followed accounts of friends (56%), professionals (56%), and news outlets (52%). One in three (33%) participants followed a health-related account while one in four (23%) used Twitter to find out information on a health topic. A large majority (83%) of participants read comments on Twitter, and a smaller percentage (48%) indicated that the comments impact the way they feel about the content. Fewer participants (35%) created comments themselves.

Table 1
Focus Group Participant Characteristics (n = 48), May 2020.

Characteristics	N	%
Gender		
Male	18	38%
Female	30	63%
Education		
High school	2	4%
Some college	7	15%
Bachelor's degree or higher	39	81%
Race/Ethnicity		
White, Non-Hispanic	35	73%
Black, Non-Hispanic	2	4%
Other, Non-Hispanic	4	8%
Hispanic	7	15%
Employment Status		
Working as paid employee or self-employed	43	90%
Not working	5	10%
Household Size, M(SD)	4.29	1.38
Marital Status		
Married	42	88%
Divorced	3	6%
Never married	3	6%
Census Regions		
Northeast	13	27%
Midwest	12	25%
South	19	40%
West	4	8%
House Membership (presence of)		
Children 2–5	7	15%
Children 6–12	28	58%
Children 13–17	28	58%
HPV vaccine knowledge		
HPV vaccine can prevent cervical cancer (=true)	46	96%
The best age to get the HPV vaccine is when my child is 16–17 years old. (=false)	40	83%
HPV is not a common sexually transmitted disease/infection (=false)	43	90%
I know where to go to get the HPV vaccine for my child		
Strongly disagree	2	4%
Somewhat disagree	1	2%
Somewhat agree	7	15%
Strongly agree	38	79%
If my doctor recommended the HPV vaccine, I would get it for my child		
Strongly disagree	3	6%
Somewhat disagree	5	10%
Somewhat agree	9	19%
Strongly agree	31	65%
What HPV vaccine information do you find most helpful?		
Scientific evidence	41	85%
Doctor's recommendations	39	81%
Other parents' experience	17	35%
Personal stories	15	31%
Age, M(SD)	44.6	6.1

All data are presented as N(%) unless otherwise noted.

Table 2
Focus Group Participant Twitter Usage (n = 48), May 2020.

Twitter Usage Characteristics	N	%
Types of Twitter account followed		
Friends	27	56%
Professionals	27	56%
News outlet	25	52%
Government	23	48%
Celebrities	22	46%
Colleagues	12	25%
Interaction with health-related content		
Follow health-related accounts	16	33%
Ever used Twitter to find out info about a health topic	11	23%
Interaction with Twitter comments		
At least sometimes read comments on Twitter	41	85%
At least sometimes comments impact how you feel about a tweet	23	48%
At least sometimes post comments on Twitter	17	35%

3.2. Thematic analysis

Table 3 presents results from the thematic analysis and is organized by content, delivery, and source of HPV vaccine information. Quotations are provided to support findings and are identified by the type of focus group participant (i.e., vaccine experienced mother, vaccine inexperienced mother, or father). Participant data described in the results are in addition to the data provided in Table 3. Participant de-identified codes are provided, demonstrating that no participant was quoted more than once to strengthen representativeness of findings from our sample.

3.3. Content of information

Parents in our sample thought that information shared on social media about the HPV vaccine should include both personal stories and evidence. Many spoke of balancing the two ways of sharing information, and that by providing real stories, or at least stories that felt real, it made the evidence and information come to life. As one noted,

> *"I think stories can enhance, but they have to be backed by reliable information." (Mom, vaccine inexperienced, ID 501)*

When discussing negative and positive stories related to the HPV vaccine, many parents indicated that negative experiences were more memorable than positive ones. For this reason, parents felt that negative experiences were also more prevalent and available to consume than positive ones. One participant suggested that a negative story makes the message or information more personal by imagining that it could happen to their family, sharing,

> *"I think I am more likely to be influenced by negative experiences, because they make me consider whether those negative things could happen to my kid." (Mom, vaccine experienced, ID 488)*

3.4. Delivery of information

Overall, parents agreed that messages, images, and videos on social media should be provided in a format that presents information in an authentic and credible way. Specifically, images could be used to enhance understanding of information, but in a way that does not distract or detract from the message. One participant described,

> *"Images work to increase engagement, makes people pay more attention – However a syringe isn't the best option, I would have used a young adolescent group" (Dad, ID 268)*

Parents were also aware that not all information on social media could be trusted. Therefore, information shared on social media must be easily verifiable. Participants described the use of links to provide additional support or evidence for messages, as one noted,

> *"I would not go by something posted on Twitter, but if interested would follow the link" (Mom, vaccine experienced, ID 433)*

Twitter allows for the use of "threads" as a way to communicate information or messages that are related. Some parents did not like information presented in a thread format as they thought reading the entire content could be time consuming and confusing at times. However, others found threads with data and statistics to be informative as it provided support and evidence for topics discussed. One participant said,

> *"It depends on the information [the thread is] providing. If it's a thread with data, statistics, etc., I'm for it." (Mom, vaccine experienced, ID 150)*

Table 3
Thematic Analysis of Focus Group Data, May 2020.

Theme	Sub-Theme	Illustrative Quote
Content of information	Content should have mix of evidence and narratives	*"The more real the story, the more real it makes the need seem to me." (Mom, vaccine experienced, ID 574)* *"Balance anecdotal evidence and fact-based research with links." (Dad, ID 271)*
	Negative experiences and stories are more memorable than positive ones	*"A positive experience means nothing happened (i.e. you stayed healthy) so they are not as dramatic." (Mom, vaccine inexperienced, ID 315)* *"I think as humans we probably REMEMBER the negative more than the positive, for the most part. Most I would imagine forget all the good outcomes." (Dad, ID 280)*
Delivery of information	Social media posts should communicate authenticity and credibility	*"It's eye catching, doesn't change the message but helps it look official/credible." (Mom, vaccine experienced, ID 571)* *"WHO is a credible source" (Mom, vaccine inexperienced, ID 555)*
	Information on social media must be verifiable	*"I would watch and search more on it. Obviously she wants to help others" (Mom, vaccine inexperienced, ID 252)* *"Be fair, honest and make sure your information is verifiable." (Dad, ID 70)*
	Threads may be useful and appreciate when they include data	*"It could get overwhelming and I would be more likely to scroll by" (Mom, vaccine inexperienced, ID 16)* *"Depends on the content of the thread. I'd be looking for statistics. If you use threads to give those to me, I'd read." (Dad, ID 137)*
Source of information	Many parents rely on their health care providers for health information.	*"I tend to listen to the medical professionals, as this is their area of expertise. I generally do not let others influence my decision" (Mom, vaccine inexperienced, ID 157)*
	Parents want to gain information from credible, expert sources	*"Any health system, as long as it's credible" (mom, vaccine experienced, ID 602)* *"More credible I suppose, just wish I'd know more about HPV Cancer Free GA - first time I've ever heard of such an org" (Dad, ID 483)*
	Parents are willing to do their own research on online sources of health information	*"I'm not familiar with the organization but it might persuade me to look up more info on them, her" (Mom, vaccine experienced, ID 484)* *"I would like to research the credibility of this institution" (Dad, ID 463)*

3.5. Source of information

While many parents discuss vaccines with their health care providers and spouse or partner, fewer opt to discuss vaccines with other parents. Many parents commented that they would want to hear from other parents about their experiences but did not know how to start the conversation. Still, hearing from other parents can help address concerns, as one participant described,

> *"I have reservations about giving it to my kids, so I ask other parents what they did" (Mom, vaccine experienced, ID 396)*

Others discussed how the polarizing nature of the vaccines dissuaded them from discussing the vaccine with other parents. As one parent noted,

> *"I don't recall any discussion with fellow parents related to vaccines, I also think people have strong view about this so refrain from discussing." (Dad, ID 8)*

Whether parents were getting information about the HPV vaccine from health care professionals or hearing about parent experiences, the credibility of online sources was important. One parent described,

> *"I love seeing the trustworthy name/organization - especially not feeling very knowledgeable myself, it makes me feel better. I want someone to guide me through this decision process - someone I trust" (Mom, vaccine inexperienced, ID 387)*

If parents are not as familiar with a source of information, they are willing to do their own research to determine the credibility and if the information can be trusted. One participant described this as more of a process than a barrier, noting,

> *"I would need to research who they are. If they are credible then the post is credible. Could be a random person with a Twitter handle" (Dad, ID 526)*

4. Discussion

Our study sought to understand if parents would be receptive to learning about the HPV vaccine from other parents, and what format this information should take on social media. We found that parents, regardless of prior vaccine experience or gender, want to hear stories from other parents about their experiences. However, it is often hard for parents to know where to find this information or have these conversations. When experiences are shared, the negative ones leave a lasting impression – the negative experiences are more memorable and seem more personal. Finally, because parents are already on social media talking to others about their kids and health, this platform could be an important space to communicate about the HPV vaccine if it is done in a thoughtful way that allows parents to feel like the information is credible, verifiable, and authentic.

Our findings provide insights into the delivery of a social media campaign, specifically on Twitter, to educate and share information about the HPV vaccine with parents. A majority of our sample indicated that they engage with Twitter comments, and that this behavior can impact how the parents think about and react to the content. While Twitter messages are limited to 280 characters, this finding indicates the opportunity to provide additional content through comments and also threads. While our sample's reaction to threads varied, the general sentiment that threads could provide additional information, specifically evidence supporting stories and experiences, is an important consideration for future content creation. The idea of a single message or tweet may be too simple of a way to think about how content can be delivered and consumed on Twitter and social media more broadly. Rather, connecting content through stories and experiences may provide opportunities for greater engagement and ultimately lead to more interaction with health information and educational materials. This finding is supported by research on entertainment education, or EE, that leverages songs, televised stories (telenovelas), social media (including games and blogs) and other mediated communication to combine theory-based behavior change with storytelling (Singhal and Rogers, 2012). Narratives and storytelling have proven effective in promoting HPV vaccination utilizing traditional media formats (Frank et al., 2015; Hopfer, 2012), and our findings indicate the need for greater exploration and application in the context of social media.

Based on our findings, we offer three insights when developing messages for parents about the HPV vaccine on Twitter. First, parents want to be able to find stories and experiences from other parents about the HPV vaccine that are backed by science. This mix of evidence-based information and lived experiences can be an important mechanism to deliver and discuss information about the HPV vaccine that is relevant to parents and their children. Stories and information shared by other parents may help address concerns that are steeped in emotion, fear, and anxiety. These same stories may help build parent confidence and foster positive emotions including a sense of community and hope (Chou and Budenz, 2020). When parents have worries and doubts that cannot be addressed by science or fact, having an opportunity to sort through concerns by hearing about other parent experiences can be a valuable resource.

Second, we must lift up positive parent experiences and make these experiences more memorable and more personal. Parents in our sample suggested that positive experiences are wanted, but they are lacking in terms of what is available on social media. This finding supports prior work that examined HPV vaccine content on Twitter and Instagram, specifically that while pro-vaccine content was more prevalent, anti-vaccine content was more likely to be described through experiences and also receive more engagement from a social media audience (Dunn et al., 2015; Kearney et al., 2019). Pro-vaccine stories have not been easy to communicate, as our participants noted that when it works, there is no news. However, we must consider how we discuss pro-vaccine stories and think about more proximal benefits and emotions that are positive and personal. Parents want to hear pro-HPV vaccine stories, but they are not that common and not easily found.

Finally, information shared on social media must be credible and verifiable, while at the same time authentic. Importantly, parents are willing to do their own research to come to this conclusion. Known organizations and health agencies can supply immediate source credibility, and at the same time provide the space to share parent stories and experiences. Parents in our sample described that this approach could help the evidence come to life. It was clear that parents are not only willing but expecting to do work to verify information from social media, as content shared on these platforms can be easily manipulated.

There are a few limitations worth noting in our study. First, while parents were recruited from a nationally representative panel, the final sample had overrepresentation in some sociodemographic categories, limiting the generalization of findings. Second, parents needed to have access to a computer or mobile device and the internet to participate in the study which may have precluded certain populations. However, a study goal was to inform social media content and messages and thus internet access would be required. While our findings may not be generalizable to the larger U.S. population, we believe that our study provides important insights to parents who use social media and who interact with health topics and content online.

5. Conclusion

When deciding on whether to vaccinate their child against HPV, parents want to hear about the science and evidence supporting the vaccination, and also stories and lived experiences from other parents. Talking directly to other parents about the HPV vaccine can be difficult because of the lack of space for this conversation to occur, and also the potential for this topic to reveal disagreement or focus on negative stories. Social media can be a valuable resource for the public health and

medical communities to create this space and to communicate evidence and science through stories and experiences. Future work must examine how messages for parents can be created and shared on social media, allowing them to learn from others' experiences and emotional struggles. Further, the use of images and which ones are most effective should also be explored, as should the use of plain language and parent understanding of messages. Ultimately this approach may help foster the confidence parents need to make their decision to vaccinate.

CRediT authorship contribution statement

Philip M. Massey: Conceptualization, Methodology, Formal analysis, Resources, Writing - original draft, Funding acquisition. **Elikem Togo:** Software, Formal analysis, Writing - original draft, Visualization. **Shawn Chiang:** Formal analysis, Writing - review & editing, Visualization. **Ann C. Klassen:** Conceptualization, Methodology, Validation, Resources, Writing - review & editing. **Meredith Rose:** Resources, Writing - review & editing, Project administration. **Jennifer A. Manganello:** Conceptualization, Methodology, Resources, Writing - review & editing. **Amy E. Leader:** Conceptualization, Methodology, Formal analysis, Writing - review & editing, Supervision.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Tweet exemplars for focus group.

The following tweets were shared with participants during focus groups. See below for textual information and an example of the original tweet that was used for the study.

Tweet Exemplar

#	Account Type	Information Type	Twitter Handle	Tweet Text
1	Organizational	Non-narrative	@HPVCancerFreeGA	The three preteen vaccines recommended for 11-year olds and students entering the 7th grade are #HPV, Tdap, and meningococcal. Find out more information for preteen vaccines here: [link]
2	Organizational	Non-narrative	@WHO	Vaccination of young adolescents against HPV is safe and prevents #CervicalCancer. Human Papillomavirus (HPV) is the most common sexually transmitted infection and causes cervical #cancer →□ [Link] #VaccinesWork
3	Organizational	Narrative	@HHSvaccines	Let's all do our part to end #CervicalCancer! Tamika Felder—@IamCervivor founder and #CervicalCancer survivor—fights every day to prevent cancer. Listen to her inspiring story and join us to help #EndHPVCancers: [Link]
4	Individual	Narrative	Redacted	Twitter Thread: When anti-vaxxers fearmonger and share lies about the proven safety and efficiency of the HPV vaccine- are they thinking that in 10 years, a young man or woman could be in my position because their parents were too scared to vaccinate their child due to these rumors? I doubt it I share my story because I want you to protect your child from getting a HPV cancer. I want to protect you from the fearmongering. If you want information – [link] and healthcare providers are the only place to get reputable information.

Note: Individual account twitter handle was redacted, and tweet text was modified in line with best practice in reporting social media data and reducing traceability.

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