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A participatory method to develop human papillomavirus (HPV) vaccine short video content for rural New York parents

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ABSTRACT

Purpose: Human papillomavirus (HPV) vaccine uptake is lower in rural areas, particularly for boys. The purpose of the study was to demonstrate how a participatory approach to developing a series of videos about the HPV vaccine better meets the informational needs of rural parents.

Methods: We recruited six rural parents to participate on a parent advisory board (PAB). The PAB met monthly spanning five months (n=5 meetings) from February to May 2023. Each meeting focused on an element of video creation, including: 1) Providing feedback on existing HPV vaccine videos created by federal agencies and developing a tailored plan for local rural parents; 2) Providing feedback on the video plan so the study team could draft scripts; 3) Editing scripts; 4) Finalizing video concepts; and 5) Providing feedback to produced videos. Between meetings, parents completed tasks to facilitate the process, which also served as a way for parent input to be documented. We worked with a local, professional videographer to produce the videos. A local parent and a nurse practitioner were recruited as actors.

Results: Six one-minute videos were produced on the following topics: What is HPV?; Does the vaccine prevent cancer?; How does the vaccine work?; Is the vaccine safe?; Who should get the vaccine?; and Where can you go to get the vaccine? The PAB was essential in clarifying source, message, channel and receiver throughout the video creation process.

Conclusions: Engaging parents to co-create a series of one-minute videos supports HPV vaccine confidence efforts in rural areas

1. Introduction

The human papillomavirus (HPV) vaccine is a safe and effective method for reducing the risk of HPV related infections and subsequent consequences of infection, including cervical, vulvar, penile, anal, and oropharyngeal cancers as well as genital warts (Meites et al., 2019). The HPV vaccine offers long-lasting protection among both boys and girls and is routinely given at age 11 or 12 years (can be started as early as age nine) and to individuals through age 26 years if not fully vaccinated when younger (Meites et al., 2019). However, disparities in vaccine uptake exist particularly when comparing rural and non-rural communities (Swiecki-Sikora et al., 2019; Vanderpool et al., 2019). Combined survey data from the 2018–2022 U.S. National Immunization Survey-Teen show that up-to-date HPV vaccination coverage among adolescents ages 13–17 varies by urbanicity, with the lowest coverage among

non-urban adolescents (Centers for Disease Control and Prevention, n. d.). Compared to 60.7 % of adolescents living in a metropolitan statistical area (MSA) principal city, and 56.9 % of adolescents living in a MSA non-principal city, only 49.9 % of adolescents living in a non-MSA were up to date with HPV vaccination (Centers for Disease Control and Prevention, n.d.). This is particularly concerning as rural communities face higher rates of HPV-associated cancers (Zahnd et al., 2019).

Residents of non-MSA or rural communities face multiple unique barriers that may contribute to lower HPV vaccine coverage, including barriers accessing health care, lower awareness and knowledge of HPV vaccination, and fewer health care professionals (Boyd et al., 2018; Peterson et al., 2020). Various facilitators to HPV vaccine uptake have also been identified specific to rural communities, and include raising awareness about the HPV vaccine among caregivers, strengthening provider recommendations for vaccination, leveraging school-based

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programs to raise awareness and offer vaccination, and offering countywide provider trainings (Peterson et al., 2020). Despite recognition of these barriers and facilitators, there have been limited interventions specifically designed to increase vaccination rates in rural areas (Brandt et al., 2021). Therefore, we sought to build from these community facilitators and learnings to develop HPV vaccine messaging to support vaccine uptake among rural communities.

Mass health communication campaigns, often targeted at the national and state levels of influence, are important strategies in health education for disseminating relevant and accurate information to a broad population, especially concerning the HPV vaccine (Anker et al., 2016). The short video format has been used successfully in many campaigns (Blake et al., 2020) and is a recommended community prevention taskforce strategy (Task Force on Community Preventive Services, 2008). To reach the widest audience, campaigns often focus on population-level characteristics and seek to promote knowledge, raise awareness, and motivate behavior change among members of populations (Abroms and Maibach, 2008). While these strategies are critical to raising awareness and educating the public, local strategies are also important to tailor communication needs and preferences to specific audiences. The reach of local health communication strategies is likely more limited in terms of the number of people who may be exposed to campaign messages; however, the tailoring of messages, based on specific community characteristics, has the potential to make information more relevant and thus more effective (Kreuter & Wray, 2003). Thus, we aimed to produce a series of short videos to improve HPV vaccine confidence among parents of adolescents living in rural communities in central New York. To accomplish this goal, we used principles from community-based participatory research (Wallerstein et al., 2018), an effective and powerful approach to improve equity and mitigate health disparities (Israel et al., 2005; Katz & Paskett, 2015). Several studies addressing intervention development to increase vaccine confidence have utilized community-engaged and participatory approaches to various extents (Katz & Paskett, 2015; Ma et al., 2022; Marshall et al., 2022). However, these studies do not describe in detail the communityengaged process that such intervention development requires.

The purpose of this study is to describe how we developed informational videos about the HPV vaccine through a participatory method, notably by working alongside a parent advisory board (PAB) comprising local, rural parents. The participatory approach led to multiple insights and changes related to the source of information, the content of the messages, and the channel through which the messages were delivered, all of which would have been overlooked had we not invited rural parents to participate in the process.

2. Methods

2.1. Setting

The project took place between January and June 2023. PAB members were residents of Delaware, Otsego, or Herkimer counties, three contiguous counties of rural central New York. The largest city in this area has a population of about 15,000 individuals. Over 90 % of the population within the three counties identifies as white, non-Hispanic, and 13.4 % of the population meets the federal poverty threshold, with 11.4 % of the population experiencing food insecurity (United States Census Bureau, 2020). The percentage of adolescents aged 13 years within the three counties who completed the HPV vaccine series was 35.9 % compared to 40.2 % for the state (United States Census Bureau, 2020; New York State Department of Health, 2024).

2.2. Establishing the infrastructure

The project team consisted of research scientists and content experts, the PAB, and a local professional videographer. In addition, the team worked with two community theater actors, and members of Bassett

Healthcare Network's HPV vaccine workgroup. This project was deemed exempt from ongoing review by the Mary Imogene Bassett Hospital Institutional Review Board.

The research scientists and videographer tapped into their local community networks to recruit individuals willing to serve on the PAB. A PowerPoint describing the purpose and tentative timeline of the study were shared with potentially interested persons. PAB members had to live in a self-defined rural community, be a parent or guardian to at least one child, be willing and able to attend virtual monthly meetings that lasted approximately one hour, and complete various "homework" assignments in between meetings. PAB members were compensated \$50 for each meeting they attended. Our PAB ended up consisting of mothers only. Four of the six mothers had children within the age range of nine to 14; two mothers only had children who were younger than nine.

Due to the nature of small rural communities, as well as our recruiting methods, many of our stakeholders knew each other from other contexts. For example, the videographer knew the research scientists from work on a prior project. She also recruited one of the parents that ended up on our PAB. The actors who were engaged in video production were recruited by research scientists who knew them from other contexts.

2.3. Overview of activities

Five stakeholder meetings occurred between February and May 2023. Within this time frame, extant data were reviewed, stakeholder-requested data were retrieved and collated, video content was developed, the storyboards were designed, and the videos were produced (Fig. 1).

Utilizing principles from community-engaged research, the project team (PAB, research scientists, videographer) embarked on an iterative process to co-design a series of educational videos. While a general outline of the goals for each meeting was provided to stakeholders (Fig. 1), decisions regarding the content for and production of the videos were made primarily based on feedback from the PAB.

We used a design thinking framework to describe our process (Abookire et al., 2020; Neuhauser & Kreps, 2014; Stoepker & Dzewaltowski, 2023). Categories and definitions were developed based on extant design thinking and process improvement models (Rosen et al., 2024). Investigate is the process of gathering information to learn more about the setting or situation. Design is the act of specifying, modifying or planning a prototype. Produce is the process of creating a prototype. Reflect involves evaluating the results of the prototype (Table 1). We relied on document review from internal team meetings, email communication, PAB meeting notes, and PAB assignments to summarize project activities as well as to frame the results.

2.4. Video planning

Video production planning was simultaneously occurring as content was being discussed and developed by the PAB. The team's videographer had extensive experience producing films for a range of organizations in our rural region and was extremely helpful in guiding our discussions on video design. Topics that were addressed included video length, filming location, the ratio of graphics/voiceover to live actors, the types of actors, best format for different types of dissemination, background music, and title design. The videographer brought examples of the choices to the PAB meetings for the group to decide on the best approach. The videos were originally designed without branding because it was important for the PAB to have input on which organization would be deemed an appropriate source of the videos.

3. Results

Based on input from the PAB, we produced six one-minute videos on the following topics: What is HPV?; Does the vaccine prevent cancer?;

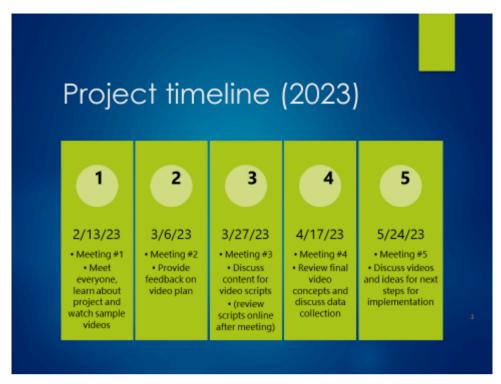


Fig. 1. Timeline of HPV vaccine video project with Parent Advisory Board meeting goals.

How does the vaccine work?; Is the vaccine safe?; Who should get the vaccine?; and Where can you go to get the vaccine? The creation of these videos was the result of intentional conversations regarding the source, message, channel and receiver (Berlo, 1960). We have therefore framed our results using the Source, Messaging, Channel, Receiver (SMCR) model, as well as included some details on the video production process.

3.1. Source

Parents indicated that they generally trust their pediatrician and therefore it was important to have a pediatric practitioner as the one delivering the message. While some video scripts originally were designed as a conversation between two parents or a parent and a clinician, parents tended to prefer just having one person speak. The videographer also indicated that having only one person speak would simplify the video and allow the viewer to focus on the message as opposed to the activity going on between speakers. Parents also indicated that the provider should not be wearing a white coat as many providers seen in rural areas choose not to. While PAB members originally did not notice the lack of branding on the videos, they strongly felt that endorsements by the Centers for Disease Control and Prevention or the local health departments would not be helpful due to issues surrounding the public image of these organizations after COVID-19. Finally, it was important that the videos carry a local, rural flavor. Therefore, every video had an opening scene (shot from a drone) of rural upstate New York, and the parent actor, a local parent in the community, was identified as "local parent" in the video.

3.2. Message

The original video outline did not include any information about HPV itself and why it is important to get a vaccine because we were focused on improving vaccine confidence in rural communities. Parents felt they needed this information and therefore a video was designed to this effect. In addition, parents wanted the videos to be transparent about how HPV is contracted. The health care system's school-based health centers had been promoting the vaccine as cancer prevention

and not describing HPV as sexually transmitted. The parents felt that it was important to disclose this information in the videos. Parents also appreciated having quantitative data to support any claims. For example, the initial response from parents was that it was okay to start vaccinating at age nine, but the videos needed to explain why; i.e., that data show a stronger immunological response at younger ages.

3.3. Channel

PAB members held a diversity of views on how the videos could best be disseminated. They appreciated the one-minute length of the videos and felt that if the videos were any shorter (as in 15-second reels), it would be difficult to get the message across. However, parents were intrigued by the idea of seeing what a 15-second reel could look like. Generally, PAB members felt that the videos would be most useful if distributed in a clinic setting. Other ideas included disseminating to parenting classes and scouting organizations.

3.4. Receiver

There were two major findings related to the receiver. First, even though rural communities are tightknit, parents felt that it was irrelevant to use a collective voice. Instead of the original tagline of "protect our kids against future cancers...get them the HPV vaccine", the group settled on "protect your kids against future cancers...get them the HPV vaccine". Second, moms originally thought that disclosure of all side effects, including very rare ones, was important for the target audience (i.e., parents who were undecided about vaccinating their children for HPV). However, after the videos were produced and the moms saw the extra description for the very rare side effects, they believed that this emphasis by itself would be overly influential and dissuade the target audience. Therefore, we revised the video to present the side effects in a more evenhanded way.

3.5. Video production

Once consensus was reached on the topic in each of the categories (i.

Table 1

Project team activities to co-design a series of educational videos on HPV vaccination, February-May 2023.

	Activities	
Meeting 1	Investigate: Research scientists share what is already known about the topic of HPV vaccination and vaccine confidence Investigate: Research scientists share regional data for HPV vaccines	
	Reflect: PAB wonders how HPV vaccine rates compare to other	
	vaccine rates in our region Investigate: PAB shares what is unique about our region regarding HPV vaccine uptake	
	Investigate: Project team views nationally produced HPV videos Reflect:	
Between meetings 1	What are the project team's responses to those videos? Produce:	
and 2	Based on feedback, video outline was produced by the content experts—seven videos (HPV vaccine norms; what is HPV; where to get HPV vaccine; vaccine cost; vaccine safety and effectiveness; vaccine is for both boys and girls; cancer prevention)	
	Investigate:	
	PAB responded to questions regarding what they've heard about the vaccine from other parents, what their experiences with the HPV vaccines are, and what their community is like Reflect:	
Meeting 2	Project team members reflected on plan individually Reflect:	
	Project team members reflected on plans as a collective Design:	
	Project team members decide to reconfigure the initial tag line to "Protect your kids from future cancers. Get them the HPV vaccine" Reflect:	
	PAB wonders how effective and safe is the vaccine; where can you get it around here? What is the cost?	
Between meetings 2 and 3	Investigate: Research scientists gather data on effectiveness, cost, safety to	
	share with project team Research scientists create infographics to share	
Meeting 3	Reflect: Project team thinks collectively on content and design of videos based on most recent data and graphics presented Design:	
Patricon mostines 2	Project team develops a more concrete plan for video scripts based on investigation and reflection Produce:	
Between meetings 3 and 4	Video scripts are drafted by content experts (what is HPV; cancer prevention; how HPV vaccine works; vaccine safety; when to get the vaccine; cost)	
	Reflect: Video scripts are reviewed by project team members individually	
	Produce: Research scientists and videographer turn scripts into storyboards incorporating feedback	
Meeting 4	Reflect: Project team reviews storyboards	
	Project team suggests various edits to improve clarity and usefulness	
Between meetings 4 and 5	Produce: Videographer produces six one-minute videos; four of these videos are also shot with alternate versions	
Meeting 5	Reflect: Project team reviewed videos	
	Design: Project team develops a plan for edits of videos, including changing intro and outro voiceover, adjusting the intro and	

Table 1 (continued)

Activities
outro rural scenes and adjusting some graphics on some of the videos Reflect: Continue thinking about branding and what the most credible source would be for these videos in order to increase vaccine confidence

Note. HPV = human papillomavirus; PAB = parent advisory board.

e., source, messages, channel, receiver), we created storyboards to outline how each of the videos were going to be produced. Table 2 shows a storyboard used for production of the video on HPV vaccine effectiveness featuring a local health care provider and includes details on the filming, location and graphics from the videographer.

We did not always easily arrive at consensus regarding the source, message, channel and receiver (SMCR). However, the intentional participatory and iterative process resulted in rich discussion and feedback. To illustrate this process, we provide examples depicting the research scientists' presuppositions, the conversation that ensued, and the end result or resolution of the conversation (Table 3).

4. Discussion

The development of a series of short videos about the HPV vaccine was co-created with a PAB and local videographer through an

Table 2Storyboard developed by the project team in March 2023 for the video "Getting the HPV Vaccine: How does it work?".

Scene #	Time	Audio	Video	Location/ notes
1	:00- :05	Music	Engaging music Getting the HPV Vaccine: How does it work?	Scene from upstate New York
2	:06- :16	When I talk to parents about the HPV vaccine, they often want to know more about how it works. That's a great question. If I was giving the vaccine to my child, I would want to know how it works too.	Nurse Practitioner, into Camera (teleprompter)	School-based clinic, up- close shot
3	:17- :28	HPV vaccines help the body make antibodies by introducing particles that look like HPV but are harmless. These antibodies stick around, so they are always ready to attach to HPV if it enters the body.	Voice Over B-roll (supplemental footage), Text & Graphic	Text graphics
4	:29- :37	When antibodies attach to the virus, they prevent it from infecting cells. This makes it harder for HPV to cause an infection.	Nurse practitioner, into Camera (teleprompter)	School-based clinic, up- close shot
5	:38- :43	Studies show that HPV infections can decrease by 80–90 % once someone is vaccinated.	Voice Over B-roll, Text & Graphic	Text graphics
6	:44- :48	This means that cancers caused by HPV are prevented as well.	Nurse practitioner, into Camera (teleprompter)	School-based clinic, up- close shot
7	:49- :53	Protect your kids from future cancers. Get them the HPV vaccine.	Voice over (same for all videos)	(same for all videos)

Note. HPV = human papillomavirus.

Table 3Selected points of discussion among the project team throughout the video development process, February-May 2023 using the SMCR framework.

Variable	Researcher Presupposition (based in literature, what others have done)	Conversation	Resolution
Source	Local flavor	All agreed with this approach.	Used actors who were clearly identified as real local parents/ providers.
Source	Two people communicating	Videographer mentioned it was difficult to do well in one-minute videos. Moms felt a conversation between two people didn't feel authentic	Used local scenes in videos. Only one person was speaking in each of the videos.
Messaging	Understand that HPV is a sexually transmitted infection	when scripted. Moms wanted the videos to say that HPV infection is a sexually-transmitted infection; health care system's HPV vaccine workgroup	Both messages were filmed in different versions of the "What is HPV?" video
Channel	Social media	promoting the message "HPV vaccination is cancer prevention". Moms preferred that videos be used in clinical setting.	reached out to HPV workgroup to ensure consistency in messaging. Implications for video production (size of videos) and for video
Receiver	Community connectedness "protect <u>our</u> kids"	Moms believed parents would be more interested in protecting their own children.	dissemination. "Protect <u>your</u> kids"
Receiver	Mention standard side effects	Moms originally thought that disclosure of all side effects, including very rare ones, was important for the target audience, (i.e. parents who were undecided about vaccinating their children for HPV). After the videos were produced and the moms saw the extra description for the very rare side effects they believed that this emphasis by itself would work to dissuade the target audience.	Revised the video to present the side effects in a more evenhanded way.

Note. HPV = human papillomavirus.

intentional rapid feedback process that uncovered nuances surrounding HPV vaccination. We integrated community engagement principles into this process, particularly the ideas of recognizing community as a unit of identity, the idea of being part of a rural community; and promoting colearning among all partners (Israel et al., 2018).

While some of the research scientists were also from rural communities, PAB members and the videographer provided key insights

regarding all elements of the SMCR framework. For example, the researchers understood that the videos would be local and rural, but did not understand what these terms meant to end users and how they should be captured. For example, one of the strongest predictors of HPV vaccination is having a recommendation from a health care provider (Oh et al., 2021). The PAB also felt that it was important that a local health care provider be front and center in the videos that were developed. However, PAB members agreed they did not want the provider in the video to be wearing a lab coat, they wanted an actual provider acting in the video, and they wanted to include the name of the provider as a caption on the screen when she was speaking. These elements support the rural values of close community relationships and that appointments with a provider are relational and not just transactional (Bernacchi et al., 2021; Farmer et al., 2012).

Researchers also did not comprehend how important seeing actual quantitative data would be for the receiver. Not only did PAB members want to know the percentage decrease in chances of acquiring HPV if given the vaccine, but they wanted to know the sources of these studies. This study occurred after the start of the COVID-19 pandemic and therefore parents may have had heightened feelings above vaccines in general, requiring them to want more information in order to feel comfortable making a decision (O'Keefe, 2008).

Another important tenet of the participatory research process is valuing all perspectives (Vargas et al., 2022). We provided several examples in Table 3 where the entire team engaged in thoughtful conversation to come to a consensus on the SMCR elements. Furthermore, we were engaging other stakeholders who were not directly involved in this project to ensure that messages were not contradictory (and the videos thus would be more likely to be used in the health care network).

Finally, we recognized and leveraged assets within our community to create the final product. The research scientists had worked with the videographer on previous projects and therefore we knew ahead of time that it would be feasible to produce professional-grade videos within the allotted time and funding. Clearly not all communities will have this service available to them. While highlighting this uniqueness limits the generalizability of the actual product we made, we believe it is possible to generalize the process of understanding a community's capitals and then using those to bring the project to fruition (Emery & Flora, 2006).

5. Future directions

Following the development of the videos, several questions have yet to be resolved including: ownership of the videos, where they will be housed, and who they are credited to (i.e., branding). Initially we had anticipated that the videos would be used on social media. However, the PAB recommended that the videos instead be used in clinical settings (as that was their preferred source of information regarding vaccines). This change had implications for aspects of filming (e.g., horizontal vs vertical formatting), but also for dissemination as there are many clinically based strategies for getting the videos to parents (e.g., patient portal, viewing in waiting room or exam room). To that end, the next steps for this research include testing different implementation strategies to determine feasibility and effectiveness of using the videos in clinical practice. Moving forward, our findings demonstrate the importance of engaging parents to co-create HPV vaccine messages, where the products can be used to build confidence in the HPV vaccine in rural areas.

CRediT authorship contribution statement

Kristin Pullyblank: Writing – review & editing, Writing – original draft, Investigation, Formal analysis, Data curation. Wendy Brunner: Writing – review & editing, Supervision, Project administration. David Strogatz: Writing – review & editing, Methodology, Conceptualization. Jennifer Manganello: Writing – review & editing, Methodology, Investigation, Conceptualization. Philip Massey: Writing – review & editing, Writing – original draft, Methodology, Investigation,

Conceptualization.

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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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Data availability

Data will be made available on request.

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