

https://dspace.org/

Using narratives to inform the development of a digital health intervention related to COVID-19 vaccination in Black young adults in Georgia, North Carolina and Alabama

Marie C D Stoner; David Tweedy; Maria G Leonora Comello; Christina Toval; Audrey E Pettifor ...

2022-11-15
https://hdl.handle.net/10539/38359

Downloaded from a DSpace repository. https://dspace.org/



Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.

Vaccine 40 (2022) 6908–6916

Contents lists available at ScienceDirect

Vaccine

journal homepage: www.elsevier.com/locate/vaccine

Using narratives to inform the development of a digital health intervention related to COVID-19 vaccination in Black young adults in Georgia, North Carolina and Alabama

Marie C.D. Stoner [a,*], David Tweedy [a], Maria G. Leonora Comello [b], Christina Toval [b], Audrey E. Pettifor [b], Margo Adams Larsen [d], Alejandro Baez [a], Allysha C. Maragh-Bass [c], Elizabeth E. Tolley [c], Erica N. Browne [a], LaRisa Anderson [b], Kathryn E. Muessig [b], Henna Budhwani [e], Lisa B. Hightow-Weidman [b,e]

[a] RTI International, Berkeley, CA, USA
[b] University of North Carolina, Chapel Hill, NC, USA
[c] FHI 360, Durham, NC, USA
[d] Virtually Better Inc., Decatur, GA, USA
[e] Florida State University, Tallahassee, FL, USA

ARTICLE INFO

Article history:
Received 8 August 2022
Received in revised form 12 October 2022
Accepted 13 October 2022
Available online 20 October 2022

Keywords:
COVID-19 vaccination
Vaccine hesitancy
Mistrust
Digital Health Intervention
Narratives

ABSTRACT

Interactive stories are a relatively newer form of storytelling with great potential to correct misinformation while increasing self-efficacy, which is crucial to vaccine acceptance. To address COVID-19 vaccine hesitancy and medical mistrust in young Black adults (BYA), we sought to adapt a pre-existing application ("app"; Tough Talks) designed to address HIV disclosure decision-making through choose-your-own adventure (CYOA) narratives and other activities. The adapted app (Tough Talks – COVID) uses a similar approach to situate COVID-19 vaccination decision-making within social contexts and to encourage greater deliberation about decisions. To inform content for the CYOA narratives, we conducted an online survey that was used to elicit the behavioral, cognitive, and environmental determinants influencing COVID-19 vaccine hesitancy among 150 BYA (ages 18–29) in Georgia, Alabama, and North Carolina. The survey included scenario questions that were developed with input from a youth advisory board to understand responses to peer and family influences. In two scenarios that involved discussions with family and friends about vaccination status, most respondents chose to be honest about their vaccination status. However, vaccinated individuals perceived more social pressure and stigma about not being vaccinated than unvaccinated respondents who were not as motivated by social pressure. Personal choice/agency in the face of perceived vaccine risks was a more common theme for unvaccinated respondents. Results suggest that relying on changing social norms alone may not impact barriers to vaccination in unvaccinated young adults without also addressing other barriers to vaccination such as concerns about autonomy and vaccine safety. Based on these findings, CYOA narratives in the app were adapted to include discussions with family and friends but also to touch on themes of personal choice as well as other topics that influence behaviors besides norms such as safety, side effects, and risk of COVID-19 in an evolving pandemic.

© 2022 Elsevier Ltd. All rights reserved.

1. Introduction

Young adults (18–29 years) are a priority population among which to increase novel coronavirus 2019 (COVID-19) vaccine uptake because of the high number of cases in this population combined with lower rates of vaccination. As of March 3, 2022, young adults ages 18–24 had a higher number of cases compared to older age groups and lower rates of vaccination; 62.2% of young adults aged 18–24 were fully vaccinated, 76.6% had received at least one dose and, among those fully vaccinated, 29.1% of those fully vaccinated had received a booster shot [1]. Low vaccine uptake has been driven by concerns about safety and efficacy of COVID-19 vaccines due to the rapid development and approval process, and vaccine hesitancy has been shown to be higher in Black individuals and those who are and younger in age

* Corresponding author at: Women's Global Health Imperative RTI International, 2150 Shattuck Avenue, Berkeley, CA 94104, USA.
E-mail address: mcstoner@rti.org (M.C.D. Stoner).

https://doi.org/10.1016/j.vaccine.2022.10.027
0264-410X/© 2022 Elsevier Ltd. All rights reserved.

[10,15–17]. Concerns around vaccines in Black individuals are connected to medical mistrust in part due to ethical violations like Henrietta Lacks and the Tuskegee study, and structures, policies, and practices rooted in structural racism that perpetuate health inequities in many Black communities [10–14]. However, few studies focus specifically on Black and African American young adults (BYA) who are an important population in which to increase vaccination update and reduce hesitancy.

Given the high use of technology among young adults [2], digital health technologies have been used as a way to increase COVID-19 vaccination. Young adults often rely on digital technologies to build their social networks, receive social support, and obtain health information [2–4]. For example, the majority of young adults access COVID-19 information from online news and social media sites [5,6]. Therefore, digital health interventions (DHI) may be an effective strategy to reduce distrust, and stigma in this population while increasing knowledge, and motivation to be vaccinated.

The use of stories in health-behavior-change contexts has also long been recognized as an important communication strategy [7,8]. Relative to other forms of communication, stories have the advantage of reducing counterarguing, reactance, and selective avoidance, while increasing perceived vulnerability and self-efficacy [9]. Narratives can also correct misinformation, which may be a crucial barrier to vaccine acceptance. Interactive stories are a relatively newer form of storytelling with great potential to "inoculate" against false information while boosting confidence in shifts of judgment in the advocated direction [10,11].

To address vaccine hesitancy in young Black adults, we sought to adapt a pre-existing application, "app" (Tough Talks) [12,13] designed to address HIV disclosure decision-making. The primary objective of the adapted app is to increase COVID-19 uptake (accept first dose of COVID vaccine, complete vaccine series, or receive a booster shot) in BYA in Georgia, Alabama, and North Carolina. The Tough Talks app includes emotionally engaging scenarios, interactivity, and automation to promote observational learning, social modeling, and reinforcement of behavioral skills. To inform app adaptation, we conducted an online survey that was used to elicit the behavioral, cognitive, and environmental determinants influencing COVID-19 vaccine hesitancy among BYA (ages 18–29) in three southern states. The survey was also conducted to inform the development of interactive narratives that might be included in the DHI; specifically, questions were included to help understand decision-making processes of BYA in social situations that might reveal vaccine hesitancy and to identify messaging, content, and potential responses to prompts for the interactive narratives within the DHI. In this study, we detail how narrative, scenario questions were developed and used to understand responses to environmental factors (e.g., peer and family influences). Information from these scenario questions in the online survey was leveraged to inform choose-your-own adventure (CYOA) narratives that are used within the app to situate COVID-19 vaccination within social contexts, and activities that address mistrust in vaccines, providers, and healthcare.

2. Materials and methods

We recruited 150 BYA to participate in an online survey as formative research for an intervention to address vaccine hesitancy/skepticism in Alabama (AL), Georgia (GA), and North Carolina (NC) between September 22, 2021, and November 18, 2021. Eligibility criteria included: (1) 18–29 years of age; (2) identified as African American or Black; (3) English proficient; (4) had access to a personal smartphone; and (5) resident of AL, GA, or NC. The survey was designed to include both vaccinated and unvaccinated respondents to compare groups and gather information about why those who were unvaccinated chose to not get vaccinated, and reasons why those who were vaccinated decided to do so. Our recruitment strategy included: (1) free and paid advertising and posting on social media sites including Facebook, Twitter, Instagram, and YouTube; (2) distribution through national organizations working with BYA; and (3) distribution through our community partners and other network collaborations. Participants completed a one-time online survey through Qualtrics. BYA interested in participating clicked on a link within an email notification or via a social media and were redirected to a study website where they completed eligibility screening, informed consent, and the survey if eligible. The survey took approximately 30–45 min to complete, and participants received a $20 incentive and were able to enter a lottery for a larger prize. The study was overseen by the University of North Carolina at Chapel Hill (UNC) with reliance agreements by the Institutional Review Boards at University of Alabama, RTI international and FHI 360. All respondents provided informed consent for study participation.

The survey included both validated survey constructs that are reported in another manuscript [14] and a narrative format whereby participants were asked to respond to scenarios that might occur in real life around COVID-19 vaccination. Scenarios were created to provide insights into how decision-making is influenced by factors at multiple levels including individual (knowledge, attitudes, normative beliefs), interpersonal (peer and family influence), institutional (medical mistrust), and structural (stigma, discrimination, racism). These factors also align with Social Cognitive Theory (SCT), which has been used to understand factors motivating health behaviors (including COVID-19) vaccination because the model considers individual behavior change while acknowledging the social environment and context in which individuals are embedded.

Within the narrative portion, participants were asked to imagine experiencing different scenarios and to choose among potential actions they could take in response to the scenarios. Narratives were related to social influences, vaccine fears, and sources of disinformation (e.g., from trusted personal sources and social media). Scenarios were developed in collaboration with youth advisory board (YAB) members to ensure they reflected the lived experiences of BYA and provided valid insights into decision making. In addition, each story included follow up questions that changed the context of the scenario to assess whether these changes might influence decisions. Short multiple choice and open-ended questions were used to assess how BYA made the choices they did and to capture their reflections on these decisions.

2.1. Process of scenario development

The study formed a youth advisory board at the inception of the project. The advisory board is comprised of individuals who are representative of the study population, as it was a requirement that 100% of them (a) identify as Black or African American; (b) reside in either AL, NC, or GA; and (c) are ages 18–29 years. The youth advisors (N = 11) are all individuals who were identified via community and social networks of the study project, and some are young adults with whom the study team has collaborated on our community-based studies. In each of the study regions, our outreach included engaging with a local historically black college or university (HCBU), given our population focus. HCBU membership was already present on our scientific advisory board; thus, some youth advisors were identified from them. Additionally, the youth advisory board is open at all times to referrals, i.e., current advisors are welcome to refer others and are also free to leave at any time. The advisory board meets every 2–3 months virtually and is paid for all meetings they attend. There is no requirement

that the youth advisors must be vaccinated, which has allowed for candid discussion about vaccine hesitancy. Additionally, at any given time, there are at least two youth advisors from each of the three study site regions to ensure adequate consideration of contextual factors related to COVID-19 vaccine decision-making.

After the scenarios were drafted by the study team, the youth advisory board for the study was consulted to (a) pilot test the survey itself; and (b) provide comments specifically on scenarios. Youth advisors were contacted by a study co-investigator via email and sent the link to complete the surveys. They were asked to record the following things while completing the survey: (1) the length of time to complete the questions; (2) any suggestions on the wording of questions for ease of understanding; and (3) the length of the scenarios and how realistic they seemed. Comments from the youth advisors who completed the pilot testing (n = 4) included that the scenarios needed to be shortened, which was done. Further, youth advisors felt that the scenarios should be equally descriptive for both those who were vaccinated and unvaccinated and should heavily emphasize the social context of vaccine decision-making. This feedback was incorporated directly into the scenarios, and afterward, were reshared with the youth advisors. At that point, no additional comments were received.

2.2. Description of final scenario questions

In this paper, we focus on two of the four scenario questions that were used (scenarios 1 and 3) to provide a more in-depth description of responses (although all questions are included in Appendices 1 and 2). These two scenarios were selected for more in-depth review because they were the two where the largest percentage of participants said that the scenario had happened to them, 27% (N = 41) and 24% (N = 36). Also, because these scenarios focused on influences from family and friends, a review of responses to these scenarios allowed for a comparison of how these sources influenced vaccination responses.

The first scenario question was written as follows: "Imagine that you haven't gotten the vaccine yet. You are at a gathering with friends/schoolmates and the conversation turns to a discussion about COVID-19 vaccine side effects. It is clear from the conversation that all of your friends have gotten at least one dose of the vaccine. One of them, assuming that you also have already gotten the vaccine, turns to you and asks what side effects, if any, you had." Participants selected among the following responses: (1) Lie and say you didn't have side effects; (2) Tell them you haven't gotten around to getting the vaccine yet but plan to soon; and (3) Tell them you haven't gotten the vaccine yet and don't plan to get it. Respondents were asked to provide an open-ended text response about why they selected the response that they selected. They were then asked if their response would change based on the race of people in the friend group (e.g., if all your friends were Black vs White) and were asked to explain in an open-ended text response.

The third scenario was written as follows: "Let's imagine another scenario: Imagine you haven't gotten the COVID-19 vaccine yet. You find out that your school/work will be providing COVID-19 vaccinations on-site which will make it very easy for you to get your vaccine. While it isn't required at your work/school, you think it is a good idea to get vaccinated but know that your family, your mother in particular, has concerns about the vaccine's safety. Over dinner, she asks what you are going to do." Participants selected among the following responses: (1) You don't want to upset her, so you tell her that you aren't going to get it even though you fully intend to; (2) Lie and say you have to get vaccinated because it is now mandatory at your job/school; (3) You explain to her that while you value her opinion, you have decided you are going to get vaccinated; and (4) Tell her you haven't made up your mind yet and then change the subject. Respondents were asked to provide an open-ended text response about why they selected the response that they selected. They were then asked if their response would change if their mother or someone else in the house had a chronic health condition like heart disease or cancer and if they would have the same response if it was their close friend who had concerns about the vaccine instead of their mother. They were then asked to explain their answers in open-ended text responses.

2.3. Data analysis

We descriptively examined characteristics reported in the quantitative survey including participant demographics and the percentage of young adults who choose different responses related to the four vaccine hesitancy scenarios. We used frequencies and percentages for categorical variables and medians with the interquartile range for continuous variables. Text answers to short-ended questions were exported and analyzed via content analysis to determine how young adults made the choices they did and to capture their reflections. Content analysis involves systematic coding to identify patterns in textual data [15]. A codebook was inductively built based on the raw data. Individual responses were coded according to themes by one coder and reviewed by a second coder to ensure reliability. Comments were organized into larger themes. Open-ended responses were analyzed separately for each question, although the same codes were applied across all questions. Within each question, we analyzed themes overall and by vaccination status.

3. Results

3.1. Description of survey sample

Among 150 BYA who completed the survey between September- November 2021, the median age was 23 years (Interquartile range (IQR) 20–26), with roughly a third in each state (AL 29%, N = 44; GA 33%, n = 50; NC 37%, N = 56; Table 1). Most respondents (59%, n = 88) identified as cisgender women. Approximately 75% (n = 112) of respondents had received two doses of an mRNA vaccine or one dose of the Johnson & Johnson COVID-19 vaccine, 7% (n = 10) received one dose of an mRNA vaccine and 19% (n = 28) had not received the vaccine. Among those who had not received the vaccine, most said that they would wait to get it until it had been available for a while to see how it was working for other people. Less than half (47%, n = 71) of those who were fully vaccinated planned to get a booster shot; however, this was before the CDC strengthened its recommendation for all individuals over 18 to receive the booster as of November 29, 2021 [16]. Less than 15% had ever been diagnosed with COVID-19 (12%, n = 18) but 53% (N = 79) knew someone who had been hospitalized or died as a result of having COVID-19.

3.2. Scenario 1 Results

In scenario 1, respondents were asked to imagine being unvaccinated, attending a gathering with mostly vaccinated friends, and being asked directly by a friend if they had side effects after vaccination (exact wording is in the methods section above). Most respondents (71%, n = 106) chose the response "Tell them you haven't gotten around to getting the vaccine yet but plan to soon" (Table 2). Across all vaccination groups, very few (11%, n = 17) chose "Lie and say you didn't have any side effects," and 18% (n = 27) chose "Tell them you haven't gotten the vaccine yet and don't plan to get it." Looking solely at the unvaccinated population, more than half (61%, n = 17) chose "Tell them you haven't gotten

Table 1
Demographics of 150 Black and African American youth who participated in the survey (September–November 2021).

	N	(%)
Total	150	(100)
Demographics		
Age, years - *median (IQR)*	23	(20–26)
Female	103	(69)
Gender identity		
Cisgender Woman	88	(59)
Cisgender Man	41	(27)
Transgender	4	(3)
Non-binary, genderqueer, gender nonconforming, gender fluid	18	(12)
Highest level of education completed		
Less than high school	2	(1)
High school	103	(69)
Bachelor's or higher	45	(30)
State of residence		
Alabama	44	(29)
Georgia	50	(33)
North Carolina	56	(37)
COVID-19 vaccination and diagnosis		
Vaccination status		
Received both doses or one dose of the Johnson & Johnson	112	(75)
Received one dose of a two-dose vaccine, intend to get second dose	10	(7)
Not received the vaccine – *intention for vaccination*:	28	(19)
Wait until available for a while to see how it is working for other people	14	(9)
Get the COVID-19 vaccine as soon as you can	3	(2)
Get the vaccine only if required to do so for work, school, or other activities	3	(2)
Definitely not getting the vaccine	4	(3)
Don't know	4	(3)
Planning to get a booster	71	(47)
Ever diagnosed with COVID-19	18	(12)

the vaccine yet and don't plan to get it". When asked if this scenario has ever happened to you, more than half of the participants (69%, n = 104) said no; of those who responded "Yes" (27%, n = 41) to having experienced this scenario, 88% (n = 36) had received at least one dose of a two-dose vaccine (Moderna or Pfizer-BioNtech).

3.2.1. Reasons for selecting response to scenario

Following the scenario question, participants were asked to provide an open-ended text response to explain their decision. Across the entire sample, regardless of vaccination status, the most common theme that emerged was honesty about vaccination status. The theme of honesty was related to whether participants would be honest about their vaccination status or choose to lie about it and why. This theme was common overall, but more differences emerged when examined by vaccination status.

For example, among fully vaccinated respondents, a fear of isolation or being shamed was a common theme that appeared in the responses of those who said that they would lie about receiving the vaccine. One respondent described why they would lie by saying *"My community circle takes vaccines very seriously and would isolate me for not taking it.*" Other vaccinated respondents said they selected the response that they chose because of *"honesty, but also to not be shunned/shamed*" and *"to avoid conflict or getting bullied.*" One vaccinated respondent who said they would lie explained this response by saying *"Lie to fit into my friends and not be the only one who doesn't have something to contribute.*" Similarly, most participants with one dose of the COVID-19 vaccine chose to be honest, but again several respondents stated that they were willing to lie due to the perception that unvaccinated people would be judged. For example, one respondent said "*people are rude and overbearing to unvaccinated people a lot of the time, not even bothering to ask why you aren't. They judge and think you're selfish or ignorant*" and another said they chose their response *"to feel like a part of them.*" Another theme among respondents with one dose of the vaccine was that they were willing to lie because being vaccinated is a personal choice and no one else's business. Respondents said they chose to lie in their response *"because it's my business*" and *"there is reason for lying about being vaccinated and we have the free will to or not to get vaccinated.*".

In contrast, among unvaccinated respondents there was little to no fear of judgment among peers for not being vaccinated in comparison to vaccinated groups. One respondent chose to be honest in their response and said "*I wouldn't lie to my friends. If they are my friends they should be able to accept my personal choice to not receive a covid vaccine*," and another said "*I'm not ashamed of not getting the vaccine.*" Themes related to vaccine hesitancy and distrust were also common amongst the unvaccinated group, with one respondent stating that they would "*freely express my distress and why I won't be getting vaccinated*" and another respondent said "*just to show them that I do take my time around any new vaccinations … all vaccinations have side effects but they are temporary*." Themes pertaining to personal choice appeared as well, such as *"Because it's my life and my body.*".

3.2.2. Would your response change based on the race of your friends?

As a follow-up question, participants were asked if their response would change based on the race of their friend group (e.g., if all your friends were Black vs White). Most participants (82%, n = 123) said their response would not change. In open ended text responses to explain why, a majority of respondents across all groups, whether vaccinated or not, believed that race was not a factor and would not change their response. However, in vaccinated groups (both fully and partially) there were some responses that described different comfort levels around their White friends versus their Black friends and the general idea of code switching. For example, one respondent stated "*My comfort with conversation and interaction is completely different with my race vs others. Black vs others. Different sides of the same conversation happen in both Black and white households*" and another said "*"Well, I wouldn't be as comfortable around my white friends, so I'd probably lie. But then I'd leave anyway.*" There was also an idea that the Black friends would be more understanding of vaccine hesitancy due to shared experiences with comments such as *"I feel like fellow Black people would understand my hesitancy.*".

3.3. Scenario 3 Results

In scenario 3, respondents were asked to imagine they were unvaccinated and planning to get vaccinated at work/school but their family, and mother in particular, has concerns about the vaccine's safety and asks what the respondent is going to do. In response to this scenario, more than half of the respondents (67%, n = 100) chose "You explain to her that while you value her opinion, you have decided you are going to get vaccinated" (Table 3). The other respondents were split between the other three answers to the scenario, with 10% (n = 15) choosing "You don't want to upset her, so you tell her that you aren't going to get it even though you fully intend to," 7% (n = 10) choosing "Lie and say you have to get vaccinated because it is now mandatory at your job/school," and 17% (n = 25) choosing "Tell her you haven't made up your mind yet and then change the subject." When asked if this scenario has ever happened to you, most respondents (73%, n = 110) said no. Of those who responded "Yes" (24%, n = 36) to having experienced this scenario, 97% (n = 35) had received at least one dose of a two-dose vaccine (Moderna or Pfizer-BioNtech).

When participants were asked if their response would be the same if their mother or someone else in the house had a chronic

Table 2
Survey responses for scenario 1 and follow up questions, by vaccination status.

SCENARIO 1						
Imagine that you haven't gotten the vaccine yet. You are at a gathering with friends/schoolmates and the conversation turns to a discussion about COVID-19 vaccine side effects. It is clear from the conversation that all of your friends have gotten at least one dose of the vaccine. One of them, assuming that you also have already gotten the vaccine, turns to you and asks what side effects, if any, you had.						
	Vaccination status					
	Any vaccination		**Not vaccinated**		**Total**	
	N	**%**	**N**	**%**	**N**	**%**
How do you respond?						
Lie and say you didn't have any side effects	15	(12)	2	(7)	17	(11)
Tell them you haven't gotten around to getting the vaccine yet but plan to soon	97	(80)	9	(32)	106	(71)
Tell them you haven't gotten the vaccine yet and don't plan to get it	10	(8)	17	(61)	27	(18)
Total	122	(100)	28	(100)	150	(100)
Would your response change based on the race of your friend group (e.g., if all your friends were Black/African American vs White)?						
Yes	19	(16)	2	(7)	21	(14)
No	97	(80)	26	(93)	123	(82)
Don't know	6	(5)	0	(0)	6	(4)
Total	122	(100)	28	(100)	150	(100)
Has this scenario ever happened to you? What was similar or different?						
Yes	36	(30)	5	(18)	41	(27)
No	81	(66)	23	(82)	104	(69)
Don't know	5	(4)	0	(0)	5	(3)
Total	122	(100)	28	(100)	150	(100)
Among those who said this happened: How do you respond?						
Lie and say you didn't have any side effects	2	(6)	0	(0)	2	(5)
Tell them you haven't gotten around to getting the vaccine yet but plan to soon	30	(83)	3	(60)	33	(81)
Tell them you haven't gotten the vaccine yet and don't plan to get it	4	(11)	2	(40)	6	(15)
Total	36	(100)	5	(100)	41	(100)
Among those who would change response based on race: How do you respond?						
Lie and say you didn't have any side effects	5	(26)	0	(0)	5	(24)
Tell them you haven't gotten around to getting the vaccine yet but plan to soon	13	(68)	0	(0)	13	(62)
Tell them you haven't gotten the vaccine yet and don't plan to get it	1	(5)	2	(100)	3	(14)
Total	19	(100)	2	(100)	21	(100)

health condition like heart disease or cancer, most (77%, n = 115) chose "Yes" while a few respondents (19%, n = 28) chose "No" and fewer (5%, n = 7) chose "Don't know." When participants were asked if their response would remain the same if it was their close friend who had concerns about the vaccine instead of their mother, most (71%, n = 106) choose "Yes", about a quarter of respondents (25%, n = 88) choose "No", and 4% (n = 6) choose "Don't know".

3.3.1. Reasons for selecting response to scenario

Following the scenario question, participants were again asked to provide an open-ended text response to the question "why would you respond this way?" Across the entire sample, regardless of vaccination status, the most common theme was personal agency/choice. Many reported that their mother's opinion had little to no effect on whether they got the vaccine or not and that they would choose to be honest about their decision. One respondent stated, "*I'm a person who doesn't like to make waves, nor do I want to have an extended discussion about my personal business*" and another explained "*I trust the vaccine regardless of my mother's opinions*." However, some respondents did choose to lie to their mother and most described that they mostly did so to keep the peace and avoid conflict with their parents. For example, one respondent said: "*She's my mother. I'm not on the best terms with her, but it's not like I want her to die, nor do I want to disrespect her. I'll just present my piece and let her do with that information what she will*" and another said, "*I will use whatever means there is so as not to upset my mother.*" When examined by vaccination status, there were no differences or other noteworthy or common themes outside of personal agency/choice and peace keeping which emerged overall.

3.3.2. Would your response change based on chronic disease status?

When participants were asked the follow-up question, "Would you have the same response if your mother or someone else in the house had a chronic health condition like heart disease or cancer?", a majority reported that their response would remain the same (77%, n = 115). Vaccinated groups (fully and partially) had several responses that stated that they would even try to convince the person with the chronic health condition to get the vaccine and would be more motivated to get vaccinated themselves. For example, one respondent said "*If anything, it would make me more motivated to get the vaccine to keep them safe*" and another respondent said "*I'd be even more adamant in my choice (and try to persuade my mother to do the same for the sake of the family member/her)*.".

4. Discussion

The purpose of this paper was to detail how to leverage scenario questions in an online survey, outline the information assessable via such tools, and discuss how narrative data can be applied to inform digital health intervention components. Using scenarios developed with a youth-advisor team, the study reveals insights about how Black young adults may negotiate social situations in which they are asked or expected to communicate about the COVID-19 vaccine. Analysis also reveals which scenarios may be more commonly experienced and therefore candidates for inclusion in the DHI.

In this online survey of 150 Black young adults ages 18–24 years, most participants reported that they would be honest about their vaccination status and intentions when asked about vaccination decisions in emotionally charged situations by friends and family. However, there were nuances by vaccination status:

Table 3
Survey responses for scenario 3 and follow up questions, by vaccination status.

SCENARIO 3						
Let's imagine another scenario: Imagine you haven't gotten the COVID-19 vaccine yet. You find out that your school/work will be providing COVID-19 vaccinations on-site which will make it very easy for you to get your vaccine. While it isn't required at your work/school, you think it is a good idea to get vaccinated but know that your family, your mother in particular, has concerns about the vaccine's safety. Over dinner, she asks what you are going to do.						
	Vaccination status					
	Any vaccination		**Not vaccinated**		**Total**	
	N	**%**	**N**	**%**	**N**	**%**
What do you say?						
You don't want to upset her, so you tell her that you aren't going to get it even though you fully intend to	12	(10)	3	(11)	15	(10)
Lie and say you have to get vaccinated because it is now mandatory at your job/school	7	(6)	3	(11)	10	(7)
You explain to her that while you value her opinion, you have decided you are going to get vaccinated	88	(72)	12	(43)	100	(67)
Tell her you haven't made up your mind yet and then change the subject	15	(12)	10	(36)	25	(17)
Total	122	(100)	28	(100)	150	(100)
Would you have the same response if your mother or someone else in the house had a chronic health condition like heart disease or cancer?						
Yes	96	(79)	19	(68)	115	(77)
No	21	(17)	7	(25)	28	(19)
Don't know	5	(4)	2	(7)	7	(5)
Total	122	(100)	28	(100)	150	(100)
Would you have the same response if it was your close friend who had concerns about the vaccine instead of your mother?						
Yes	86	(71)	20	(71)	106	(71)
No	30	(25)	8	(29)	38	(25)
Don't know	6	(5)	0	(0)	6	(4)
Total	122	(100)	28	(100)	150	(100)
Has this scenario ever happened to you? What was similar or different?						
Yes	35	(29)	1	(4)	36	(24)
No	85	(70)	25	(89)	110	(73)
Don't know	2	(2)	2	(7)	4	(3)
Total	122	(100)	28	(100)	150	(100)
Among those who said this happened: How do you respond?						
You don't want to upset her, so you tell her that you aren't going to get it even though you fully intend to	2	(6)	0	(0)	2	(6)
Lie and say you have to get vaccinated because it is now mandatory at your job/school	1	(3)	0	(0)	1	(3)
You explain to her that while you value her opinion, you have decided you are going to get vaccinated	28	(80)	1	(100)	29	(81)
Tell her you haven't made up your mind yet and then change the subject	4	(11)	0	(0)	4	(11)
Total	35	(100)	1	(100)	36	(100)

among partially and fully vaccinated respondents, many said they would lie about being vaccinated to friends to avoid shame and judgement from vaccinated friends. This is consistent with research that shows that earlier in the pandemic, social norms and a desire to protect friends and family was a large motivation for vaccination behaviors [17–19]. However, vaccinated individuals seemed to perceive more social pressure and stigma about not being vaccinated than unvaccinated respondents. Unvaccinated respondents commonly said they were not ashamed to say that were unvaccinated to friends and that it was their personal choice. A systematic review of 13 studies found that the most common predictors of vaccine hesitancy in Black and Hispanic people were medical mistrust and history of racial discrimination, beliefs about vaccines, and concerns about the safety, efficacy, and side effects from the COVID-19 vaccines [20]. Therefore, those who remain unvaccinated may have other strong motivations or concerns about vaccination such as vaccine safety that are more important than social pressure. Relying on changing social norms alone may not impact motivations without also addressing these other barriers to vaccination.

When asked if race of their friends influenced their decision to disclose to friends, respondents overwhelmingly said no, but several who did say yes mentioned comfortability around their Black friends. Since race is a social construct, race may be a proxy for having a shared understanding about medical mistrust, experiences of discrimination, or shared concerns about how Black people are treated by the medical community. BYA may be more likely to share their experiences and perspectives with other BYA who they perceive to have had similar experiences to themselves or be understanding of their point of view. This finding resonates with evidence showing that peer networks can influence vaccination decisions and that receiving information on the experiences of COVID-19 vaccination from those who are of the same race and ethnicity can increase willingness to receive a vaccination [17,19,21,22]. Therefore, involving peers in interventions to change COVID-19 behaviors may be an important strategy.

When asked about lying to their mother about vaccination decisions, most respondents reported that they would choose to be honest about their decision because of personal choice/agency and that their mother's opinion had little to no effect on whether they got the vaccine or not. However, several mentioned that they would lie to their mother about their vaccination decision mostly out of respect for their mother. Therefore, maternal influence did not appear to have a strong effect on vaccination decisions in this populations when compared to discussions with friends, but participants did consider how to frame vaccination conversations out of respect for parents and their health.

Information from scenario responses was used to adapt narratives in an interactive CYOA portion of a DHI (Fig. 1). Based on feedback in the survey, some scenarios were revised; however, narratives in the DHI did touch on discussions with family and friends as these were the two questions that resonated most closely with respondents. Given the themes around personal choice, scenarios that involved discussions with friends and family also emphasized considerations about personal choice versus social influence. In addition, narratives included other topics that were still barriers to vaccination in more recent stages of the pandemic including side effects, risk of COVID-19 given the current context of



Fig. 1. Example of a choose-your-own-adventure narrative within the adapted Tough Talks app.

the pandemic (e.g., loosening mask mandates, return to "normalcy"), and immunity from the vaccine versus natural immunity.

There were several limitations to our study. Our study uses a convenience sample of young adults and may not be representative of the larger population of BYA in GA, NC and AL. We found that 14% of our sample were unvaccinated, which is much lower than national and state-level data for vaccination among young adults these states [17,33]. The low rates of vaccination in our sample may be because unvaccinated BYA are less likely to want to participate in research or because the survey was a convenience sample and we did not recruit within the social networks of unvaccinated individuals. In addition, our sample size was small and included only 150 BYA with 28 unvaccinated. Given the small sample size, we had limited power and ability to make statements about this population. Lastly, the scenario questions include hypothetical questions where respondents were asked to imagine that they were not vaccinated. These questions are most relevant to the unvaccinated population, although both groups were included for comparison purposes and to understand vaccination motivations. To address this concern, analyses were stratified by vaccination status, although the sample size for the unvaccinated group was low.

In summary, we used scenario questions in an online survey with BYA to inform the development of a DHI with a narrative component to support decision-making about the COVID-19 vaccine. The two scenarios that resonated most closely with respondents involved discussions with family and friends and provided insights about how BYA negotiate these social situations when asked to communicate about their vaccination status. Most respondents chose to be honest about their vaccination status, but vaccinated individuals perceived more social pressure and stigma when asked to imagine not being vaccinated than unvaccinated respondents who were not as motivated by social pressure. Personal choice/agency was a more common theme for unvaccinated respondents. Relying on changing social norms alone may therefore not impact barriers to vaccination in unvaccinated young adults without also addressing other barriers to vaccination such as safety. Narratives in the DHI were adapted to include discussions with family and friends but to also touch on themes of personal choice as well as other topics that influence behaviors besides norms such as safety, side effects, risk of COVID-19 in an evolving pandemic and immunity from the vaccine versus natural immunity.

Data availability

Data will be made available on request.

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.

Acknowledgement

We would like to thank the respondents and study team. This study was funded by a grant from the National Institute on Minority Health and Health Disparities (R01MD016834).

Appendix

See Tables A1 and A2.

Table A1
Survey responses for scenario 2 and follow up questions, by vaccination status.

SCENARIO 2						
Let's think through another scenario: You scheduled your first appointment to get the COVID-19 vaccine but are getting "cold feet" as the day of the appointment nears. Most of your friends are skeptical of the vaccine. One believes the COVID-19 vaccine will microchip you; another is worried that it will make you infertile, and a third doesn't think that COVID-19 is a big deal. You just got a text notification to confirm your appointment.						
	Vaccination status					
	Any vaccination		**Not vaccinated**		**Total**	
	N	**%**	**N**	**%**	**N**	**%**
Do you?						
Cancel your appointment, and don't reschedule	4	(3)	12	(43)	16	(11)
Cancel your appointment, reschedule for next month	14	(12)	5	(18)	19	(13)
Keep your scheduled appointment	104	(85)	11	(39)	115	(77)
Total	122	(100)	28	(100)	150	(100)
Has this scenario ever happened to you? What was similar or different?						
Yes	30	(25)	1	(4)	31	(21)
No	90	(74)	27	(96)	117	(78)
Don't know	2	(2)	0	(0)	2	(1)
Total	122	(100)	28	(100)	150	(100)

Table A2
Survey responses for scenario 4 and follow up questions by vaccination status.

SCENARIO 4						
Nearly done! One more scenario for you: Imagine you have not yet gotten the COVID-19 vaccine. Your close friend does not want to get the COVID-19 vaccine. She has posted stories on social media about the vaccine causing long-term side effects and has convinced many of your other friends not to get it. She asks you if you are getting the vaccine and if you want her opinion.						
	Vaccination status					
	Any vaccination		**Not vaccinated**		**Total**	
	N	**%**	**N**	**%**	**N**	**%**
What do you say?						
"Yes, I am getting it and can explain why"	87	(71)	5	(18)	92	(61)
I'm not sure (even if I have decided to get it)	15	(12)	8	(29)	23	(15)
No, I have seen her stories and agree	7	(6)	11	(39)	18	(12)
I'm not sure (truthfully)	13	(11)	4	(14)	17	(11)
Total	122	(100)	28	(100)	150	(100)
Would your response change if you were having the conversation on social media versus in person?						
Yes	16	(13)	2	(7)	18	(12)
No	99	(81)	26	(93)	125	(83)
Don't know	7	(6)	0	(0)	7	(5)
Total	122	(100)	28	(100)	150	(100)
Has this scenario ever happened to you? What was similar or different?						
Yes	24	(20)	1	(4)	25	(17)
No	96	(79)	24	(86)	120	(80)
Don't know	2	(2)	3	(11)	5	(3)
Total	122	(100)	28	(100)	150	(100)

References

[1] CDC. COVID Data Tracker. https://covid.cdc.gov/covid-data-tracker/#national-lab. Published 2021, Accessed July 13, 2021.

[2] Hightow-Weidman LB, Muessig KE, Bauermeister J, Zhang C, LeGrand S. Youth, Technology, and HIV: Recent Advances and Future Directions. Curr HIV/AIDS Rep 2015;12(4):500–15. https://doi.org/10.1007/S11904-015-0280-X.

[3] Pingel ES, Thomas L, Harmell C, Bauermeister JA. Creating comprehensive, youth centered, culturally appropriate sex education: What do young gay, bisexual and questioning men want? Sex Res Social Policy 2013;10 (4):293–301. https://doi.org/10.1007/S13178-013-0134-5.

[4] Allison S, Bauermeister JA, Bull S, Lightfoot M, Mustanski B, Shegog R, et al. The Intersection of Youth, Technology, and New Media with Sexual Health: Moving the Research Agenda Forward. J Adolesc Heal 2012;51(3):207–12.

[5] Lee JJ, Kang KA, Wang MP, et al. Associations Between COVID-19 Misinformation Exposure and Belief With COVID-19 Knowledge and Preventive Behaviors: Cross-Sectional Online Study. J Med Internet Res 2020;22(11):e22205. , https://www.jmir.org/2020/11/e22205.

[6] World Health Organization. Social media & COVID-19: A global study of digital crisis interaction among Gen Z and Millennials. https://www.who.int/news-room/feature-stories/detail/social-media-covid-19-a-global-study-of-digital-crisis-interaction-among-gen-z-and-millennials. Published December 2021. Accessed July 20, 2022.

[7] Petraglia J. Narrative intervention in behavior and public health. J Health Commun 2007;12(5):493–505. https://doi.org/10.1080/10810730701441371.

[8] Kreuter MW, Green MC, Cappella JN, Slater MD, Wise ME, Storey D, et al. Narrative communication in cancer prevention and control: a framework to guide research and application. Ann Behav Med 2007;33(3):221–35.

[9] Sangalang A, Ophir Y, Cappella JN. The Potential for Narrative Correctives to Combat Misinformation. J Commun 2019;69(3):298–319. https://doi.org/10.1093/JOC/JQZ014.

[10] Basol M, Roozenbeek J, Van Der Linden S. Good News about Bad News: Gamified Inoculation Boosts Confidence and Cognitive Immunity Against Fake News. J Cogn 2020;3(1). https://doi.org/10.5334/JOC.91.

[11] Green MC, Jenkins KM. Interactive Narratives: Processes and Outcomes in User-Directed Stories. J Commun 2014;64(3):479–500. https://doi.org/10.1111/JCOM.12093.

[12] Muessig K, Knudtson K, Soni K, et al. "I Didn't tell you sooner because I didn't know how to handle it myself". Developing a virtual reality program to support HIV- status disclosure decisins. Digit Cult Educ 2018;10:22–48.

[13] Hightow-Weidman L, Muessig KE, LeGrand S, Al. E. Narratives were related to social influences, vaccine fears, and sources of disinformation (e.g., from trusted personal sources and social media). Scenarios were developed in collaboration with youth advisory board (YAB) members to ensure they reflected. In: AIDS Impact. London, England; 2019.

[14] Stoner M, Browne E, Tweedy D, et al. Exploring Motivations for COVID-19 Vaccination among Black Young Adults in Three Southern States. J Med Internet Res Form Res.

[15] Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005;15(9):1277–88.

[16] Zimmer C, Corum J, Wee S-L, Kristoffersen M. Covid-19 Vaccine Tracker: Latest Updates. The New York Times. https://www.nytimes.com/interactive/2020/science/coronavirus-vaccine-tracker.html. Published March 25, 2022. Accessed March 28, 2022.

[17] Jaffe AE, Graupensperger S, Blayney JA, Duckworth JC, Stappenbeck CA. The role of perceived social norms in college student vaccine hesitancy: Implications for COVID-19 prevention strategies. Vaccine 2022;40 (12):1888–95.

[18] Padamsee TJ, Bond RM, Dixon GN, Hovick SR, Na K, Nisbet EC, et al. Changes in COVID-19 Vaccine Hesitancy Among Black and White Individuals in the US. JAMA Netw Open 2022;5(1):e2144470.

[19] Graupensperger S, Abdallah DA, Lee CM. Social norms and vaccine uptake: College students' COVID vaccination intentions, attitudes, and estimated peer norms and comparisons with influenza vaccine. Vaccine 2021;39(15):2060–7. https://doi.org/10.1016/J.VACCINE.2021.03.018.

[20] Khubchandani J, Macias Y. COVID-19 vaccination hesitancy in Hispanics and African-Americans: A review and recommendations for practice. Brain, Behav Immun – Heal 2021;15:. https://doi.org/10.1016/J.BBIH.2021.100277100277.

[21] Kricorian K, Turner K, Camacho-Rivera M. COVID-19 Vaccine Acceptance and Beliefs among Black and Hispanic Americans. PLoS ONE 2021;16(8):e0256122. https://doi.org/10.1371/JOURNAL.PONE.0256122.

[22] Black KZ, Hardy CY, De Marco M, Ammerman AS, Corbie-Smith G, Council B, et al. Beyond Incentives for Involvement to Compensation for Consultants: Increasing Equity in CBPR Approaches. Prog Community Heal Partnerships Res Educ Action 2013;7(3):263–70.