Developing video education materials for the return of genomic test results to parents and adolescents

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A R T I C L E  I N F O

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A B S T R A C T

Objective: To describe the development, implementation, and revision of a video to provide information about genomic testing and the return of genomic research results to adolescents and parents.

Methods: Formative, community-engaged research was conducted in three stages: development, implementation, and revision. Existing research participant advisory groups were used for focus groups and convenience sampling was used for interviews. Participants included parents, young adults without children, and adolescents. Transcripts of recorded sessions were used for formative analysis.

Results: Video was the preferred format for delivering genomic testing information to adolescents during the development stage. During implementation, adolescents identified video length as an impediment to recall. During the revision stage, participants preferred the video in separate short segments, supported plan to require only one short video and leaving other short videos optional. Participants were divided on whether the required short video provided enough information, but all participants reported that watching additional videos would not have changed their decisions about receiving test results.

Conclusion: Genomic education videos should be brief (<4 mins) to improve the odds that participants will view the entirety of any required video.

Innovation: The development of participant materials should incorporate plans for monitoring implementation and plans for revising materials.

1. Introduction

Adolescents and their parents have increased opportunities to learn personal genomic information as a result of testing in clinical, research, and direct-to-consumer settings. Results from any setting can yield clinically relevant information about themselves [1-4]. Parents and adolescents both have requested they receive individual test results from genomic research studies in which the adolescent participated [5-9], but the return process is complicated by the range of possible results (e.g., positive results, negative results, carrier status, etc.). Further complications exist in returning results to adolescents because of the need to assess their decision-making capacity [10-15], as well as concerns about their rights to self-determination and control over information about themselves [10,14,16,17]. The receipt of negative results can be further complicated by the absence of clinical findings, incomplete assessment of risk factors, and the many caveats about testing limitations [18-20].

The variety of concepts and the complexity of research-based genomic test results make return of individual adolescent's test results to research participants challenging, and necessitate a range of tools to educate adolescents and their parents [21]. While parents have indicated a preference for general information and the return of results by a healthcare provider [22], the number of individuals sequenced in research-based genomic testing can make face-to-face return, particularly of negative results, unfeasible [23-26]. Research teams have developed multiple approaches for returning results, including virtual and face-to-face meetings, letters summarizing results, specialized patient-facing test results, and audiovisual materials [27-34]. Online tools and videos can effectively address the need to educate and inform adolescent research participants and their parents.
However, such educational materials cannot be pulled “off the shelf” from third-party providers since video materials should incorporate considerations of cultural awareness for the pool of potential research participants [17,37].

The goal of this paper is to describe the development, implementation and revision of an audiovisual tool that reflects the concerns of potential research participants and provides information about genomic testing, the meaning of positive, negative, and carrier results, and the return of research test results to adolescents and their parents.

2. Methods

This study is a formative research project to develop, pretest, evaluate and revise an audiovisual tool about genomic testing and the return of results [38,39]. The video was developed for use in the return of research results to adolescents and their parents. This formative study employed both focus groups and interviews with adolescents and young adults aged 13-25 and parents or legal guardians. The project was divided into three stages of development, implementation, and revision (Figure 1). In the development stage, focus groups 1-3 were conducted to assess understanding of key concepts, reactions to possible test results formats, and a review of the video “Whole Genome Sequencing and You” (available https://youtu.be/fhnMvEUShXU) to identify issues to consider when developing a new video for adolescents and their parents. Focus group 4 was used to assess the storyboard proposal originally developed by the research team for the video. In the implementation stage, the 17-minute video was deployed as part of a large-scale genomic research project incorporating return of individual results. Parents and adolescents were provided a link to the video to review prior to consent for the larger project. Video contents were discussed during the consent process. Researchers returning individual results gave parents and adolescents a reminder about the video and its content prior to the return of results, as well. Research team members of the larger project reported adolescent participants misunderstood key concepts. As a result, authors MI and JL conducted interviews with adolescents during which we reviewed the video and asked them to identify memorable content and lessons learned. Based on feedback, we segmented the video into smaller topical segments in preparation for revising the original 17-minute video. During the revision stage in focus group 5, adolescents and parents reviewed the 17-minute video (available https://youtu.be/fhnMvEUShXU) to identify important content by providing rankings for all topics presented. Moderators probed the reasons for the rankings and solicited participants’ overall reactions to the video. Focus group 6 involved the same study participants viewing a narrated PowerPoint of the proposed segmented videos after which reactions to the proposed videos were elicited. The study was approved by the Institutional Review Board in three stages: development focus groups in 2015, adolescent interviews in 2017, and revision focus groups in 2019 and 2020.

2.1. Recruitment

Except for one development focus group, all focus group participants for development and revision were drawn from a research participant advisory council and a community research advisory board affiliated with a pediatric hospital in the United States. These groups were chosen because they reflect the demographics of the community. Participants for an additional development focus group were recruited through flyers and announcements posted at the pediatric hospital. Adolescent interviews were conducted with a convenience sample of adolescents recruited from the surrounding community, and adolescents known to the study team. None of the adolescent interview participants were part of the focus groups. Study participants were compensated using reloadable debit cards for their time and effort. Focus groups participants received $35; interview participants received $25.

2.2. Focus groups

Focus groups 1-5 were divided into parent and adolescent sessions, and focus group 6 was divided into three sessions: parents, adolescents (13–17yrs), and young adults (18–22yrs). All focus group sessions (i.e., each

![Development Stage](image1.png)

**Fig. 1.** Timeline of video development, use, and revision activities. Video development occurred in three stages. In the development stage, four focus groups were held (F1–F4). In the implementation stage, the original 17-minute long video was deployed as part of a large scale project incorporating the return of results. During the implementation stage, the research team identified misunderstanding of key concepts by adolescent participants. In 2018, the research team conducted interviews with adolescents where we reviewed the video and asked them to identify memorable content and lessons learned. After implementation, the research team started a revision process involving two rounds of focus groups (F5 and F6). F5 assessed participant ranking and attitudes about informational topics, and F6 involved participant review of narrated PowerPoints of the revised videos before final production and redeployment.
parent, adolescent, and young adult session) had between 13 and 16 participants. Given the large number of participants in each group, a lead focus group moderator was chosen for each session but additional advisory group coordinators and research team members acted as co-facilitators to ensure that all participants were able to provide their feedback and were not overlooked. Focus groups were audio recorded. Advisory group coordinators and research team members took detailed notes about reactions and comments provided by focus group participants. Audio recordings were transcribed and identifying information was redacted from transcripts.

2.3. Interviews

After the 17-minute video was deployed, the study team identified a series of recurring misunderstandings of video content among adolescents [36]. To further explore the misunderstandings, a convenience sample of adolescents watched the video, completed a demographics survey, and answered a series of open-ended questions. These questions addressed their impressions of the video and specific recollections of content, which were compared with the original content to identify misunderstandings. Responses from adolescents were spontaneously probed to identify how recollections developed to determine how to revise content to improve understanding. Interviews were transcribed and identifying information was redacted from transcripts.

2.4. Data analysis

The research team first used qualitative coding of the interviews and combined it with triangulation to identify themes in both focus groups and interviews. For the interviews, JL and MI developed a coding scheme based on a close reading of the transcripts. Inter-rater reliability was reviewed after the first five transcripts were coded. An inter-rater reliability of 0.743, indicating “substantial” agreement, was determined using Cohen’s kappa. JL and MI then coded the remaining transcripts, and resolved disagreements through consensus.

Themes for the interview coding and the focus group materials were generated using methodological and investigator triangulation. Methodological triangulation involves using multiple data sources to enhance the findings from the focus groups [40]. Data sources in this study included audio transcripts, notes from focus group observers/comoderators, and topic and video ranking sheets used in the revision focus groups. Investigator triangulation is when multiple investigators identify potential themes and findings prior to discussion and collaboration [40]. Members of the research team had a range of backgrounds and specialties including community-based research, genetic counseling, health communication, pediatrics, and public health. The multidisciplinary nature of the team provided a broad set of perspectives that helped establish the credibility and dependability of the themes identified [40,41]. Members of the research team identified potential themes and issues for video development in the transcripts and notes with final themes and issues determined by consensus. The final videos were posted to YouTube for easy access for future studies (playlist available https://youtube.com/playlist?list=PLzQyg0rzF5S8S3fdyyko5Wr22ZKi2NdM-).

3. Results

3.1. Demographics

Demographic information for all participants can be found in Table 1. Development focus groups included 39 participants. About one-third identified as Black. None identified as Hispanic/Latino. Two-thirds were female. Interview participants included 10 adolescents. The majority identified as White and were between the ages of 13-14 years old. Half were female. Revision focus groups included 66 participants across the topic assessment and revised video focus groups. Half of the participants identified as Black. Two-thirds of participants were female.

3.2. Development focus groups

During the development stage, focus groups 1-3 reviewed return of results templates, discussed their understanding of categories of results they might receive, and reviewed a video created by a third-party for returning genomic test results (available https://youtu.be/IXamRS85hXU). Findings from the focus groups guided the production of our original 17-minute video.

3.2.1. Reaction to test template

In the focus group 1, participants were presented with a template for genomic test results that included positive results for monogenic disease risk, carrier status, pharmacogenomic associations, and alleles conferring small to moderate risk for health conditions. Responses to this template were overwhelmingly negative among both parents and adolescents. Both parents and adolescents reported being overwhelmed by the information,
and stated that the test results were written for medical professionals and not for laypeople. One adolescent noted, “It’s just a lot to read.” A parent said, “This wouldn’t help me at all—like I look at it and open it up, then I would just shred it up because I wouldn’t know what to do with it.” Participants stated all return of individual genomic test results ought to happen in face-to-face settings because of the format of information provided.

In the focus group 2, a new group of participants was presented with a different template that indicated negative test results for monogenic disease risk, carrier status for cystic fibrosis, and some pharmacogenomic results. Adult and adolescent participants thought the new template was easy to understand, but still found the information complex and overwhelming. One parent said, “I am confused and lost.” Another parent said “[The test results are] just a whole lot of backwards words to me. You’re either good or bad and that’s...tell me if I’m sick. Speak American.” After the moderator described the results form to them, an adolescent participant said, “[It] definitely helps to have someone explain it to you.” Parents had a mix of preferences for how to receive results, with no clear group preference for face-to-face, mail, or online methods of return. About half of the adolescent participants indicated they would be comfortable receiving test results by mail or online.

3.2.2. Positive and negative results

In focus group 2 and focus group 3, participants were asked about the terms “negative results” and “positive results.” Parents typically understood that “negative results” meant that no genetic variant related to a condition was found. As one parent observed, “It does not rule out everything, but there’s not a precursor. There’s not a genetic marker.” Many adolescents understood negative results as no genetic variant for a condition being found. One defined the term as “things that you’re not getting.” Yet, about one-third of adolescent participants viewed negative results as indicating bad news about one’s health. One said, negative meant “results that you wouldn’t want to hear.” Another adolescent claimed the term was “bad.” In contrast to negative results, parents and adolescents both correctly interpreted the term “positive results” and had no concerns about it.

3.2.3. Responses to sample videos

Participants in the focus group 1 and focus group 3 viewed a third-party video as an example of the supplemental information they might receive alongside genomic test results. Participants who saw both test result templates and videos felt the videos helped explain the test results. One parent remarked, “I think the video clearly helps... It breaks it down very well and I think it gives you enough information of things you probably already heard to make you connect with it.” One adolescent reported, “Most of the stuff they said in there was mostly in this packet, but it did, like, break it down more so you could understand it.” Some parents were concerned about the length of the video. For example, one parent said, “I think 10 minutes is a little bit long. I think it is very well laid out, but personally, if I see a 10-minute video, I’m generally not going to watch it.” Yet other parents indicated that 10 minutes was appropriate considering the type of information one might receive from genetic testing, especially if the video was divided into sections people could select individually. One parent asked, “Could it be a little bit more, choose your own adventure or like? So if all the, if the 10 minutes of video was there but I got to click and hear about different pieces of it?” As a result of the focus group feedback, the research team created a 17-minute video with bookmarks to allow participants to choose sections to view.

3.3. Adolescent interviews

Adolescent responses to the 17-minute video indicated challenges with length and content. After reviewing the video, four of the 10 adolescents described it as “informative.” Throughout interviews, adolescents identified several concepts and facts they learned from the video, including specific facts about the genome and the possibility that one could be denied life and other types of insurance following genomic testing. Despite the generally positive reactions, five of the adolescents struggled to recall specific content when asked. One participant described the video as “pretty long” and said they “got lost in the middle.” Another adolescent said, “I mean, I wouldn’t remember it if I watched it once obviously I wouldn’t remember all this stuff.”

When asked what positive results meant, adolescents offered a range of definitions that reflected correct information. Four adolescents noted that positive results meant there was a risk of a disease. Five adolescents suggested that positive results would reveal a disease diagnosis. Two adolescents also explained that positive results meant other family members could be at risk as well. Yet, some adolescents struggled to distinguish positive results from negative results. Significantly, one participant incorrectly suggested that positive results meant there was a treatment for the condition, whereas negative results meant there was not a treatment for the condition.

Most adolescents understood that a negative result meant they may still be at risk for a condition, or that a gene variant associated with increased risk could not be found. Although most adolescents indicated some understanding of the concept of negative results, they also reported a lack of confidence in their knowledge. One adolescent struggled to frame their response to questions about negative results, despite correctly understanding the concept:

“It means that... your- there was not a genetic cause found for a certain disorder or condition. And, it means that you’re less likely to get something, like, if... you- the test was looking for a disease that develops, like, it’s passed down through generations and you get a negative result it, means you’re less likely to get that disease.”

When answering questions about negative results, most participants framed their responses as a question, or sought affirmation from the interviewer that their response was correct.

3.4. Revision focus groups

After the implementation stage and receiving interview feedback, the research team started the process of revising the video. Focus group research guiding the revision process occurred in two parts: topic assessment and revised video assessment.

3.4.1. Topic assessment and video review

During focus group 5, held in 2019, participants ranked topics included in the initial video as a prompt for discussion of the video content (Table 2). Using a Likert Scale, participants ranked the following topics as “most important” after viewing the video: basic genetics/genomics concepts, testing options and questions to consider before testing, what happens with results post-test, impact on family, and insurance issues. The negative results section had the fewest “most important” rankings of all topics in the video, but most participants ranked it as “somewhat important” or neither “important or unimportant”.

Participants then explained their rankings in subsequent group discussion. Participants said they ranked the “negative results” section low because they felt the material was confusing or unclear. One parent participated explained, “I got lost in the negative part and exactly what I was supposed to take away from that.” While some indicated the topic might be important, a few individuals in one focus group compared discussions of negative results to the list of side-effects provided at the end of pharmaceutical commercials. One parent said, “It kind of felt like it was just the hospital covering their bases.” Another parent said, “Like on a consent form, it’s like the legal part... that you have to put that in there as like a legal statement.”

Participant discussion highlighted a split in opinions regarding to the “Reactions to Genomic Testing” section that described some of the emotional responses individuals might have to the return of results. Some participants liked the section, with one adolescent saying, “I thought it was the best part.” One parent thought it helped “if you’re thinking in the mindset of a 13- to 17-year-old that is an individual reacting to it. How am I going to feel and what’s this going to be like?” Yet, many adolescent participants had a strong negative reaction to it. These adolescents offered
three reasons for their negative reaction. Some felt the section was too long, especially the segment describing anxiety about test results. Some thought the section was too limited and did not describe the full range of emotions they might feel. One adolescent said regarding the types of reactions, “They didn’t give us enough information.” Finally, a few adolescents felt the section was telling them how they ought to feel and resented those projections: For example, one said, “I don’t want to expect to feel a certain way.” Adolescent participants suggested they would rather see actual examples of what adolescents who agreed to testing and receiving results did or said during the decision making and return of results processes. As one participant said, “Just show us a video of what people’s reactions are when they tell you something like a reality show.”

All focus groups participants indicated that the video was too long. Parent participants in one focus group session thought the video was too long, but they still wanted video content on all the topics presented and suggested multiple, shorter videos.

### 3.4.2. Revised video assessment groups

In 2020, participants in focus group 6 watched narrated PowerPoints presenting a storyboard of the revised videos to assess the content of the video and whether the videos helped with deciding whether one would want to learn genomic test results. Participants were shown content for one required, and four optional, videos (Table 3). After watching the required video, participants were asked if they had enough information to make decisions or if they would want to watch any of the optional videos that had been prepared before making a decision. After watching the optional videos, they were asked if they would alter the choices they made about learning genomic test results.

Most participants felt all the narrated PowerPoints were clear. Most participants emphasized the importance of the information in certain narrated PowerPoints, including a proposed required video, a proposed third optional video featuring impacts of results on family, and a proposed fourth required video on the genomic test results impact on healthcare, insurance, etc. One adult participant noted of the required video, “I think it’s self-explanatory.” A young adult participant said the required video “was pretty straightforward and simple to understand. I didn’t have to be – like, have a background in it to understand what it was talking about.” Adolescent focus group participants were the least likely to find the videos clear, interesting, or informative. Several adolescents said they needed to see video examples of how teens would make decisions in order to feel more informed. One participant said, “I don’t want to be rude, but I kind of got lost in it. I kind of zoned out a little bit. So, I feel like if they have like a story that I could follow or something. Like if someone found out they had a disease.”

When considering decisions about which, if any, genomic test results to receive, adult participants indicated that they received enough information from the required video to make decisions about which information to learn concerning their adolescent, and adolescent participants indicated they received enough information from the required video to make decisions about what to learn about themselves from genomic testing. Young adult participants were split on whether the required video was sufficient to make these decisions. Some participants felt that the required video “was definitely enough” and provided “a nice foundation” for making decisions, but several participants indicated that the required video did not provide enough information to make decisions about genomic testing and which genomic test results they would want to receive. One young adult said that after watching the optional videos, “I can make a lot better decision—you know, an educated decision on what I would want to do.” When asked, six participants thought the third optional video should be required, and six other participants thought the fourth optional video should be required. Yet, young adult participants indicated that watching the existing optional videos would not change their decisions or preferences about the types of genomic test results they would want to receive. One participant said, “I don’t think it would change my mind.” Another said that the optional videos “reinforced my [initial] decision.”

### 4. Discussion and conclusion

#### 4.1. Discussion

The return of individual genomic test results to adolescent research participants and their parents or guardians is a process complicated by the variety and complexity of genomic concepts and the need to make sure materials are comprehensible for adolescents and their parents [35]. Research groups have developed decision aids, educational videos, improved genomic test reports, interactive online tools, and summary letters to facilitate the return of individual genomic test results [27,28,31-33]. In this study, we describe the development, implementation, and revision of educational videos for parents and adolescents, employing best practices in formative research [38]. Development focus groups affirmed that using a video to provide information to adolescents and their parents helped minimize concerns about receiving genomic test results, which was in line with findings of other projects using video [32]. Group discussions also supported extant findings that the concept of negative test results was a source of confusion [19]. As a result, the original video prioritized explaining negative test results before positive test results in the video. Parents in the development focus groups were concerned about the length of the video but stated that a long video with bookmarked sections allowing viewers to select topics would be sufficient. Based on demographics of the hospital patient population and the region, the research team surmised that the racial and gender demographics of the development focus groups was sufficient for producing culturally and socially appropriate material. This led to the creation of the original seventeen-minute video, with a list of bookmarks of key topics viewers could select at their discretion.

After the initial deployment of the video as part of the return of results in a larger research study, the research team found that while parents understood the video content, adolescents were less confident in their understanding and comprehension. Adolescents identified the video’s length as an impediment to learning and recall. These results indicate the need to continue developing specific video material for adolescents, while ensuring the educational needs of parents are met, as they can, in turn, communicate information directly to adolescents.
Table 3
Revised video content for March 2020 focus groups (FG6) and proposed new video.

| Required Video: "Genome Testing: Expectations and Results" (3:45 min) |
| --- |
| • Basics of genetics |
| • Questions to consider before testing |
| • Preview of remaining videos in series |

Optional Video 1: “Types of Results” (3:44 min)
- Positive test results
- Negative test results
- Carrier status results

Optional Video 2: “Options for Learning Results” (2:08 min)
- Preventable Diseases
- Non-preventable diseases
  - Treatments
  - Delay Symptoms
- Adult-onset diseases

Optional Video 3: “Possible Family Impacts” (1:08 min)
- Disease heritability
- Unexpected information about family (e.g., nonpaternity)

Optional Video 4: “Genetic Impacts on Healthcare” (1:51 min)
- Placement of results in medical record
- Insurance coverage of new treatments/tests
- Genetic Information Nondiscrimination Act (GINA)
- Impact on life, disability, and long-term care insurance.

New Video: “Teens Considering Genomic Test Results” (3:44 min)
- Not presented to focus groups
- Vignettes from adolescents who made decisions about genomic testing
- Waxed a required video for the ongoing Engaging Adolescents clinical trial (ClinicalTrials.gov number: 04481061)

Because the majority of interview participants identified as white, as were most participants in the genomic research where the video was used [42], the research team felt it necessary to have greater racial diversity in the revision stage to make sure that observations from the interviews as well as changes to the videos were socially and culturally appropriate. The revision focus groups confirmed reports from the interviews and the implementation stage about video length. Topic ranking sheets and subsequent discussion in focus group 5 allowed us to identify topics participants felt most and least helpful. As a result, overview and introductory material was substantially reduced, and an extended example about high cholesterol was eliminated based on participant rankings. Discussion of rankings helped the research team identify problems with important discussions, like the description of negative results and the description of reactions one might have to test results. These issues were addressed in the revision.

As a result of discussion in focus group 5, the research team made four major changes. First, we split the original 17-minute video into five videos which were each less than four minutes long. Second, we reorganized content to reflect focus group participants’ information preferences as reported in the topic ranking sheets and subsequent discussion. For example, the required video provided a primer on basic genetic information and then provided a list of questions and issues for participants to consider before undergoing research genomics testing. Third, much of the content was made “optional” so participants could review it at their leisure. Fourth, adolescents requested, and we added, a video that presents the range of reactions adolescents might have with regards to choosing which genomic results to receive and actually receiving them. These requests reflect adolescents’ need for narrative identification, allowing them to identify with someone to improve knowledge about genomics and attitudes toward making decisions about test results [43,44]. The final set of revision focus groups confirmed that parents, young adult, and adolescent participants found the re-organization of video material into five shorter videos satisfactory. The final video requested by adolescents was not presented to the focus groups, as it was still being produced as those groups were held.

Working closely with focus groups allowed the development of materials that reflect participants’ preferences which in turn should improve comprehension and their ability to make decisions about genomic test results. One key finding in this research is the importance of time. Participants want the amount of time spent on any one educational video kept as short as possible. Longer, easily divided videos were acceptable to some parents, but were unacceptable to adolescents, young adults, and other parents. Future research will need to assess the ideal length for educational materials in genomic research studies.

A second key finding involves conflicting feelings about revised video content and the amount of information needed to make decisions. Parents and adolescents generally felt that the required video in this project provided enough information to make decisions about which kinds of genomic test results they would want to learn for an adolescent research participant. Parents would identify material in the videos they thought might be valuable to know. Young adults felt the required video did not provide enough information and identified other videos they thought should be required. Yet, all three groups—parents, young adults, and adolescents—indicated before and after watching the optional videos that they would not have changed their decisions about the kinds of test results they wanted to receive. The optional videos appear to have provided more information that confirmed participants’ choices, but adolescents continued to feel some uncertainty and anxiety [45–47]. It is possible the uncertainty about what type of result one might receive led to the continued call for more information.

This study also has several limitations. First, participants were drawn from research advisory groups, so they might trust the information they receive more than people naïve to genomic research. Second, there were very few Hispanic and no Asian-American participants in the interviews or focus groups. The demographics of this study as well as the nature of qualitative research may generally limit the generalizability of our findings. Future research could increase the demographic diversity of participants. Future studies should further assess relationships between tolerance of uncertainty, comprehension of information provided, trust in research information, and comfort with decisions made.

4.2. Innovation

To the best of our knowledge, this is one of the first studies to report both the development and revision of participant-facing audio-visual materials for genomic research involving adolescents and their parents. Incorporating plans for revising and updating materials is necessary to address changes in research participants’ attitudes and concerns in general and over the life of specific studies. Research teams producing educational materials for participants may benefit from developing relationships with community groups and research advisory boards to allow for continual engagement with relevant research populations as study materials are produced.

4.3. Conclusion

We have implemented a process of formative focus group research that allowed for the development and revision of video materials to explain the return of genomic research test results to adolescents and parents. Future research will need to explore the tension between wanting more information while wanting shorter videos and how satisfaction with decisions is impacted by this tension.

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Declaration of Competing Interest

The authors declare that they have no competing interest that could undermine the objectivity, integrity, or perceived conflict of interest of this publication.
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