

TRANSCRIPT

ELSI Friday Forum

Widening the Lens: Using Arts in ELSI Research

Friday April 9, 2021

TotalCaption:Captioned stenographically by Joshua Edwards, RDR, CRR

>> DR. SABATELLO: Just going to take one more minute for folks to Zoom in and we will start. All right. So hi, everyone. I'm Maya Sabatello, associate professor of medical sciences at Columbia University, and I'm delighted to welcome you to the ELSI Friday Forum, which is held on the second Friday of every month for one hour starting 12:00 noon Eastern time.

We also have a Zoom room reserved for more informal discussion immediately after the panel for 30 minutes. So please stay tuned for the link that will be posted in the chat box at the end of this session.

As a reminder for those of you who are joining us for the first time, ELSI Friday Forum is a monthly series of the Center for ELSI Resources and Analysis, or CERA, for short. For those of you who might be new to CERA, CERA is a multidisciplinary, multi-institutional center that provides resources to support research on the ethical, legal, and social implications of genetics and genomics, otherwise known as ELSI, and serves to connect a community for scientists,

Scholars, policymakers, journalists, members of the public, and others to engage in ELSI issues.

CERA is funded by the national human genome institute at NIH and managed by teams at Stanford and Columbia University in partnership with the Hastings Center and Harvard University. CERA's online platform ELSIHub.org was launched in

November and we invite you to access resources there including the recording and transcript of this forum, associated reference material as well as an ELSI literature database research instrument repository, scholar directory, news, events and much more.

Please also go to the website to sign up for newsletter and other events like this one at ELSIhub.org. And get daily updates and news on Twitter [@ELSIHub](https://twitter.com/ELSIHub). We are pleased to announce also the publication of a new addition to our concept series, ELSIHub Collections. And you can see, you can use the link in the chat to access empirical evaluation of arts-based informational aids for ELSI issues in the clinic and beyond, a collection of empirical works curated by Gretchen Case and Darren Hackney that's that explores the utility of several art-based communication tools for communicating ELSI issues to healthcare professionals and the public.

Just some housekeeping tips before we move to the substantive discussion for today. If you wish to use closed captioning, please turn the CC button at the bottom of your screen. We encourage an active exchange of ideas between our panelists and all of you. So the panelists' presentations will be very brief, so we hope to use a significant portion of our time in discussion.

Please use your Q&A button which you will find at the bottom of your screen to ask panelists questions that you have. You can also register your enthusiasm for a question and elevate it up the list by using the upvote button in the Q&A box. The chat box is available for further engagement where you can find the links to resources referenced in today's discussion.

And if you have questions, please e-mail info@ELSIHub.org at any time. So with that sort of introduction of the housekeeping issues and CERA, I want us to move to discuss the topic for today. And today our topic engages in conversation about the use of arts in genomic research.

(Background noise)

>> DR. SABATELLO: This is a growing field in ELSI research, one that shifts from a conversation that has historically focused almost entirely on the state of the art of genomic technologies and into a landscape that explores how artistic expression can express, inform and improve genomic research as well as translational efforts; that is, the efforts to apply lab-based discoveries in clinical settings.

Now, from a first glance, these two fields of art and genomic research seem to be unconnected and even opposite. Art represents a more subjective understanding of our lives and has a strong emotional and sociocultural communicative nature to it. While genomic researches is a more objective and empirical-based process of discovery of what exists.

But these two fields may have more in common than we might think. They both involve use of cognitive skills, conceptual tools and knowledge of processes in plural. They both reflect social practices and they are both grounded in creativity. As we will also hear today, rather than reflecting on one another from the outside, these two fields of art and genomics can also inform one another in unique ways.

Now, since the completion of the Human Genomic Project almost two decades ago, we have seen a great number of art exhibitions featuring contemporary and future views on human genomics, as well as films that mimic existing ELSI conversations or highlight prospects of an ELSI related to genomics and genomic research.

What is unique in the work of our presenters today, however, is that they incorporate art in ELSI-related genomic research projects as a way to increase enrollment of diverse populations in genomic research and to connect with potential participants via platforms that are perhaps better-tuned and representative of their experiences.

That is, instead of using art to critique or reflect on genomic research per se, they use art and artistic imagination as a way to solve some of the key challenges in ELSI research. This type of work calls for new collaborations, enhanced interactions across disciplines, and processes that are geared toward creating a shared language, all in order to develop more informed efforts in translational genomics.

Today we are honored to have with us three scholars who are leading this field and who will share with us the philosophical and practical grounding for their work. And so I will move to introduce our speakers by the order in which they will present.

First, Dr. Sydney Cheek-O'Donnell is an associate professor in the department of theater and associate dean for research in the college of fine arts at the University of Utah. Her research focuses on how theater can support the health and well-being of individuals and communities, and she's a faculty collaborator with the University of Utah's Center for Excellence in ELSI Research.

Dr. Erin Rothwell is the associate vice president of research in the Office of Research Integrity and Compliance, also at the University of Utah. She is a professor also in the department of the OB/GYN in the School of Medicine. Dr. Rothwell has extensive experience in bioethics and human subject protections, having served on the IRB and hospital ethics committees, as well as completing a competitive bioethics fellowship from the Medical College of Wisconsin.

She also brings a wealth of experience from her successful program of research on informed patient decision-making and the ethical implications of emerging technologies within the context of genomics, population screening and public health across the reproductive continuum of care.

And then finally we will have Dr. Erin Talati Paquette who will be joining us shortly and who is an assistant professor in the Northwestern University Feinberg School of

Medicine, Department of Pediatrics and the Northwestern University Pritzker School of Law by courtesy. She's also an attending physician in pediatric critical care medicine, Chair of the Ethics Advisory Board, associate director of clinical and organizational ethics at the Ann and Robert Lurie Children's Hospital of Chicago, a member of the steering committee for the Northwestern University Institute for Public Health and Medicine Center for Bioethics and Humanities, and a founding member of the President's Council for Equity, Diversity, and Inclusion at Lurie Children's where she co-chairs health equity activities for the hospital.

Our speakers' brief presentations will be followed by moderated discussion as I post some follow-up questions to them. And then audience discussion. I encourage you to write your question in the Q&A box and I promise to get to as many of those as we can for our discussion.

So with no further ado, I will give the stage to Sydney to Dr. Cheek-O'Donnell to give her presentation.

>> DR. CHEEK-O'DONNELL: Thanks so much for inviting me. It's a pleasure to be here. I am coming to you from the traditional and ancestral homeland of the Shoshone, Paiute, Goshute and Ute tribes. And I'm European-American cisgender white woman with long brown hair pulled into a ponytail. I'm wearing green cat eyeglasses and a green tunic with a pattern of blackbirds sitting on white trees. And I'm in front of a wall covered in gray concrete tiles with an abstract pattern on them, just for anyone who may be visually impaired.

So I have been asked to kick off the session with a brief overview of how the arts can be employed to bolster public access and understanding of ELSI research. And before I go further, I just want to acknowledge that I'm using the term "art" broadly to encompass all forms of art. Next, please.

So why might we want to use art to help communicate ELSI research to the general public? Cognitive scientists Donald describes the function of art as a means to engineer attention and to influence the minds of an audience. He further argues that works of art elaborate and refine mental models and world views and that art is self-reflective.

And it's all of these properties, I would argue, that make the arts extremely useful when we're trying to communicate new or important information to the public. The artist functions as an engineer of attention in order to teach their audience about something in relation to their own lived experience and imagination.

And in order to effectively engineer attention, the artist must be able to anticipate audience reaction to the work of art. I am going to focus my attention on artistic forms that employ story or narrative because that's my area of expertise. Next, please.

The foundation of most dramatic story telling is the agon, which means conflict, struggle, or contest in ancient Greek. And the agon is fundamentally a debate in which ideas are tested against one another and refined until one character achieves their goals. And the central characters in the dramatic story are of course the protagonist and the antagonist. And they enact the central conflict of the story which is what makes dramatic storytelling an excellent vehicle

To explore ethical problems in particular. Each character presents a point of view in a debate, and the audience members are then given the opportunity to understand and empathize with that point of view within the context of the characters' given circumstances. Next, please.

Another reason that story-based art forms may be particularly useful in this context is that stories are information chunking machines. When you think about a film or a play or a novel that you've read, you can remember a remarkable amount of information when it's organized through story rather than presented in a list or even like this.

I've provided a little kind of graph of typical sort of Western dramatic story structure, particularly in film, television, plays, et cetera. And that structure is very familiar to us and it helps us to map information and recall it.

So story is really useful in the context of teaching and learning. So let's talk about that for a moment. Next, please. When we produce a show, theater artists engage in dramaturgy. And that's really a process through which the team figures out the story that it wants to tell, and then determines how to tell that story effectively in a given context.

And as we do this, we try to anticipate how our audience will understand and respond to the piece we are going to present and engineer the experience to get them where we want them to go emotionally or cognitively, et cetera. So if you are interested in trying to use art to communicate something about ELSI research to the public, I would propose you begin with this dramaturgical process and ask yourself or your team

What's the story we are trying to tell? Which is really similar to the backward design process that we use in teaching when we ask what do we want our students to be able to do or to understand or value as a result of engaging with this lesson or this course?

So really before anything else, one needs to define the goals of the communication or your intended outcomes. What is your audience? What do you want them to know as a result of encountering this thing that you are making, that you would like to make?

And then ultimately that story becomes the North Star of any collaboration. It's the thing that really guides all decision-making. Next, please. So last thing I wanted to just touch on briefly is offering a few thoughts about building successful collaborations for arts and ELSI work.

The first thing that I would strongly encourage is including an expert in the arts on the research team, and they should be involved from the very beginning of the

process if at all possible, and they should be included in all of the process, including things like study design. And then gathering feedback from an audience.

I would also highly recommend and this may seem obvious, but sometimes it gets forgotten, that one needs to budget to engage a professional artist to create the thing that you want to make. And I would urge folks to engage professional artists for this rather than, you know, a friend or a volunteer.

The other thing to remember in all of these types of collaborations is this really is interdisciplinary as Maya indicated earlier, we are working across pretty vast vocabulary differences. And so you will expect that there's going to be some challenging communication on a team. But one of the ways that I find is really useful to address those is by being willing to ask what are basically maybe seen as silly questions?

Use your ignorance as a resource in a sense, and your curiosity. And those can really help with making sure everyone is on the same page and is in agreement about what the objectives of the project might be. So thank you very much. I want to, I have one more slide. I think that's my, yeah, my works cited. And I am going to pass it over to Erin Rothwell now, thank you.

>> DR. ROTHWELL: Thank you, Sydney. First of all it's a pleasure to come and talk to everyone today. So I think Sydney really laid the groundwork of this, an overview of this process. And now I am going to transition and talk about a project that we specifically reached out to Sydney and asked her to help us with. And we developed a comic using, of course, the story line that she mentioned about expanding carrier screening.

Next slide. The reason first of all that we wanted to create an intervention to better educate pregnant couples about expanded carrier screening is because of the, I would say, lack of informed decision-making about really what is expanded carrier

screening, the purpose? We conducted some research, some interviews with women that received positive results.

And a number of them mistakened the expanded carrier screening positive results for prenatal screening which has a much different set of procedures and outcomes during your pregnancy. The other reason is that, you know, the chances of testing positive for expanding carrier screening is because you can get up to 75 percent depending on the type of panel you are using.

But the chances of your partner, the father of the baby testing positive for the same condition is quite low. So there's a number of reasons to try to improve the education materials around expanded carrier screening. So what we did is with these interviews we did was 17 or 18 women and we tried to capture their lived experiences of what it was like to be offered expanded carrier screening, what it was like to receive a positive result.

How did that play out with their partner or the father of the baby if they were willing to get tested, if they tested positive? So we did a number of interviews and really captured that. And I think you will see that one of the manuscripts is up in the chat box.

And then we just followed Sydney's guidance. We worked with her directly to help develop a story. And I will have to admit that it was a lot harder than I thought. And thank goodness Sydney was there to help draft the script. But we also reached out to a professional comic who has an expertise in drawing this type of, I would say, materials.

And so between the two of them and the research team which included me, Jeff Botkin, Rebecca Anderson, we were able to come up with a product. And what that ended up looking like, you can see on the next screen basically was a story. And if you go to any of the publications that are in the chat box, you can see the full link. We made it publicly available on the CERA website.

But it tells a story about what it's like first to have this joy of getting a positive -- I mean, finding out you are pregnant and then to go through that process of getting a positive carrier screening result, having two scenarios where the father of the baby does or does not get tested. What happens if, you know, having a positive result for a baby with cystic fibrosis? And then we kind of, we really let the comic drive the, I would say what the picture should look like.

Right. I'm used to very avatar, very specific pictures. But she really wanted to keep them more vague so that people could think maybe that kind of looks like me or maybe that kind of looks like my partner, right. So we really liked the way that this came out. And so you can see that this is, like, 12 pages. The thing that I want to point out here is the reason that we -- if we go to the next slide, please.

The reason we also liked the use of a graphic novel -- I can't use graphic novel. Sydney has corrected me on this. It is a comic. We need to embrace the word comic which is something that she also educated me about. And that's the use of these two theories. The first theory is the extended elaboration likelihood model. And I won't go in depth in it. But if you look at our two manuscripts that will be I think in the chat box,

The first one really looks at how do people process information in order to make a decision? It's like this dual processing theory. And you can either go through your central processing or your peripheral. And if you can force information to go through the central processing, people pay more attention to it. They put more thought into it and the decision is likely to be more lasting, versus peripheral like if you are buying a car.

You just look at the stimulus. Oh, look at the color, look at the tires, right. And so you are trying to really force people to engage in a more in-depth thought process. And then this theory combines entertainment overcoming resistance model. So by putting

things into a story, people are more readily to believe the information because, one, they are transported into the story. So you are no longer in a doctor's office reading a brochure.

You are transported into the story about this woman who finds out they are pregnant in a positive result. You are also able to identify with the characters. And in our focus group publication, you know, that was one of the most positive aspects that we heard from the participants that participated in the groups is that oh, I can totally see myself doing that. I get a positive expanded carrier screening. I am going to Google it immediately, you are right.

And so that identification with the characters is part of this entertainment education model. And also similarities, like, I know what it's like to go to the doctor. I know what it's like to test positive, I mean, you know, be excited that you are pregnant. I know what it's like to try to convince my partner to go do the expanded carrier screening testing.

And then there's a bond with the character because you can empathize with that. And all of that helps to retain the information. Next slide. And we did two studies to test the comic in comparison to other ones. And again, I'm just keeping this very high-level. The first one was an online survey with a convenience sample of pregnant women.

And they were randomized to three groups, the video which was a decision aid support tool for should you do expanded carrier screening, the comic, or the traditional brochure that's offered for them through ACOG. And what we just found was knowledge was significantly higher for those that were in the comic group.

And I was a little shocked how high it was because, you know, in our RO1 when we looked at differences for consent with newborn screening we saw significant increases in knowledge. But this was, like, eight more questions correct. Like, it was a big difference! We didn't really see a big difference in preparation for decision-making or conflict or shared decision-making.

But this course was a hypothetical test of if you were to -- you are pregnant, if you were to be offered, you get your materials. So that was enlightening for me. Sydney probably was not as shocked as I was. And then we also did focus groups like what do you like? What do you not like about the use of a comic?

And I also wanted to just disclose that in every focus group out of the six focus groups, there was at least one or two people who said you know what? This could be a great source of material, but I don't read comics, right. So I want to make sure that I'm not just presenting this one-sided view, that a comic sometimes is not acceptable material to some people.

But I would say 80 percent of the people in every group or almost 90, they really were surprised how they liked this information being delivered. And the specific reasons for why is they related to the story. They are, like, oh, this is totally, I have done some of these behaviors.

The simplicity of the story talking about what is expanded carrier screening in laymen's terms, and just being able to understand what's going on in everyday language, they really liked that the comic included multiple outcomes. Because one outcome, you know, when you are pregnant one of the things we found out is they don't want to read materials that are upsetting, right.

And so to have multiple outcomes where one, the baby does have a condition, does not have a condition, one where the father does get tested, where the father doesn't, it allows them to think through the different options in and that you don't just undergo expanded carrier screening and you test positive, right.

That there's other outcomes that could occur. And then, of course, I mentioned the barriers to comics. And then I think that is all we are going to talk about here before we turn it over to Erin. But I think as I reflect back on my work with Sydney and our

professional comic artist, we are already looking at doing another project with this because of the impact on knowledge.

That was just a very, I think, the use of arts is a journey for me. I'm still learning, but just to see that difference in knowledge, I would like to further test this collaboration in other settings. So thank you. And I think Erin, I am turning it over to you now.

>> DR. PAQUETTE: Excellent, thanks, Erin. Thanks Maya and Sydney and everybody for the opportunity to join in this conversation with you. I'm going to share, I think some similar themes that we've already heard about with a project we did looking at the use of video in a pediatric biorepository program. Next slide.

I don't have any conflicts of interest to disclose. My funding is shown here. Next slide, please.

Next slide.

So we did a pilot study in our pediatric ICU looking at people's perceptions, parents' perceptions in particular about enrollment in a biorepository, and saw that in this initial pilot that we did there were many opportunities to improve understanding of biobanking and to consider whether that would relate to participation.

So we found misperceptions among parents during an initial period of trying to enroll individuals in the biobank including parents that believed that the biobank would benefit their child, so personalizing involvement, to full lack of understanding with parents commenting on things like I don't understand anything, as long as it's for my son, again, that notion of personalizing, it's all right.

Notions that they would get results back when they were told in the process of consenting for the biobank that they wouldn't be returned and then concerns about trust and privacy and information that was obtained being linked or tied back to their child. And

so we did this pilot using a traditional consent or an opt-in version of consent that was a written consent form.

And we were moving forward from it trying to identify ways to both improve understanding as well as to diversify participation because we did find some sociodemographic differences in who was willing to enroll. And we didn't do quantitative analyses on this qualitative interview data that we had to look to see about whether the things were differentially distributed.

We had some concerns that there was differential understanding as well as misperceptions and that that might impact enrollment. So we decided to move forward with a program to develop a video about biobanking to see whether we could change some of those misperceptions. Next slide.

And we did this using a process we've heard about a couple of different sort of frameworks in which to utilize different formats of information delivery. We did use a process prior to video development of public deliberation, or some may have heard of the process of deliberative democracy. You can move forward. Next slide.

And in that process, there are two phases where you are trying to sort of elicit the understanding, perspectives of individuals on a given topic in which you want to bring everyone to a similar level of awareness of the issues that are involved in order to be able to then have a conversation about their informed perspective

So we held these public deliberation workshops. In the first part, they were day-long workshops. In the first part of the day, we asked, we asked individuals to engage with us in learning about different topics including what is a biobank where we covered genetics, the importance of learning from large groups, notion of return of results, risks and

benefits of biorepository-based research, the protections that were involved, particularly relating to privacy,

And then general concepts of consent, what broad and specific consent mean, issues of assent and re-consenting. And then we conducted focus groups with the workshop participants in order to elicit their thoughts about based on the information they had learned, what kind of content should go into a video? As was mentioned earlier, in this process we talked about the importance of individuals understanding their own stories

And how those could translate into conveying information for others. Next slide.

In the workshops we had several themes that emerged, including the idea that using a video, using a visual could enhance understanding of the written form. So I put a couple of representative comments here. One individual indicated, that's why I said it would be better if it was visualized on the screen more so than a consent form, and then you could have a consent form in the room already and just let them know the form is there.

The videotape would be great because I would actually listen to it, but and see you have a lot of parents who don't understand what they are reading. But if you are breaking it down and you are explaining it to them, it doesn't have to be a long video, just basically cut down to the point that this is what it is, this is what we are doing, this is what we are saving it for. Because of this, you might have a better turnout as far as that way.

So and these were represented in several statements that were made across focus groups. You can go to the next slide. We also heard about the importance of language. So both in the setting of being able to translate to a language that other individuals were speaking, and the importance that language was a reflection also of diversity and the importance of the video or any visual, really, being able to reflect that diversity.

Next slide. I think one of the points that, while this doesn't specifically relate to the development of the art, I think one of the things that we were very mindful of in developing the video that would come was the idea that trust and transparency were key to individuals who would then view the video.

And so making sure that there were words and images that conveyed very clearly the concepts that were confusing was really important. And in particular, there were a couple of comments related to issues of trust, broken trust in historical research violations. And I think this comment reflects that.

With African Americans, there's a bias, so researchers have to go some ways to show that it's in the best interest. It hasn't helped with the syphilis experiment and it haunts our community and we don't want to participate.

Also with Henrietta Locks, doesn't help from a genetic standpoint (reading the slide).

And I think this really highlighted the importance of stakeholder involvement in all phases of developing materials that would serve as educational adjuncts to the biorepository consent process. Next slide.

Okay. So to talk a little bit about our video development, you can move to the next slide, after we held these focus groups, we gathered an interdisciplinary team that included a group that's working on different ways in which the research process can be demystified through a video program. A group of research coordinators, IRB representatives and investigators. We took the content and specific content from the focus groups, but in addition to those general themes I shared,

The focus groups really identified what were the key areas of content to include in the video, and began developing some dialogue around what that content would

look like. We then moved that content onto this group of clinical and research team professionals that developed the story that would then be turned into a video. Next slide.

So we developed the initial script guided by this focus group data and then we partnered, we heard earlier about the importance of using a professional partner. We partnered with an organization called Boostershops Media to develop story boards for the video. Next slide.

Before we moved onto developing our final videos, however, we also engaged additional groups of parents through a parent advisory board and children through kids advisory board and local high school students where we spent a couple of periods with them where we asked them after we did a similar workshop introduction for them to draw how they would convey these concepts to others.

And many of the background parts of those drawings we shared with our Boostershops partner in order to develop the story boards that came out. Next slide.

So we had slides that started with what is a biobank? Next slide. And if we go to the next slide, sorry, yeah, okay. So we started with what's in a biobank. This image of this person came from an image that was very similar to one of the ones that the high school students drew for us. So the idea that samples could come from many places and that they would be stored. Next slide.

We spent some time thinking about why biobanks were important and how to convey that in terms of illnesses as well as treatment for illnesses and how biobank data could be used to identify those. Next slide. One of the things that was really key was conveying the idea that we needed diversity among individuals. And so we spent quite a bit of time I think Erin commented earlier on how much depth to give the images, how specific to make them,

In order to make them specific enough that people recognized them as individuals, but also reflective enough of the breadth of diversity in terms of not only racial and ethnic diversity, but gender diversity, age diversity, ability diversity. And so we spent a lot of time. These were some of the initial images that weren't filled out. But thinking about how we would convey this concept. Next slide.

We also had used some of the material that our high school students helped us develop to convey concepts related to genetics and what that meant. Next slide. We actually used an analogy that had been developed previously of a library to kind of one of the ideas that came out of our focus groups was that analogies were helpful if they were concrete and clear.

And people liked this idea of a library being very similar to a biobank. So we utilized that to convey, to help convey some of that information about taking, being able to take materials out but having still multiple people that could borrow from it and return things to it. Next slide.

And we also, one of the things that came out was that in concerns about privacy, also came out this idea of data sharing. I trust you as an institution, I will give it to you as you're a hospital. But I'm concerned about, you know, it going elsewhere. And we wanted, you know, we spent some time talking about, well, you know, there is a possibility that samples could be shared.

How do we make that clear in the video and explain, you know, how that might happen and encourage individuals to ask the study teams individual questions about how their samples might be shared? But this was one of those concepts that we talked about trust and transparency. We wanted to really make sure it came across clearly that samples could go across the country, could go to other investigators, but that people had a right to discuss this with their research teams.

Next slide. We also spent a bit of time thinking about how to convey concepts about privacy and coding, since that was an issue that came up as concerning to our initial focus groups. Next slide.

And then finally, we wanted to make sure that we had conveyed in general the idea that people would not be treated differently if they didn't enroll in the biobanks. So there were concerns about whether they would take more blood from individuals to donate to a biobank. In some circumstances discarded samples were being used, or if they wouldn't be able to continue treatment with a particular investigator who was also their doctor if they didn't participate.

So we wanted to make that a very clear concept that came out. Next slide. For children, we also wanted to convey the idea that they would need potentially to be approached again when they became an adult to give their actual consent for participation. Next slide.

And then we wanted to convey the idea that if there was value that emerged from the use of biosamples, that individuals wouldn't necessarily benefit. This was I think another area where we really wanted to make sure that people trusted the information they were receiving. Next slide.

And then as I mentioned earlier, individuals had questions about or misconceptions about return of results. So we addressed this very directly in the video as well. Next slide. After we created the video, we went back to our initial groups for additional feedback and to ensure that our visuals really did address the questions that they had.

We had eight children that were able to participate in this, and a couple of them mentioned concepts about having participated already in a biobank, but not understanding it until they saw the video and were able to kind of understand what they

actually signed up for. This gives some of the other data. We might get to any questions. I want to leave enough time for that so we can move to the next slide.

We got feedback from all of the initial groups that had contributed information to the video creation, so it was an iterative process. Next slide. And then we pilot tested it with a group of 20 individuals. We are actually in the process of testing it in a randomized study where the control is a written form. So I don't have significant statistics here because this was a pilot group. We saw similarities in presentation.

But some differences in other aspects in the video evaluation. Next slide. So if you look at these questions, you know, looking at agree and strongly agree, for the written form we saw about 75 percent where we saw over 90 percent for the video learning something new. Next slide.

Whether the video helped them understand, again, about 74 percent in the written form, and up to 100 percent in the video form. Next slide. But they are more likely to take part in a biobank after the video, here we saw about 50 percent in the written group, and we saw over 70 percent in the video group.

Next slide. That they wanted to learn more, about 40 percent, 45 percent in the -- I'm sorry, 40 percent in the written group, and we saw about 80 percent in the video group. Next slide.

So I will end there. There were a lot of people involved in this. I want to acknowledge them. And I think we are going to move onto questions next.

>> DR. SABATELLO: Thank you so much. Everyone. That was great. I wanted to start with a quick question for all of you, but then move on immediately to the Q&A. The first question is really revolving around the question of diversity in arts, and how can narratives that are not Western narratives can be portrayed in arts?

How can we use arts to address disparities? And is the storytelling different when it comes to diversity in art?

>> DR. CHEEK-O'DONNELL: I would say that, yeah, by and large, well, two things. One is that the kind of very -- that the Western agon-based story structure that I talked about has become so dominant in popular culture, in films, in particular, that it is something that a lot of folks around the world who have access to that type of narrative story would recognize.

However, I would say that one would, if you are working with a very specific population where different story structures are meaningful, that you would want to explore those and understand those before creating a story in order to communicate with that community.

I would say, and honestly, the story structure that I presented and the story structure that's quite dominant is pretty, for lack of a better word, kind of masculine or patriarchal. And a lot of stories that are driven by female identified characters even in sort of Western culture, the stories are often a little less driven through that really, I mean, there's conflict.

But it has a different tone to it which is kind of an interesting thing. And it also, the structures are often more cyclical in other types of narrative art forms rather than linear. So there are definitely considerations to be made as one thinks about the stories and the communities that you are working with.

>> DR. SABATELLO: Thank you. All right. So moving to the Q&A, I think there's a question for all the panelists. When you are providing information to help people make decisions in a narrative format, how do you work through how your product might push people in one or another direction? In other words, when you craft a story that

communicates the benefits and risk of a certain type of testing, how do you communicate without creating new fears or biases

In the audience?

>> DR. ROTHWELL: That is a great question, Diana. And I think this is something when you look at decision aid research in general, this is always a challenge in terms of balance, right. Because when you think about let's say making the decision to pursue genetic testing or not, there's somewhat clinical -- in terms of this person has the right to not do genetic testing and this person has a right to do genetic testing.

It's very similar to some other types of decision aids. So a lot of times I refer to The International Patient Standards for Decision Aids making sure that all the components could be talked about and weaved in. And so that's something that I would just present to Sydney and her team. And then they would take these key components and weave it into the story.

Like, I didn't realize that I would be this anxious after getting a positive result. Right. And the second thing that we have done is in the online survey and in the focus groups we asked, do you think this is pushing you towards genetic testing or do you think this is not pushing you towards genetic testing?

And in the focus groups, people are, like, it's kind of slanted towards testing. And so we need to address that, I think, further. But online, the participants, we didn't include it in the manuscript, they thought it was completely balanced, right. So I think it depends on the context and how you are asking it.

But Sydney or Erin might have more to add to that.

>> DR. PAQUETTE: I think I would only add to that that one of the mechanisms that we use was to ask individuals for information that might have this effect of making them either more concerned about participation or not to tell us how would they explain it to

somebody else? And really try to from a variety of people kind of get that direct perspective so that we weren't presuming that we had the right words or the right art, but really allowing them to help us

Develop that.

And then I also think the principle or the idea that we would risk to lose more if we didn't include that information in a transparent way, we would risk losing potentially trust more than if we included it even knowing that it might bring, it might dissuade some from participation, but it was critically important that we took on the difficult or the risky issues in a very honest way if we were going to have something that would be believable and would engender trust from those who saw it.

>> DR. CHEEK-O'DONNELL: I will just add quickly just from I guess maybe a nuts and bolts point of view in the comic project. We did a couple of things. One was to, we had, there was one story, there was one narrative arc. But at the end, we presented three other kind of narrative arcs very briefly so that we indicated that there were many different possible ways to engage or not with expanded carrier screening,

And ways in which to make decisions based on what you find out in expanded carrier screening. So that was one very practical approach that we took trying to help our readers or audience understand that there are various options available, and that we're not suggesting one route, necessarily, as well as outcomes possible.

And then the other thing I think that the story structure and character can do is, you're providing information that is very clearly from one person's point of view. And as Erin mentioned, you are embedding things like the research based on increased anxiety waiting for results and things like that. And so I think that when you embed it in a character,

people intuitively can understand that they may have a different experience from that particular character.

Maybe not, but that's some of my sense of the trying not to push people towards one particular solution or answer.

>> DR. SABATELLO: Thank you. Another question from Sabrina. She's curious, I think Erin Rothwell for you, how you measure changes in knowledge and if you can describe the survey measures that you used for that purpose.

>> DR. ROTHWELL: Sabrina, I'm happy to e-mail you. The survey is included in the D. article. So in our first cycle, the grant when we were exploring and tackling this expanded carrier screening, we actually couldn't find a good survey out there. So we worked with our genetic counseling program and we developed one really based off of some of the ACOG recommendations, piloted a couple of times, you know, with different format.

Like a research match and other settings with patients. But they are true/false statement, is expanded carrier screening voluntary? Is expanded carrier screening, the goal of it to look at the mom's health or the baby's health? Like, is insurance, does it -- does insurance typically pay for expanded carrier screening? So they were true/false statements and the survey was developed in a separate project a couple of years earlier.

>> DR. SABATELLO: Thank you. And then we will take one more question here from Stacy regarding comics, and she asked when you know that some people didn't like the comic so much, can you say a bit more about why that was? Did they feel it was sort of patronizing? Do you have a sense in your research about who might be more responsive to this format and who might be resistant?

>> DR. ROTHWELL: Stacy, that's a great question. And something that I am actually interested in. And Sydney can probably comment on it. While Erin was presenting, I was pulling up some of the old transcripts. And really people didn't elaborate on that. And in hindsight, I should have asked. But they just said I don't like comics, period. I don't like the pictures. I just like to read text, right.

So I think that is something that we need to look at preference for learning styles. And I think it speaks to the point that one size doesn't fit all for patient education. And if we have multiple choices, then they can choose what they prefer. But Sydney might have more on that.

>> DR. CHEEK-O'DONNELL: No, I absolutely agree. It really is about personal preference, I think, in many cases for learning style as well as just, you know, I think a lot of us have certain associations with comic books or what have you. I mean, these fall into the category of graphic medicine rather than, like, you know, Superman comics or whatever.

So they are different, but yeah, I think there's just an embedded attitude forward them that some people may have a negative association with.

>> DR. SABATELLO: Erin, do you want to say something? I just want to remind everyone that we will be joining, we have the post-forum discussion as well to continue the discussion. And so please if you can join us for that as well, I think the link was just posted in the chat box. So please do that as well.

But before we close, I wanted to say Erin, do you have any other things to add to that question of preferences of comics or the concept that might be harder to translate across cultures or at least from your study what you found particularly challenging in translate across cultures?

>> DR. PAQUETTE: I think we didn't specifically use comics, so I'm not sure I can comment on that in particular. But I think one of the things that we did find the most

challenging was how much we could communicate with the visual knowing that in a narrated video, we were likely going to be able to initially and we did initially produce in English and Spanish, which covers about 90 percent of the languages spoken in our hospital,

But recognizing that we were going to still miss a group of people and not being able to have them hear the video or read the language in their native, in their primary language. And so one of the things that we spent a lot of time on was trying to create images that could create concepts without words. And I think it was a challenging thing to do, but I think, you know, it made the ultimate product better because we had to be very, very careful about how we used and put images together.

>> DR. SABATELLO: Thank you, Erin. So thank you, everyone, for joining us today. Next week, please join us for our ELSI conversation series on challenges and opportunities of implementing precision medicine at the national scale. And that will be on April 16th from 12:00 to 1:00 Eastern Time.

We hope to see you also in the next ELSI Friday Forum which will be in May. It will be on genomics, data sovereignty, policy and deliberative approaches for engages indigenous communities. For now, I just want to take another again an opportunity to thank our panelists here for their time and presentations and remind you you are very welcome to join the post-forum discussion which you have the link in the chat box. Thank you, everyone, and I look forward to seeing you shortly.

>> DR. CHEEK-O'DONNELL: Thank you.

>> DR. SABATELLO: Bye, bye.

>> DR. CHEEK-O'DONNELL: Bye.