SHEETHAL JOSE: Okay. Good morning, afternoon, or evening, depending on which part of the world you are Zooming into today. I am Sheethal Jose, and I'm delighted to welcome you to our April ELSI Friday Forum, Visual Storytelling in ELSI Research. So the Forum is hosted by the Center for ELSI Resources and Analysis and held on the second Friday of every month for one hour, starting at 12:00 noon Eastern Time. We also have a Zoom room reserved for more informal discussion immediately after the panel for 30 minutes.

For those of you who might be new to the Center for ELSI Resources and Analysis, or CERA, we provide resources to support research on the ethical, legal, and social implications of genetics and genomics, and serves to connect scholars, scientists, policy‑makers, journalists, members of the public, and others to engage ELSI issues. It is funded by the National Human Genome Research Institute at the NIH, and is managed by teams at both Stanford and Columbia Universities in partnership with the Hastings Center and Harvard University.

I encourage you to visit CERA's online platform, ELSIhub.org, for the recording and transcript of this forum and the related references. Also, please use the link in the chat to access the new ELSIhub Collection, The Disability Rights Critique of Technologies that Eliminate Human Genetic Variation, curated by Rosemarie Garland‑Thomson. This reading list centers the lives of individuals, families, and human communities to analyze the harms of eliminating the variations we think of as disabilities. Please also go to the website to join the ELSI Scholar Directory, sign up for newsletters and other events like this one at ELSIhub.org, and get daily updates and news on LinkedIn and Twitter.

So now I just want to go over some quick housekeeping information. So if you wish to use the closed captioning, please turn on CC at the bottom of your screen. The panelists' presentations will be very brief in order to conserve 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 write in questions for the panelists at any point during the session. You can 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. We will post links to resources referenced in today's discussion there as well. A portion of today's presentations will be posted in the chat and will also be made available on ELSIhub following the Forum. And if you have any questions, please e‑mail info@ELSIhub.org at any time.

Okay. So now I'd like to introduce the moderator for today. So, Dr. Sara Ackerman is a medical anthropologist and associate Professor of Social and Behavioral Sciences at the University of California, San Francisco. Her research draws on ethnography and community engagement to understand social, ethical, and equity issues in emerging precision medicine initiatives. She is collaborating with Booster Shot Media and a subset of families participating in a multiyear genomics study on the design of a comic book conveying findings from an embedded ELSI project.

So I'd like to turn it over to Sara.

SARA ACKERMAN: Thank you, Sheethal. I'm really delighted to introduce our panel today focused on the use of visual storytelling in ELSI research. I imagine this topic is both tantalizing and mysterious to many in the audience. On the one hand, most of us understand from experience the powerful appeal of visual metaphor and the ease with which we're able to identify with characters? In comics, graphic novels, and other stories told with and through images. On the other hand, not much has been published about the use of visual storytelling in ELSI research. And many of us are wondering how we can draw on this compelling medium to improve how we engage with communities, explain genetics to research participants, and disseminate findings to diverse stakeholders.

Fortunately, there is a rich and expanding library of visual storytelling approaches to learn from, including the exciting work of our two expert panelists. In health education and science communication, for example, visual storytelling has long been used to explain complex topics. A recent example is a project called The Side Eye, which uses a combination of static images and GIF animation to create visual metaphors for explaining how the coronavirus replicates and spreads.

And we'll post a link to this project in the link.

Visual stories also portray peoples' lived experience of illness and medical care, as in The PD Movers ‑‑ We Keep Moving. This powerful book ‑‑ which I have to say was shared to us by one of our presenters today, Liz Cohn ‑‑ it presents a series of brief visual narratives developed by African‑American and Black individuals and caregivers who, in their words, are living and thriving with Parkinson's disease. So we'll also post a link to this amazing book in the chat.

So now I'd like to briefly introduce our two speakers for today. Dr. Elizabeth Gross Cohn is the Rudin Professor of Community Health at Hunter College, City University of New York. She is an Obama White House Champion of Change in Precision Medicine and Health Equity with a focus on ELSI issues in Precision Medicine. She is the current author of the seminal text produced by the CDC and the NIH, the Principles of Community Engagement, which is now in its 30th year and third edition. Her work has been featured in the New York Times, on NPR's All Things Considered, and in Men's Health.

Gary Ashwal is a health communication writer, designer, and producer. He is a cofounder, with Alex Thomas M.D., of the health‑focused creative company Booster Shot Media. Since 2008, they have used visual storytelling to help people understand complex health information and make medical decisions. Gary has a master's degree in health communication from Emerson College and Tufts University School of Medicine. And I've been fortunate enough to be able to collaborate with Gary and Alex on a project at UCSF.

So with that, I'd like to turn over the floor to our first speaker today, Liz!

ELIZABETH GROSS COHN: Thank you so much. And thank you to the committee for allowing us to share this work today. It's a great opportunity, and I'm thrilled to be here.

So I'm gonna go ahead and share my screen. Can you say this from the beginning now? Does this look right? Yeah?

SARA ACKERMAN: Yes.

ELIZABETH GROSS COHN: Great. That's great.

So I'm gonna talk a little bit about some work that we've been doing over the past couple of years with a method called Photovoice, and its intersection with ethical, legal, and social issues, and the work that I've done. And my work essentially sits in the ELSI space. My ‑‑ way back in the day, my dissertation was on better informed consent. So we've been wrestling with some issues in the ELSI space for some time, and continued that work.

A few disclosures. Much of this work has been done over the past couple of years through a number of NIH grants that we have, and the Mellon Foundation through The Trust Collaboratory at Columbia University. And then of COURSE, of course, the participants, all of whom took ‑‑ I'm sharing work that's been done by community members across New York City, in Weill‑Cornell's research academy class, in places where we've tried to use Photovoice to really elevate the voices and the vision of the communities that we work with.

So in general, I'm going to share one project that we think was very successful and one that we think was less so? And I'm hopeful that it can lead us to a discussion of where this work ‑‑ how this method can be best used.

So I think everyone on the call knows that ELSI issues are fundamentally based on trust, understanding, and communication. This is from the NHGRI website. We work in building relationships with communities through understanding, through diverse views, communal views, helping see what the ‑‑ see and set community priorities. And there's reasons why, in the... in the genetics and genomics space, this becomes really even more vital and foundational to, to the work that we're doing and advancing it equitably for everyone.

And then, Photovoice is a tool that is, ah, elevates the community voice. And essentially, at its core, it helps us see what other people see. So it captures the person's view of their environment and their experiences. And we accompany that with captions or video to really bring the lives of the people that we work with home to, ah, practitioners like ourselves, clinicians, public people, and perhaps most essentially policy‑makers. So it's a really important piece to think about politics and society and really of change.

And because so, SO much these days has been focused on how do we study trust, how do we build it, how do we maintain it, how do we repair it, we ‑‑ three years ago, we started working with community health workers, talking about and thinking about... how trust is established, maintained, and worked. And we used Photovoice after, actually, after a pretty contentious town hall. We launched a Photovoice project, a three‑round Photovoice project, to really dig into the issues around trust. And it, ah, it resulted in this very large Photovoice exhibit. This is on permanent exhibit at my, in my laboratory at my collaboratory in midtown Manhattan. But currently it's touring New York! And it's actually coming to Columbia next week! So, it opened in a gallery in Columbia, and it's actually going on tour for the nation now. Thinking about how community health workers, what ‑‑ who are they, what do they do, and how do they promote trust within communities.

So, I think most people know that, here in New York City, but in many, many places, and certainly in a multiple of cultures internationally, community health workers help connect hospitals and health providers and doctors with our, with services in the area and also with community health resources. They communicate medical knowledge in culturally, ah, resonant ways. They provide access. And they are really the bridge to the community.

So we wanted to understand what their experiences were like during COVID, and how, where, where trust was built, where it was broken, and what we could do.

And I wanna tell you that you can visit this entire exhibit online for free, in English and Spanish. The videos are absolutely beautiful. The entire exhibit can be, can be viewed ‑‑ although it's pretty magnificent when you see it in real life as well.

So I'm not gonna go over the findings, so much of this? Although they are fascinating? And again, the entire exhibit is in English and Spanish. But I know we're here to mostly talk about the method. But what happens is we ask people to take pictures and, in their own words, provide a narrative about where we are with building trust, maintaining trust, and repairing trust. And then, essentially, we draw themes from that and try to really understand better what is happening in the community. And you can see here ‑‑ and I know the, ah, because the exhibit is available and the slide presentation is also available, I won't read it to you. But, we heard and saw themes of being present in the community, understanding the community, and speaking the language. So I'm gonna do one of each.

So, this is what trust means to the community health workers. Then there was, we asked about things that promoted trust or broke trust, and how to, what it would mean to repair it ‑‑ since, during COVID, that was and remains a very important issue of the day. So, ah, people were talking about things in the community that we didn't see as suspicious, but. This is very prevalent in New York, these wireless cell phones that... that you can be given a government‑issued wireless cell phone. But a lot of people in the communities didn't trust ‑‑ to, to access medical care and help with appointments, with like video appointments. But people didn't trust them. Because they were, they felt like people would take information from the cell phone and it could be used against them, in immigration purposes and stuff like that. So, some of the things that we overlooked, they were interpreting as, you know, barriers in trust! And then, what would, what could help us, ah, what could help us build trust. And that really reduced to being present over time.

And then, how can we see what people see? How can community health workers bring the challenges that the people that they're working with, bring those to the medical team and our policy‑makers to, to enact change! So, this one on the, on my left, the picture of the stairs and the car, that ‑‑ I just bolded the part that was so impressive to us. So she wanted ‑‑ this community health worker wanted the medical team to see that every time the family left the house with somebody in a wheelchair, they had to navigate these very steep steps, with the wheelchair, no ramp, get the person into the car. And what they ‑‑ all they were really asking was for multiple doctor's appointments on the same day. So they were trying ‑‑ it was a systems change. Can we ‑‑ we're willing to do this, but can you help us by grouping our doctors appointments together? So I think this is really the point of Photovoice is to show people what there is on the other side that they're not seeing.

And then there's another example of helping people navigate a physical space during COVID, when they could not, when they were not allowed to have visitors or people to accompany them.

And then, of course, it opened in the forum in Manhattan. And we had policy‑makers present! We had the Department of Health present. We had people who fund community health workers, who needed to better understand community health workers. To see the work, to hear from the community health workers themselves. And of course, elevating their voice and experience is very empowering.

And so we, we really wanted to kind of show the whole method from, from identifying the issues that are important to them, to bringing it to policy‑makers, to showing how change can be enacted. And you can see that we're publishing some of that work under these two ‑‑ we can link you to these articles, as they ‑‑ one is out already, and the other one is coming out in just a few months.

So, that is just one example of kind of the whole process going forward. And I just inserted two very brief ones that we had done in the past. One of them was... again, just that intersection of, like, racial and ethnic oppression and, and a history of racism embedded in some of our medical work ‑‑ and genetics not excluded, genetics included, of course. Where this statue of Marion Sims stood in East Harlem, the center of a place of people of color, ah, you know, having had quite a bit of roots around a racist history of, of medicine. And so that has been since removed. And will be replaced with a tribute to the women on whom Dr. Sims did many, many of these early experiments. Done by an artist of color.

And just one more, so that we can have it for discussion, and then I'll move to the one that is, was less successful. This is one that we did around two different, ah... garage, sanitation garages. And this is after engaging the community. This is actually the current status, in 2022, just last year, of a rebuild of a sanitation garage.

So it IS trying to move people along? In seeing what the community sees and helping create some of that change.

Here's one that DIDN'T go as well? So ‑‑ and it's, it's short. But this one was a try from Dr. Paul Appelbaum's ELSI center that looks at genetic return of results for autism, and what it means, what genetics means in the autism world. And we tried to ask our advisory board and other people who had been interacting at the community level with the center if they would be interested in talking about their experience in understanding autism. And we worked with some people to provide a couple of examples. You can see one here. About autism in daily life. And another one here, about how touch is so different? Um, how somebody who is... who is autistic has this difference in touch, and. And, ah, and sensory models? But this particular one didn't actually take off. We didn't have a lot of people, ah, who wanted to participate. So we weren't able to, to complete it, to execute it all the way through. We, I would, we would love to talk about the successes but ALSO what may have happened there, if people on the call have thoughts about it.

So, to wrap up: We pose just a couple of questions, which will be answered I think after the next speaker. And that is: So, what's the best and most helpful use of visual and artistic approaches? Can it help us explore other ELSI issues, in research, in precision medicine? What are some aspects that we could have improved or done differently? And then, if this audience HAS any thoughts on the integration of science and art to improve understanding and impact, we'd LOVE to have that, ah, that discussion with you now or at the end of the call.

And with that, I will turn it over to Gary for the second part of the call!

GARY ASHWAL: Thank you, Liz. Those were, those were great projects. It's been really great to see the Photovoice work. I'm gonna, I'm gonna share my screen here. Let me know; does everyone see that slide up now? Okay.

So, my name's Gary. Thank you for having me here. I have a company called Booster Shot Media. It's a health‑focused creative company. And this is a picture of me and my partner in the company. His name's Alex Thomas. He's a physician and a cartoonist.

And, just for disclosures: We're a for‑profit company. So we work with clients. Some of our clients are researchers; some of our clients are medical companies; hospitals; all kinds of different folks.

So, we see our job as using visual storytelling to communicate complex information. And... our work is really grounded in comics. And. So, we think of applying principles of comics to ANY type of visual storytelling we're doing. You know, sometimes a comic book is not always the best tool for some communication challenge. So. But we have principles of comics that we use.

So, these are things like words and pictures together. These are things like sequential art, or, you know, how we lay out images on a page, juxtapose images. It's also things like character, visual metaphor, and story. So these are things we have in mind, even when we're not doing something that you might think of as a comic.

So I thought what would be useful today is that I could just share a few different examples of work we've done and how these support engagement and conversations. And then kinda leave it up to the discussion to see what's most useful, what you'd like to talk about. So.

One of the things we very often do is we create content that's used to prompt focus groups or survey responses. So, this is an example where ‑‑ you know. It's ‑‑ we think of it as visual storytelling? It's not necessarily a narrative. This is a video. It's not like a beginning, middle, and end story? But we're sort of trying to use a visual story to explain certain facts. So this, the visual story in this project was about how, you know, we have a brain organoid and a person's brain, and that the genetics information in both is the same. Because the cell for the brain organoid came from this person. And we depict things in a certain way here, but we might depict a brain very differently if we were trying to explain a different type of project.

We've also used projects to inform a patient before they have a conversation. So this is for a patient, a series of videos for a patient to watch before their meeting with a genetics counselor. And the visual story here is that you get half your genes from your mother and half from your father. We chose to use color and we chose to use chromosomes here, 'cause it sets up this particular conversation? But if we were setting up a different conversation, we might have a different visual story we're trying to tell.

This is a project that was used for informed consent conversation. And during the conversation and during the reading of the document, there were a few videos that highlighted different points. And we use these characters in each video to kinda have a throughline visual story that was, you know, just like these characters, you as the person receiving this information have the choice to say yes or to say no to being a participant in this research. So that's the visual story we kept reinforcing here.

This is a different kind of project. It's meant to support a conversation about a medical decision. And so... one of the comics principles we apply here is this juxtaposition ‑‑ kind of, it's two panels side by side, where there's a family who decided to say yes to chronic mechanical ventilation and a family who decided to say no. And you know, a family, a patient, can sit with a clinician and go through this, look at the visuals for the story and the characters? But actually, in this project, they can hear the character voices speak to them about their decision. And they can imagine what it might be like for their family and what they choose to decide.

So, sometimes a very serious topic needs very serious visuals. Sometimes a very serious topic needs... lighter visuals! So, this is a project for childhood immunization, and. We decided to use more kid‑friendly‑style images, even though it's for parents. There's a lot of humor in these videos; there's emotion. And it's really meant to kind of open up a conversation, kind of reframe the issue. We're still communicating scientific facts? But we kind of come at it through a different angle through the story. And that sets up a, maybe a more open conversation between physicians and their patients.

So, one of the other principles in comics that we use a lot, it's simplification. So this, actually, there's a comic book that supports this tool, but this is a pain scale. And it's a simplified pain scale, where a child can be asked either to say yes, they're in pain and they need something, or no they're fine, or just come back and ask me again later. And so you can see it's a very, very simple tool ‑‑ although it was kind of a complicated process to get here and explain it.

This is a VERY different project. This is in a public space. And it is, we're telling a visual story here of the metaphor of seasons as a cycle of life. So, in this project, it started with blank canvases. And it's in a public space; people were invited to come up and write... either a memory, or an idea, or a quote, related to some season in their life. And then they were also approached by people from an organization that wanted to talk to them about advanced care planning. So it's part of national health care decisions day. And throughout the day, people in the public wrote things; the artists illustrated those things; and in the end, there's this big mural where, depending on the angle you look at it, it says a different season of the year. So it could sustain conversations throughout the day with the public.

And I just wanna end on a few more traditional visual storytelling narratives. So, this is a storybook for children. It supports home visitation curriculum. And so a lot of the curriculum is really where the home visitation program talks to the parents and the family. But this was a tool that the parent could use to talk to their child. And it's just a simple story that reinforces some of these health behaviors that are taught in the curriculum.

And then, this ‑‑ back to end where I started, this is a comic. This is the project we're working on with Sara. This is a more traditional comic that tells a story of a family going through a diagnosis. And it's meant to kind of reflect back to the research participants an experience that would resonate with them. And then also, it communicates some of the medical information, as well as some of the findings of the research study. So... this is, ah, kind of a more traditional comic. And, it's... the thing we like doing the most, but we really feel that sometimes, you know... it's good to start a project not knowing, you know, what format you might use! So, that's why we kind of think very expansively and just kind of think of the principles of comics communication and how those can set up different conversations.

So that's, that's the end there. I'll turn it back over to Sara for our discussion.

SARA ACKERMAN: Great. Thanks so much, Gary and Liz. These were really fascinating presentations, with a lot of great visuals as well. Thank you.

So this next section of our session, I'll be asking Gary and Liz a few questions, and then we'll really turn it over to the audience. I hope you're all thinking about questions you might have about Liz and Gary's work, and their use of visual storytelling. And feel free to post those in the Q&A.

So, let me start with a question for Liz about Photovoice. And that is: You know, there may be some folks watching this presentation right now who are interested in using Photovoice but don't have any experience with it. And do you have any advice for them, or alerts about pitfalls that novice Photovoice practitioners might fall into?

ELIZABETH GROSS COHN: Yeah! So I ‑‑ thank you for that question. So it's a method! Right? So we definitely would refer you to the literature ‑‑ of which there is, ah, enough now? Just in, like, peer reviewed publications. And it's outlined in the reference that's provided in the slide. So it actually has a method behind it. On the plus side! Back in the day, when we first started doing this, people didn't ‑‑ we needed to issue people like little disposable cameras and get the films developed. It was really complicated? But now since everyone has cell phones, it's definitely a more accessible method than it's ever been! And I think people really WANNA take pictures now! And it helps people describe what they're seeing. So, like that step picture. Even though somebody could describe that, seeing it from the patient's perspective gives such an immediate understanding of what the barriers are!

So I think it IS a method, so like any new method, you know, it would be great to have somebody who's used it before advising you. Most of us would never just jump into a method that we've never used and be like, okay, I'm good with that. So it's great if you can get somebody on your team who's published in the area, who knows Photovoice. It has discrete steps.

And then, not unfamiliar to the people on this call, there's a level of conceptualization that's required. And that, too, is a process of reflection and real consideration of what, what you're being told and how it all fits together in, in BIG ways, in higher‑level ways. So THAT requires some additional thought. And it's always helpful to have smart people who have done that kind of reflective work before ‑‑ some of whom are on this call and on this panel right now. But people who can do part of that conceptualization, especially if you're new. It's, you know, it's drawing themes from qualitative work, and that can be trickier than it sounds.

SARA ACKERMAN: Thanks, Liz. And if you or anyone else on the call is aware of any training? In Photovoice? That would be great, that we could put in the chat. I've definitely been asked about that for, but I didn't know where to refer people. So, yeah. Any resources you can share would be fantastic.

Yeah, so, question for Gary! Gary, it was so interesting how you said that you don't always start off a project knowing exactly what format or what approach you're gonna use. It sometimes, it can evolve. Can you tell us a little bit about your design process and how you work with your clients to develop a story?

GARY ASHWAL: Yeah! I would say it's very different for each project. You know, as we've evolved in this work over the past 15 years, we've tried to be more open to kind of... say someone says "I want a video." You know. And we say, okay! Well, let's... (chuckles) Let's see. What are you trying to achieve? And then say, well, maybe a video's not the best thing! Maybe you need just a set of images, or maybe you need an interactive website, or maybe you, you know, need a comic! You know, we try to figure out what is the right tool for the job.

Sometimes, though, we DO ‑‑ someone has a really strong vision. They say we really need a video for this reason, really need a comic for this reason, it makes sense, and we just get going.

We try to structure our process so that there's feedback at many stages. And, it really depends on the length of the project and the type of project. But we kind of had ‑‑ you know. We sort of always start with some concept phase, a writing phase, and then a production phase, very broadly.

And more and more, we spend more time in the concept phase. And that's a kind of, a time where... it's very important, for maybe the subject matter experts or the team that's involved, to really make sure that we're approaching something in a way that is accurately conveying information. But then as we move through the process, maybe towards writing or towards the steps in production, it's really wise to involve more people ‑‑ say, members of the target audience, or community advisory board at that point. Because as the project starts to take shape, there's something very tangible that those people can respond to. So that's the best moment in the process for that type of work. And it allows you to gut‑check things, and then try to leave things open still at that point to change course as needed.

So we try to build in those multiple points as much possible. Ideally there's time and, you know, budget, to have multiple rounds? Sometimes there's only, say, two rounds, you know? But anything you can do is important, and. The other ‑‑ my rule of thumb, also, is like even if there's not an advisory board, or if there's no budget to have lots of focus groups? Just showing something to a couple people that are members of the target audience will, you know...! Solve a lot of your main problems, and answer ‑‑ you know, find a lot of errors, very quickly. So there's kind of a quick‑and‑dirty way to do it? And then there's the more, you know, official, health communication, pink book kind of, you know, formal way to do things.

SARA ACKERMAN: Thanks, Gary. Yeah. And for the project that we worked on with you, I think we did something maybe in the middle. We actually did share the draft and storyboard with about 15 of our families, asked them what they thought. And like Gary said, we got a lot of REALLY helpful feedback. Wasn't like a, an overhaul of the story ‑‑ which is great. They loved the story. They just gave us some ideas of adjustment! Which really was a wonderful thing to be able to... to make those changes in response to the people who are actually going to be receiving the story in the long run.

So, I DO have some more questions for both of you, but I ALSO see that we have some really interesting questions coming in from the audience. So I think I'm gonna shift to those questions, and we can always come back to some of my questions if we have time. But I'm going to just kind of go through these questions here.

We have one from someone asking, to both of you: Are there features of social and ethical issues that particularly lend themselves to visual storytelling?

ELIZABETH GROSS COHN: You know, that's a, that's a really good question. And I'll kind of start, maybe, and think about them. I mean, again, I think some of the, some of the ELSI issues, like... like trust! Which is certainly the big one on everyone's mind right now. But, but other things I think really DO ‑‑ and historical injustices, and equity. You know, some of these I think really ARE ones that we have ‑‑ I guess I'll say it in reverse! We haven't had a lot of success in, in just addressing them in peer‑reviewed publications. We NEED some other type of approach to, I think, involve more people to better understand. ELSI has often ‑‑ you know, it's a high‑level thought process. And it hasn't been altogether accessible. I think more broadly, we've been talking for years for how to get more people interested in ELSI research! So I think as we think about some of the ethical, legal, and social implications of things, this pathway in can help us with our accessibility and bringing more people into the field and more thoughts around it. So, I think that's a great, that's a great question. We would actually ask THIS audience the same. And ‑‑ (mutes self)

GARY ASHWAL: Yeah. I would say, you know, thinking of our own style, one thing that is... useful ‑‑ one thing it's very useful for is being able to kind of reflect a certain type of experience. And because, you know, as a contrast to photography, right. When you're doing art and drawing ‑‑ and especially a comic style, where you're really stripping things down to the most essential elements? Is you get to really, um... focus someone's attention on the issue that you want them to talk about. So whether that's the certain way you're representing a character, a certain environment you're putting that character in, certain things that you want to happen. There's a lot of control you have, when you're creating THIS type of artwork and telling a story in this way? So that you can keep very narrowly focused on an issue that you want to present, and not... get distracted with other, other things that are, you know, unimportant or confusing. And it's even useful on a couple of our projects. You know, we actually have done things where we're kind of switching out different variables? So you're saying, okay. I want to see... maybe these three different characters, but in the same situation. So we can focus on, well, what does it mean to have a different person experiencing the same thing? And different than maybe using actors or photos or film. You know, when you're doing drawn artwork, it can be extremely precise. You know, here, the person's gonna be smiling; here, the person's gonna look confused. You know, those types of elements.

So that's, that's one of the ways you can really fine‑tune visuals to highlight certain issues and kind of keep your viewer, whether it's a research participant or a different type of audience, focused on what YOU wanna keep them focused on.

SARA ACKERMAN: Thanks to you both. That's, those are really helpful insights. It's a complex question. So, appreciate your responses.

We have another question, and this one's for Gary: What is your team's process for learning about, and then simplifying, complex medical topics that are new to you?

GARY ASHWAL: That's, that's a good question. I feel like we're very... omnivorous, when we're at the beginning of a project. So we first, if we're working with a client who's really the expert, you know, we take in as much as we can from them? But then we have a wide range of other sources. So maybe we're looking at other, you know, videos or other communication that's been done by other organizations on a topic. You know, generally not the same angle that we're taking, but a way for us to learn? Even ‑‑ we try to always learn MORE than what we're gonna communicate. So even if we're communicating to a patient, we're sort of reading about, you know, information that's targeting towards a medical professional. And what's great about ‑‑ I mean, with us, you know... my partner Alex is a physician, so. Even if he's not, it's not in his area, he can come up to speed pretty fast on any kind of medical issue.

The other thing that we try to do a lot is... do ‑‑ we don't always have the luxury of doing, say, field work where we're, you know, convening panels of patients to learn about their experience, but. We try to read... published research on patient experience, and anything that's out there already about how people are understanding an issue? But then also, we even turn to things like social media, looking on Instagram, patient communities who are out there sharing their experience, sharing things through ‑‑ through photography, often. To kind of get a sense of, okay, what's this really, what's this experience really like?

And then we kinda put all of that together, when we try to come up with how are we gonna explain this. So that we're not just simplifying a medical issue, but we're... contextualizing it in a way that's actually gonna be meaningful to the audience and relevant to them. So, that's, that's kind of our approach. It's all over the place? But it works, it works for us!

SARA ACKERMAN: Thanks, Gary. I'm going to go to a question that's for both of you, and then I'm gonna get back to a question from Brandy for Gary. But first of all, Julia Brown is asking: What scale of financial resources is needed to facilitate these audio/visual storytelling efforts? How feasible is it for smaller teams to embrace these methods? So I think this is a question for both Liz and Gary.

...Cost. How much does it cost?

ELIZABETH GROSS COHN: You wanna go first, Gary? 'Cause I think they're probably asking about, mostly about yours.

GARY ASHWAL: Well, I'll say it's actually ‑‑ something Liz said earlier is related to my answer. Which is that the cost of technology ‑‑ you know, the fact that everyone has a camera in their pocket. Right. So one of the things I've often done is teach workshops on making whiteboard videos? Which is something we've done a lot? 'Cause everyone now has like a full, you know, film studio in their pocket. So there's a way to do this that's very simple. You know... communicating visually doesn't mean necessarily you're using the best artist you can hire, the best artwork, the best technical approach? It's really about just finding out what's gonna work for a particular audience. So, this can be very DIY? But then also, you can go full‑scale, you know, where you're spending a lot of time, a lot of effort creating something.

So... you know. I mean... like, you know. Our projects, the type of work that WE do is, you know, in the thousands, tens of thousands, and more? But that's because you're pulling in experts to do it! You know. But I always try to encourage people to just try stuff on their own with their internal team, 'cause you're closer to what needs to happen, and you can kind of also... figure out maybe what you want by trying it out, in a very low‑cost, immediate way. And THEN making a decision about, okay, maybe we really DO need someone on the outside to do something.

But I think it's really accessible to anybody who wants to begin.

ELIZABETH GROSS COHN: And I'll also say, 'cause maybe many people on the call ‑‑ I'm assuming most of the people on the call are probably researchers themselves. That you could be ‑‑ for example, your costs could be written into the grant. If you're writing a grant, you know, you could design it so that the costs for YOUR services, whatever they, you know, whatever level they would want, could be written in, and SHOULD be written in! As part of the creation of, of the materials. So I think that's ‑‑ I think I may have worked ‑‑ it's not impossible that we worked together way, way, way in the past and I'm remembering a little bit about that. So, I think that that's one thing.

For the Photovoice, I have to say that we did it, you know, mostly ourselves. Obviously the pictures are from people's phones that they just uploaded to a, like, a Dropbox, which was totally fine. We did the website and the curation was done by one of the people on staff at Columbia. But the, ah, but in order to make a really beautiful visual exhibit, we did have the pictures mounted; we hung them ourselves.

There is a little bit of a curation ‑‑ I'm not a curator? But we did get the services. We definitely, ah, had a curator as part of our team, so that the show could be curated beautifully. That's a skill in and of itself.

So I think there's some ‑‑ you know. Just like we have, there are professionals that are sort of around this space that know more about... space flow, and how things look together, and things that we don't ‑‑ I don't generally know about.

But I would say the costs, as Gary said. You know, to try it out? To, to begin? It can be just what's, what you have available and what's in your pocket.

SARA ACKERMAN: Your trust project is really beautifully laid out. That, that's very clear when you see it. And Liz, are there ‑‑ now that the, the costs of developing film and buying cameras is, is in the historical archives. (chuckles) Are there, ah, are there costs related to involving your community collaborators in a sustained way? Whether it's either... resource‑sharing, or incentives. I'm curious how you managed that.

ELIZABETH GROSS COHN: Yeah. We DID have ‑‑ there WERE some incentives available, to some of our earlier, to some of our early groups? It is the case? So thank you for, for pointing that out. When we launched it actually, I didn't know that they were giving incentives, but. Later on, we learned that a few of the groups had been, had been given some like minimal gift cards. This was still during COVID? So, the entire project was designed and run on Zoom. The opening was, as you can see, was in person. But the, most of the work was done on Zoom. And there WERE gift cards offered to the first, I think, two groups who participated. And that would be a fair thing to do.

But in the end! People felt ‑‑ I mean, people were in tears. That their voices and their experiences, during this incredibly difficult time, were being expressed and elevated, and that our local New York City health commissioner and local politicians and board members were coming to see it. So, so I think it pays ‑‑ it pays back, in a number of important ways. But, yeah, that's a great point.

SARA ACKERMAN: Thank you, Liz. That's really helpful.

So, question from Brandy Fox for Gary. And this is about how you present your visual storytelling and comics in a way that doesn't seem like you're, quote‑unquote, "dumbing things down." Some points of view see comics as only for kids, and if I'm in a scary, unknown situation and want the doctor to think I'm competent, I might reject this method of learning as being patronizing. I.e., I can't understand medical information "the regular way," so I need extra help.

GARY ASHWAL: Well, I think ‑‑ yeah, the first thing I'll say is, yeah, sometimes comics are not the right solution, but kind of THINKING like a comics creator helps us get to the end goal. But to kind of answer more specifically, I think that... there's a lot of things that an artist and a storyteller does, in terms of setting the tone and the expectation for someone that's encountering any kind of communication piece, that communicates a LOT. So, you know. If you are an adult dealing with some very adult issue that you are very ‑‑ that's very scary, you know, maybe you DON'T want cartoony animals talking to you. Right? But, you COULD have very sophisticated, you know, realistic drawings... of adults, you know, dealing with the same type of emotional situation. That can be communicative ‑‑ that can FEEL like it's a respectful and... almost, like, a lot of work went into creating something to help explain this to you. And it also ‑‑ you don't ‑‑ no one ‑‑ you don't have to ‑‑ you don't say that verbally? Right? But it can kinda be evident in the piece itself.

And so, when it's done right, we think it CAN feel like a... grown‑up piece of literature. Right? But... it is NOT always the right solution. So I think a lot of the... a lot of the success has to do with the execution, not just the idea that, oh, I'm gonna tell a visual story, or oh, I'm gonna use a comic book.

So I would say that's kind of my general answer for that concern.

ELIZABETH GROSS COHN: Actually, Sara, can I say something about that?

SARA ACKERMAN: Of course!

ELIZABETH GROSS COHN: In a random unrelated ‑‑ unrelated to this talk. Way, way back. I'm a cardiovascular nurse by training. And it was SO many years ago. Almost 30 years ago. I wrote a book, now in its third edition, called Flippancy ECG. And it was originally written for nurses and paramedics. It's based on ‑‑ in the old days, we were able to put the head of a chicken on top of a dog. We had a flipbook, and you could put parts of animals on top of other animals. It was before the internet! Way back. But I made a book. It has cartoons. It has this flip part, where you can put cardiac rhythms next to each other. 'Cause I realized that's what I was actually doing in my head! Right? I was like, I have in my head the normal one, and I'm saying how does this compare to normal? So we sort of translated that to the page. Anyway, long story short ‑‑ and the book is still selling now, even 30 years later. But most of the mail I get is actually from physicians in training, right. They're like thank you, thank you, thank you, because a simple explanation helped me build this much larger body of knowledge that I have now, but I needed the simple foundation so I could build on it! I thought it would be limited to kind of paramedics and emergency room nurses.

So, I think a respectfully done book that isn't ‑‑ it's not comics‑funny ‑‑ although this one has funny comics in it, but. It doesn't have to be like funny childish; it can just be simple, helpful, and straightforward. So, yeah. I think there's lots of good reasons why that can really help us start the right conversation.

SARA ACKERMAN: Yeah. Thanks, Liz. And to you both, that's really helpful. I mean, I think that the popularity among adults of graphic novels, manga, and comics has really gone a long way in changing this sort of assumption that comics are only for kids? When we showed the draft of the comic that Gary and Alex developed for us with some families, I remember a parent saying: Oh, when I first saw this, I thought really I should just ‑‑ this should be for our kid, not for me. But the minute I opened it I realized, oh, this is for me, too! So, to Gary's point: It's really how it's... delivered? You know. How it's presented to people.

So we DO have some more really interesting questions here. For both panelists, from Ramona Pindus: Have you worked on any projects conveying information about data management in research? Especially projects involving multiple parties accessing data, some of which may be governmental bodies, commercial, or academic organizations.

GARY ASHWAL: I can try to answer this. I think ‑‑ and I'm not sure if I'm getting the question right, but. We've often... We've done a lot of work related to consent issues, whether it's an actual consent document or, you know, explaining possible methods of consent and all this kind of stuff. And so, we've used visuals to really helpfully show... if you were participating in research, and you were getting some of your data ‑‑ whether that's your health information data, your personal data, your bio‑specimens ‑‑ these things, or data from these things, is shared with multiple organizations. And visuals are really helpful. We often show a little story, so people can kind of connect. Like, this is Gary, who gave this sample to this bio‑bank. So Gary's sample is gonna go here, here, here, here; but it's NOT gonna go here. You know... Sara is the researcher at this! So she gets Gary's data ‑‑ you know. So kind of framing the procedures and the process, in terms of characters and story, and how it works for ONE person? Can really help someone imagine how it's gonna work for THEM. And once you sort of tell a certain story, then you can also even say ‑‑ in certain research we've done, you know. People have the option to say, okay, I wanna be in this research, but I don't want my genetic information shared. So you can kind of, once you have a baseline story, you can also help use that to kind of explain what their options might be, if you have that type of research project.

So I'm not sure if that's the question, but that's one of the things that we've done that comes to mind.

SARA ACKERMAN: Thanks, Gary. Yeah. That is ‑‑ that's really interesting examples you provided. And I appreciate that. 'Cause that's a big, big topic. (chuckles) An important one.

So we have a question ‑‑ this is really, this is also a really important question, from Demetrios and Yekaterina, about how we can evaluate the impact and success of these types of visual storytelling projects! Have either of you been involved in some kind of either quantitative, qualitative, mixed methods evaluation?

ELIZABETH GROSS COHN: So, I'll start, and then Gary maybe can fill in. I mean, the ultimate goal of Photovoice is... you know, civic action. Is a change! Right. Is a change in how we do things, or. Or, you know, sort of a little bit like the one that I was showing ‑‑ you know, we're ‑‑ the work that we do links things in the greater context, in the greater societal context. So even something like removing the statue of Sims and replacing it with a monument that celebrates the women who, you know, ultimately contributed their bodies and their lives to advancing... gynecologic medicine, something like that. We DO think of that as, as part of our success, part of our metric or our measure. (ding) So I think that is the, um. That, for us ‑‑ in Photovoice, anyway, the ultimate, ultimate goal would be for more people to see and understand the nature of what we're doing, the role of the CHW or whatever the theme of the project is. And then, and then ultimately to have change... for there to be change.

So, that's what we're looking for there? But I think the, um... we see collateral lifting‑up of people's voices and empowering people. We did another, different project with frontline health and hospital nurses, who also just said we ‑‑ you know. We feel so celebrated, we feel so appreciated. So I think there's a ‑‑ we haven't measured THAT? But I'm starting to sense that, especially these days, with things being as complex as they are, that that would be another outcome that we would really wanna think more about.

GARY ASHWAL: So, for our work, I would say it really depends on what the goal of the project is. You know. So, for a type of project that's really meant to elicit a certain type of focus group conversation or survey responses, it's really: How well did this set up, so that we've gotten meaningful data for our research? You know. And that often comes because you... you know, tightly associated the visual storytelling with the questions or focus group that you're going to be facilitating.

But on the other hand, you know, for our clinical work... a lot of ways, a lot of times, you know, our gold standard, I guess, for outcomes is: Did this make a clinical difference? And so, for example, our inhalers project, some of the earlier research on that was looking at just knowledge change. Did like a child or a family, after they read this, did they have improved knowledge about asthma? But later people have taken that same project and kind of done more, did it reduce hospital admissions? Did it improve, you know, adherence? All these types of things.

So, I think you can evaluate it like you evaluate any other medical intervention? But it really depends on what your particular goal is. Whether it's knowledge, behavior change, or, you know, supporting some other larger program like a research data collection.

The other thing I would say about it, too, is that... one thing I feel very strongly that you have to keep in mind ‑‑ I know, before ‑‑ I'm kind of both sides of this issue! Right? I'm advocating for DIY, try to do it yourself, you know? But when you're evaluating something that's a visual story, you know, the craft of it... makes a difference! So, you know, something that is drawn by someone who has a lot of training and a lot of skill at visually explaining something... Certain characters, constructing a story in a certain way? My vote would be that that would probably have a greater impact and greater success than someone who doesn't have a lot of training in how to visually draw, or how to create some kind of visual communication piece.

So I know that there are certain studies where someone says, well, this didn't work! Well, it's also like, well, let's see your... What did you make! You know, is it drawn really well? Is it a good piece of art, by itself? Because that relates to the outcome. So, that's another way of thinking about how you're evaluating. So, depends on the project.

SARA ACKERMAN: Great. Thank you so much. We do have several questions we didn't get to; I want to acknowledge that. And, but I'm gonna have to turn it back over to Sheethal now, and she'll tell us a little bit about the next half an hour, where we can address some of these questions that we didn't get to. But I wanna thank Liz and Gary for your outstanding presentations and conversation today.

SHEETHAL JOSE: Yes, thank you! I'd like to echo our thanks to all our panelists today for their presentations and for moderating a great discussion.

So for those who can, please do join us in our post‑event discussion, and hopefully we can get to those really important questions that were left unanswered. The link is in the chat.

So we hope to see you on May 12th for our next ELSI Friday Forum, Value and Values in Payment for Gene Therapies, joined by panelists R. Brett McQueen and Renske M.T. ten Ham, and moderated by Hadley Smith. The registration link is also in the chat. Please visit ELSIhub.org and subscribe to our newsletter for more details. Also, you will receive a post‑event survey. I encourage all of you to complete this, as our organizing committee takes your comments and suggestions seriously. It has informed us on how to improve the forum and bring new topics and speakers to you. So please do fill that out.

All right, thank you, everyone, and I wish you all a wonderful weekend. And hopefully see you in the next Zoom.

ELIZABETH GROSS COHN: Do we exit ‑‑

AUDIO: Recording stopped.

SHEETHAL JOSE: Yes. Yeah.