

Transcript

Matters of Engagement podcast

Episode: "Engaging in Storytelling (Part 3) – Creating Spaces for Storytellers – episode produced by PEP Talks"

<https://mattersofengagement.com>

Jennifer 00:00

Hey, it's Jennifer from Matters of Engagement. This is our third and final episode in our miniseries produced with SPORcast and PEP Talks. This episode is produced by PEP Talks and is called "Creating Spaces for Storytellers". And now, I'll hand it over to Paul and Sandra!

Paul 00:18

How can stories be used to advance health research and health care? How do storytelling approaches help patients and communities share their experiences? Listen in on Part 3 of a collaborative 3-part podcast series about engaging in storytelling.

Paul 00:33

This is PEP Talks, the Patient Engagement Podcast. This episode is the last in a special 3-part series called Engaging in Storytelling, a 3-part collaborative podcast series with SPORcast, Matters of Engagement and PEP Talks. Each of these podcasts covers a different angle on patient stories and storytelling, painting a picture of the challenges and opportunities encountered when engaging in storytelling. And we're sharing all three episodes on all three of the podcast platforms. In part three, this very episode, Amy Hill, from The Story Center US, talks a little about the history, methodology and impact of storytelling, and provide some examples of digital storytelling in the context of public health and health research. Sandra Zelinsky and I first asked Amy to tell us how she came to the world of digital storytelling,

Amy 01:24

I actually come into the world of digital storytelling from the world of public health as it happens. And so my first kind of official job after college was at Planned Parenthood. And then my first official job after getting a master's in gender studies was for a local county public health department and I was doing a lot of work around addressing gender based violence and youth violence. And I kind of stumbled across digital storytelling as a great methodology for engaging community members in talking about those kinds of really sensitive issues. And then it just sort of went on from there.

Paul 02:11

Do you remember what first struck you as like, digital storytelling was a big thing for you?

Amy 02:21

I was working for the California Department of Health Services on a small capacity building project where the whole focus was on building the capacity of domestic violence shelter agencies and prevention programs to use new and emerging technologies. And this was way back in 1999 - sort of the first wave of the web and all of that, but well before, you know, social media, and any of this and YouTube. And I was always doing research on interesting ways to engage these, you know, relatively small nonprofit at grassroots organizations in trying to be

interested in technology. And I came across digital storytelling, and I just thought, Wow, what a great way to combine a focus on people sharing real stories from their own lives with learning to use new digital technologies. And, and it just kind of, it really struck a chord for me, because I actually come from a family where there was a fair amount of disruption and violence. And so, you know, my first exposure kind of led me to let me see what this would be like to tell a story from my life. And so I participated in a workshop. And it was, it was such a powerful experience that I just thought this would be a great way to engage advocates, and work directly with survivors to really bring their voices forward. And this was all in a public health context. So it was, you know, the projects were funded by the California Department of Public Health.

Sandra 04:03

So Amy, you mentioned right at the beginning, something around a methodology with digital storytelling. Can you talk a little bit more about that and perhaps the importance of the methodology that you use when engaging people in storytelling?

Amy 04:22

Sure, so Story Center has been around since the early 1990s, believe it or not, and, you know, kind of the quick origin story is that the organization used to be a community based theatre and in the early 1990s, our (still) director Joe Lambert produced a show called Next Exit with this guy, Dana Ashley, who would get up on the stage in a live theatrical performance and tell short anecdotal stories from his own life and then he would have projected behind him still photos and like old super eight video footage. So he would sort of perform this live version of what we now know as a digital story. And after the success of that show, Joe and Daniel were invited to Los Angeles by the Los Angeles Film Institute to experiment with a workshop format, actually, with documentary filmmakers. And so they, they sort of invented this group process workshop that brings small groups of people together to, over the course of several days, to share intimate personal stories from their own lives, and then develop and craft them as short videos. And so that was such a successful event that Joe immediately came home, and shortly thereafter, shut down the theater and sort of morphed it into the San Francisco Center for Digital Media, which then became the Center for Digital Storytelling, which then became Story Center. So it's had a couple of iterations. But throughout, this particular workshop methodology has really been kind of one of our core offerings that we do. And, you know, you could describe it as a form of participatory media. It's, as I said, you know, it's an intensive workshop process where a small group of people come together and share their own stories and then are supported by facilitators.

Amy 06:30

And kind of the heart of the workshop, we might say is, is the story circle process, which of course owes a debt of gratitude to Indigenous communities around the world that of course have used storytelling, since before even time was recorded, as a way to kind of transmit knowledge and information, build relationships, etc. But in the Digital Storytelling context, or approach, it's essentially a time when each storyteller in the workshop gets to verbally share their story, and then receive comments and feedback from the group. And that's always a really wonderful way of building connections and relationships among the group. And helping the storytellers really get clear on what story it is they want to share, and what meaning or insight they're taking from sharing the story.

Sandra 07:29

In regards to that, so thinking about that story circle, or people, I think we've all shared stories, we all have so many stories to share. But when we look at asking people to share their stories for you know, like, if we're talking about in health research, or within a healthcare context, what would be the difference of inviting somebody to share a story in a live format, or written format, versus digital storytelling? And how can we choose or even learn from sort of some of that digital storytelling methodology?

Amy 08:07

I think in the context of health research, digital storytelling is most closely analogous, for instance, to a focus group session where essentially, you're doing kind of a group interview process with people and bringing them together. But the distinction really is that while a focus group is pretty explicitly a qualitative research methodology, you know, if it's being used in that way, digital storytelling is really a creative arts and reflective practice. So it can be framed as a form of qualitative research within a health context, but it has all of these, you know, other added components in terms of skill building, in terms of really supporting people and kind of digging deep and reflecting into their lives. And helping them develop skills for telling stories, both verbally and written, using video to develop their stories and so on.

Amy 09:08

In terms of, you know, the distinction between... it's a good question to think about what are some of the differences between, for instance, learning how to tell a story, sort of impromptu, just orally, you know, like The Moth or something like that, where you just get up and speak your story and sort of perform it... versus what are the skills required to write your story down, which is a whole separate set of things that you need to pay attention to... versus for instance, being interviewed. Those are all really different ways and formats for telling stories. And in our basic methodology, we sort of combine this idea of more like an oral history type of experience where somebody speaks their story, together with then learning how to craft it as a piece of writing. But of course, in contexts where there may be literacy issues, or where we're working with multiple languages, then of course, we adapt and modify the approach to help people be able to develop a story, even if they don't feel comfortable, or if we can't really support them as a writer.

Paul 10:28

This all does make me think about some of the things we've been thinking about as a team, which is the idea of ethical considerations and just sort of making sure that we're engaging in ethical practice both as both as a team and and sort of inspiring, hopefully others, to do the same in their projects. So are there any ethical considerations that you sort of weave your way through when supporting people creating a digital story of their own?

Amy 11:00

Yeah, sure. So we actually have a whole set of ethics guidelines that underpin all of our work at Story Center. And I think, probably the most significant of those is the very first one, which really addresses the need to support and enhance storyteller well being. So to whatever extent that's possible. And, you know, given lots of different variables of how that can be set up and supported, that's always kind of first and foremost in our

minds. You know, there's always a delicate dance between wanting to create a rewarding and meaningful experience for a group of people, and then wanting to develop really compelling stories.

Amy 11:51

And, you know, so one thing that differentiates our work from more traditional media making practices is that focus on enhancing and protecting storyteller well being. The whole set of ethics guidelines really came out of some work that I was doing more than 10 years ago, down in South Africa. And I had some experiences where, you know, through no fault of my partner organizations, just given how, how quickly YouTube was taking off, and how much there was sort of a culture in the NGO and development sector of you know, sort of collecting stories, narratives, images, and splashing them about. And I really felt concerned with the ways that some of the organizations were representing people without necessarily even going through a proper permissions kind of process. And not really thinking through what it meant to just put their stories all over the place. And so, so we actually partnered with Photovoice UK and got permission to adapt some of their very good ethics guidelines to create a whole specific set of guidelines for digital storytelling and other participatory media practitioners. So that's a really great resource that people can find on our website.

Sandra 13:29

Yeah, we also have sometimes researchers that ask similar questions around the ethics, not necessarily coming from those ethical considerations of how to support people, but even through, sort of, how do we apply for ethics? And, and ultimately, like, "Who does this story belong to?" And so to your point, you know, with YouTube out there, and we all know people can post all kinds of comments, some of them not nice (on YouTube). What happens if at any point a storyteller doesn't want their story out there anymore? So who do the stories belong to? And how do we navigate some of those bits and pieces if a storyteller either chooses to not share their story at the end of a workshop or creating their own digital story? Or, you know, if it's two years or five years down the road, and their lives change and they say "I don't want that out there anymore. Can you remove it, please?" What is our responsibility around that?

Amy 14:42

Sure. I think the way that I've always approached it in my public health practice is to just be really clear and transparent from the outset about any and all plans, agendas, goals, hopes, dreams for how, where, why and when stories will be shared publicly. So for instance, with some of the partners that we work with in health related projects, the the focus of a project is pretty solely on really creating a positive experience for the storytellers. And there's really no agenda for for stories being shared publicly beyond the immediate group within the workshop and the storytellers themselves. So in that instance the whole process is really much more of a kind of creative arts therapy experience, which can be really beautiful.

Amy 15:31

However, many funders and researchers are interested in supporting people in developing work that can be shared. So you know, where and when that's the case, I just think it's important to be really clear that you know, that there is a hope for that, from the beginning, from the very first moments of when you start talking with potential storytellers, and developing proposals and all of that. And in those instances, I've really found that in our public health work, one of the most effective approaches can be to engage storytellers from the perspective

of... not from this idea of "Oh, come and share your deepest, most private personal story, and then we're gonna splash it around for the whole world." No, actually how I approach it is, please work with us in this storytelling process so that we can support you in creating a video that you feel really proud of that can speak directly to others in your community about these particular issues.

Amy 16:39

So really more engaging people as sort of partners and collaborators in the creation of a story that can be useful in a particular kind of way. You know, obviously, in terms of health literacy, health, education, health advocacy like that - and in that way, you're really offering them a lot of agency and viewing it as a solidarity and collaborative experience, rather than sort of extracting stories from a particular community.

Amy 17:12

To the point about removing things from... Well, first of all, so when it comes to story release, one of our ethics guidelines has to do with viewing the release process as a process. So we like to talk about a living consent process. And as I've said, you know, kind of weaving discussions about what it will mean for people to say or share certain pieces of information, certain images in their story. So that you're being responsible as a facilitator in providing them with the support and guidance and good advice about what they're going to feel comfortable and safe sharing and showing. And then when it comes time for the release, we often do release forms that actually allow people to tick off specific boxes that indicate different ways that they're open for their stories to be shared. So everything from "Yes, you can share my story in a public community setting. But no, I would prefer that you not put it on YouTube" - so things like that. And then when people do give permission for their stories to be shared, for instance, online, it's really important that they understand the limitations of subsequently removing it, if they do wish to remove it. So of course, if they do wish to remove it, then that needs to be honored, and it needs to be taken down right away. But it's important to also explain that doesn't have 100% guarantee that no one out there might still have a copy just because of the the nature of the virtual world and the fact that people can download things and copy them relatively easily. So just making clear the what those limitations are.

Amy 19:05

But we have had situations where, for instance, we do quite a bit of work with current and former foster youth. So young people growing up in care situations outside of their biological families. And we have had situations where, you know, young people who told stories, maybe at age 18, or 20, are now well into their professional careers and they've really grown and changed a lot. And they've written to us and said, you know, "could you please take my story down now because I feel like I'm at a different phase of life. And I'd rather not have that out there." And so of course, then we have to just respect that. And I think that's a really natural progression of just this idea of, you know, not sort of commodifying stories and assuming that this story is like this static permanent representation of a person and just remembering that all storytellers are humans with lots of different lived experiences, stories, experiences, histories, etc.

Sandra 20:11

I like how you frame to the idea around bringing people's partners to storytelling as I think it kind of talks a little bit to the methodology used where people really spend time in sort of a reflective stage. So, yes, we all have

stories, but we haven't all had a chance to really share and sort of reflect and figure out that the nugget or the insight, like you said, or emotion around that story. So it gives that person the opportunity to think of like, what's that call to action? What is it that I want to share with the public space? What do I want people to learn from, you know, my experience. And so it takes some digging in to figure those things out from an individual perspective, as opposed to just sharing, you know, a very personal story and kind of putting it out there. And then having other people think about, perhaps how they might fix that problem, or, you know... so I'm thinking in healthcare context, for example, I like the idea of really sort of bringing the people with the lived experience to also think about how they might improve on certain aspects of their experiences that they've had within a healthcare setting, to help inform health research. So yeah, I really like those ideas, as well as the last point you're making around, you know, ultimately, it's up to the person whether they want to continue sharing a story or not, and not owned by anyone else but that individual.

Amy 21:49

Right, you're reminding me of this great project we did. About eight years ago with the University of Massachusetts, it was a pretty large scale project funded by the Ford Foundation that was looking at stories by pregnant and parenting young women, mostly teens. And one of the papers that came out of that was this piece on this concept of strategic authenticity, and really kind of digging down into this idea of what it means to self represent. And looking at the decisions that the young women made in terms of how they framed their own stories and experiences. I was a really great term, I think, this idea of strategic authenticity that kind of disrupts this notion that somehow oh, you know, ultimately, there's this deeply true authentic story and experience that we have when actually how do we even know when our own stories are true and authentic? You know, so we're always making decisions about how we represent ourselves and remember things. So I liked that concept.

Paul 22:55

So we've been talking a lot about process, and I'm interested in maybe exploring a little bit, sort of impact or, or outcomes of storytelling. So do you have any good examples of how using a digital storytelling approach has impacted policy or healthcare practice? Or...?

Amy 23:13

[laughs] That's always the big question. You know, it's interesting, we've done so many projects in collaboration with health and public health researchers, and almost always people default to wanting to research the impact of the process on storytellers. And I think it just points to the difficulty of researching the impact of viewing stories on viewers, decision makers, etc, etc. Because it's just, you know, people that do Media Studies know that that type of viewer response research is just notoriously difficult. Nonetheless, I think, you know, when we're talking about... so in terms of impact, first of all, you know, I think it's important just to a little bit challenge this notion that the only impact worth having is if a story goes viral, or something like that. You know, so we have this whole context of social media and online activity that assumes the more views, shares, whatever... the better. When that's not actually a very good measure of much of anything other than the fact that lots of people have watched something.

Amy 24:29

Sp when we're working with specific health projects that have strategic advocacy goals, we try to narrow down the audience to who is it who really needs to see this story. So for instance, we have a pretty long term project with the hepatitis B foundation. We've done about six or seven workshops through this Just B project. And so you know, so their policy goals are pretty traditional, and yet I think they're really important, which is they want to get the stories of real people, and the impacts that B has on them, in front of policymakers and decision makers who have the ability to make decisions about funding allocations for research towards a cure.

Amy 25:20

And so you know, so in that sense, they've been really successful with integrating stories into the the different policy events that they do in DC every year. And they've been really successful also in positioning the stories, especially across different ethnic media platforms that are tailored specifically in languages other than English. So channels and platforms that are... because we've done so many stories in languages other than English... and that's been really successful to. But I think, I would put the question back to researchers to really get creative about what specific impacts you're hoping stories will be able to contribute to, and kind of figure out how to how to research that. One of the things that I've seen is that, you know, sometimes people in the public health or the health world have this very romanticized notion of you know, oh, well, if we just help these people tell these stories, then somehow, you know, some miraculous changes are going to occur. I think it's important to remind people that the effectiveness of your advocacy strategy is only going to be as good as the strategy is. Like, the stories are not the strategy, they have to be woven into an actual strategy, if that makes sense.

Sandra 26:50

If we were to ask you, thinking about the audience, like, Why are stories important to health care? Or in health research? Why should we be looking at stories or collecting stories or sharing stories in the context of health care and health research?

Amy 27:16

In the context of public health or health care, there's a great tradition of work with Narrative Medicine. I don't know if you're familiar with that work at Columbia University, but just this idea is that, that people and patients are so much more than these, you know, sort of one dimensional patients, and that looking, of course, at data and more quantitative kinds of research is important. But that unless we can actually hear from individual people about how they experience a particular health issue, we won't be as effective in being able to provide quality care.

Amy 28:01

Another great example is that classic book that came out years ago, "If the spirit catches you, you fall down", which was about which was about about Hmong immigrants in the Central Valley in California, and really dug into the assumptions that healthcare providers were making about members of this community, and then really kind of inverted that, and looked specifically at the beliefs and the cultural practices, that that community had brought with them. And it was just this incredible disconnect between the community members and the health providers - culturally and in every way you could think of - and I think that stories and storytelling have a way of breaking some of that down. Because they so much focused on particular anecdotal individual experience when when they're well told.

Sandra 29:12

Yeah, it just brings up a thought, you know - we often ask patients, so people with lived experience in health care to share their stories but and.. I'm just putting this out there because I also am aware that we have a health care system that doesn't support health care professionals in sharing their own stories and experiences... and so this just, hearing you talk has brought up that thought of like, what's the importance to even just to kind of equalize those relationships a little bit and understand each other? I mean, we are all humans, ultimately, at the end of the day, and is it important to also to create a space for healthcare professionals as well as, you know, people living with various chronic diseases or whatever health conditions to be able to share their stories.

Amy 30:16

I'm so glad you said that. And I couldn't agree more. That, you know, you've just kind of pointed to the foundation of our whole approach to training facilitators in digital storytelling, which absolutely requires that as a foundational piece of that people need to learn how to tell their own story and actually participate in digital storytelling. And it's amazing how often we get inquiries from people who say "Oh, I want to be trained to do this" without even thinking about, you know, is it really appropriate to train to do something that you haven't yourself been willing to actually do. But more importantly, just to that point, about the lack of safe accessible spaces for providers themselves to share stories.... And that's been kind of the foundation of our work with the Nurse Story project that has been working for years to support nurses and nursing professionals from all different kinds of backgrounds and sharing stories.

Amy 31:22

And it's a chance for reflective practice for people to share and explore why it is they they went into nursing, to share their experiences in nursing. And I have to say, you know, during this time of pandemic, it's just been so powerful, the sessions that we've done. You know, we haven't been doing full online digital storytelling workshops with that group - although we have been doing lots of that since we don't really have a choice to do anything in person! But we've done so many Story Circle and story writing and sharing sessions with nurses, and we would love to be able to expand that out to other health care providers. But I think, you know, it's a bit of a, it's a bit of a delicate situation, knowing how overwhelmed and overtaxed people are too. You know, I'm not sure that the timing is right for some groups, especially, of course, here in the US where the system is on the verge of becoming totally overwhelmed. But yeah, sorry, to make a long story short, I completely agree. And I think that process of health providers and health researchers of sharing their own stories is really, really valuable.

Sandra 32:46

What advice do you have for others?

Amy 32:49

Well, just building on what we were just talking about, I would say the key piece of advice is to urge people to explore their own stories and get comfortable with doing so. And to urge people to play around with what it feels like to share something pretty personal, and make yourself vulnerable. You know, I had a comment the other day and one of my COVID... so I've been doing these almost weekly COVID storytelling webinars since the

beginning of the pandemic, and I had this... I've developed kind of a friendship with this woman in Norway and almost every time at the beginning of the session, I read a poem and I cry because I'm so grateful to have the companionship and I'm so grateful to see people's faces without the masks. And she made this comment, she said, You know, I feel like the most successful marker of a good facilitator is being willing to just be vulnerable and be real. You know, so the extent to which researchers themselves who are interested in working with storytelling can develop those skills, and so many people already have them, of course, or they wouldn't be in the health care profession. But I think that just helps immeasurably in terms of being able to really create safe environments where people can sort of let down their guard and feel comfortable sharing.

Sandra 34:19

Yeah, thank you. And Paul, do you have any final questions for Amy and perhaps Amy might have some final thoughts that you would like to share with the audience before we wrap up, but Paul, did you have any other questions?

Paul 34:34

Yeah, I was actually just gonna mostly ask you if you had like one takeaway message for people listening today. Only one, what would you what would you say?

Sandra 34:46

No pressure [laughs]

Amy 34:51

Well, gosh, you know, I don't want to get too long winded about it, but I'm earlier in my digital storytelling years, I was much more focused on impacts and outcomes and applications for research and this and that. And I have to say honestly that more recently, in the past five years, having been working a lot more with performing artists and visual artists, I feel like at the end of the day, digital storytelling is about making art. And making art is about healing. However you slice it and look at it. So if health care providers and people working in health care can have that kind of value around storytelling as an art form than I think that's fantastic. So not necessarily looking at stories as a way to sort of extract data or share important public health messages, but really just looking at it as an art form.

Paul 35:55

Awesome. Thanks so much for joining us on the podcast today.

Amy 36:00

Thank you so much!

Paul 36:03

Thanks so much for joining us for this episode of PEP Talks, The Patient Engagement Podcast, brought to you by the Alberta Strategy for Patient Oriented Research Patient Engagement Platform. Special thanks to Sandra Zelinsky and Sadia Ahmed for their co production. Make sure to subscribe to this podcast wherever you found it.

And we hope you'll join us again for more interesting discussions about patient engagement in health research and health care.