

# Podcast Series: Let me just share my screen

**Episode Title:** Equity and Accessibility in Participatory Visual Methods for Online Spaces: A conversation with April Bell and Keri-Lyn Durant

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## Introduction (0:00-3:27)

### Teaser

This is not my story to tell. Because sometimes people will tell you a story that you're like, "Oh my god, that is the best thing ever," but then they decide that's not the story they want to tell, and you gotta be okay with that. If I'm going to stick to my principles and my ethics of centering the participant, then I got to be okay with that.

- April Bell

### Podcast narrator

Welcome to *Let Me Just Share My Screen*, a podcast where we dive into conversations with seasoned and up-and-coming researchers about new directions in online, participatory visual methods research. Each episode is packed with fresh ideas, practical tips and ethical considerations to help you plan, create, and exhibit your visual research projects. This podcast is inspired by a CIHR-funded research project that gathered experiences of health researchers conducting photovoice and digital storytelling projects online with diverse communities. It is produced in partnership between the Center for Community Based Research and the Arts Informed Methods team at Trillium Health partners, listen in for more.

### Janna Martin

Hi everyone. Welcome listeners. We're so glad to have you tune in today for a conversation on equity and accessibility in online digital storytelling projects. My name is Janna Martin, and I'll be your podcast host for today. I'm a senior researcher at the Center for Community Based Research. I'm personally hosting this conversation from my home in Guelph, [Ontario] as situated within the Dish with One Spoon territory. I'm very glad to be joined by our guests today, Dr. Keri-Lyn Durant and Dr. April Bell. Thank you both for coming. To begin, can you tell us a little bit about the work that you do with communities?

## **Keri-Lyn Durant**

Hey, thanks Janna. Yes, I'm Keri-Lyn Durant. I'm affiliated with Lakehead University in beautiful Thunder Bay on the Superior Robinson treaty lands. I am a qualitative researcher, currently with the School of Social Work, and I work with people who have accompanied someone who used medical assistance in dying or MAID at the end of their life. I use digital storytelling to do that. MAID has been our focus since 2016 when it was legalized in Canada.

## **Janna Martin**

Thanks Keri-Lyn. How about you, April?

## **April Bell**

Thanks Janna, I'm April Bell. I am an assistant professor at the University of California, San Francisco. San Francisco, which is local located on Roma to Aloni land here in California. My research, the research that I'm going to be talking about today is a digital storytelling project with Black women who created digital story about their abortion experiences.

## **Addressing the digital divide and balancing structure with flexibility (3:28-6:48)**

## **Janna Martin**

Thanks for that background. In your experience, what are the advantages or the drawbacks of doing digital storytelling online when it comes to equity and accessibility?

## **April Bell**

Well, I'd say one thing that comes to mind in terms of equity and accessibility is that you can open it to more folks, because they can choose where they're going to access the workshop from. But that also raises issues around access to the internet, which they would need to participate. And so for one project, we actually had remuneration that we were offering participants, but we said that if you don't have a computer, we will give you a Chromebook that you can use for this project, in lieu of the financial remuneration, and give you like a hot spot so that you would be able to participate in the workshop. So that's one way we try to address equity issues. I have to say, our budget for that storytelling project was pretty small. And so while we would have preferred to offer the financial remuneration and the computer, we were not able to do that. And so we only had one person take us up on it, but she was able to participate. And because it was her remuneration, she was able to keep the Chromebook after the workshop. So I think in that way, it can make it more accessible, but it does, you know, highlight that not everybody has access to internet. Not everybody has access to a private space, and so, you know, I'm sure some people kind of took themselves out of the running for participation in the workshop for that reason.

I also think another challenge of going digital, especially with equity, again, life happens, right? So one of the things that I tell people generally, when we start these workshops online is that I will keep contacting you to finish your story until you tell me to stop contacting you, because people stuff happens like they can't make a session. So the compromise that we make in our workshops, is that we say that there are two sessions that you have to be present for. We usually do the workshop over six sessions, right? And so six, two hour sessions spread out over seven weeks, and we say the story

circle session, where you tell the story. Everybody tells a story that they want to make their story about. You have to be present for that one, and you have to be present for the final one, because that's where everybody debuts their story. So we say that because that is where you get a lot of the group buy into the process in those two sessions. And so we want people to have that group facilitated, group process, group mediated process. And so to do that. They have to be in those sessions. But outside of that, if they miss, we are committed to getting them caught up and helping them finish their story. And again, I will keep contacting people until they tell me to stop contacting them. And so far, nobody has said, stop contacting me, and everybody has finished.

### **Fostering trust, safety, and care (6:49-14:24)**

#### **Janna Martin**

That's a really great practice that you described there. How do you think that practice of like being flexible with checking in with people, rather than requiring them at every single session; Why is that important for when you're working with equity deserving communities?

#### **April Bell**

Well, I think it's important for working with any community, because people have lives. And I think that when you're working with folks who have been dealing with inequity, it is important to center them in the process. And to center them in the process, you have to understand that sometimes, despite best intentions, they cannot show up for the thing, right? And so I think it's just a good practice to be flexible in that way, because it also shows people that you're willing to work with them and that you're committed to helping them bring their story to life, right? You're committed to like, providing them the technical support that they need to make their story come to life, and it also helps us show that we're not pushing a particular agenda. We just really want to help you bring the story out into the world. And that also is challenging sometimes because folks have participated in storytelling things before and they've been pushed towards a certain story. And so often people don't trust it initially, when we tell them, "No, we want you to tell [the] story you want to tell." We try to keep our prompts pretty open. For example, for the abortion storytelling project, it was "tell us about your abortion experience." Because we don't want people to feel like we're pushing them towards a certain story. So I think that was a lot of rambling to say that being flexible is a big part of how we show people that we are centering them in the process. Because we're working with them, where they are, how they are, to bring the story to life.

#### **Janna Martin**

No, I think that elaboration was so valuable and provided a lot of things to think through for folks who are wanting to be accessible and addressed, like equity barriers in online spaces. And how about for you, Keri-Lyn, when it comes to this question of advantages and drawbacks when doing this method online?

#### **Keri-Lyn Durant**

Yeah, that is a big question. And I think because I conduct these research studies in the field of grieving, automatically the acceptance that people are actively grieving, and that's going to take a lot of flexibility in terms of, as April said it so beautifully. You know, life happens, and there are going to be times when people just really aren't able to show up to a session or show up for a specific task.

Perhaps, but there's also the understanding too, that it's going to take some emotional bandwidth and some of that emotional energy. We on the research team had a social worker who could do that emotional check in; "Hey, this is heavy. How are you doing with processing this?" Because what we were, you know, completely averse to was we didn't want to be re-grieving people in the process as they were trying to create the story that they wished to tell. What we had was a group of people who were adamant that their story about medical assistance and dying needed to be heard far and wide by public, by healthcare professionals, by policy makers, by Joe Public. So there was this drive to create this story, but we had to really take into account at what cost to the research participant? In terms of their emotion, emotional state, in terms of where they were at. How was the grieving? Were we switching off our computers at the end of a session [and] was that person alone in their space? Were they able to be as safe as possible in the space that we had? I guess [we] opened for them and really asked them to invest in us for those hours.

So the other thing I just want to add [about] that online space, I loved what April said about that issue of geography, right? You know, you can take all comers. We are a big country, just like your country, to the south of us, April. So we had people from several provinces involved in the study that we were doing. That didn't mean that we could have a meet up in person. One study we did, we could have a meet up because it was in the province of Ontario, and we were able to kind of all meet in the City of Toronto. But with this one, we were all over the place. And while that was so much of a benefit [to be] online and be able to kind of Zoom in from everywhere, again, that idea, when those computers were switched off, um, with whom were we leaving our people, right? And were they going to be okay? And were we going to be able to check in and make sure that from session to session, that we weren't leaving people in those kind of limbo, spaces of kind of grief and not quite knowing what to do with themselves?

### **April Bell**

Can I just add to the idea of creating a safe space? I mean, one thing that we're very deliberate about in the workshops is making sure people feel like they're coming into a safe space to talk about this, in particular around the abortion work. Because so many of the spaces are unsafe to talk about abortion. And so having people be able to come into the space knowing that they were going to be affirmed and supported is really important. For our particular workshop online, one of the things that we did was we decided this project was Black women only. So it was a Black women only space. We created a playlist. We had them give us songs. So we created this playlist so that whenever there was work within the group, like online, we had the songs playing in the background. We also made sure that we had a person available, so that if somebody needed to like, decompress a little bit we could put them in a private breakout room so that they could talk to them there. But more importantly we kept the space safe. Sometimes, you know, people are having their own experience, so they start to co-opt other people's experiences. And so we were very deliberate in that we didn't allow that, you know, that this, that was this person's experience, and we would just gently steer the person you know, who was trying to co-opt the experience away from it, right? Um, and we took that very seriously, because we wanted people to feel like they could come and be themselves and relax.

## Building a container of care in online spaces (14:25-19:31)

### April Bell

And so when the project was ending, we had one person say, “I’m so sad that this is ending, because I love coming here every week just talking to you guys like, I love it. I’m so sad.” We’re going to have to have some meetups, whatever, so they do have a virtual chat group that I’m in that they added me to, but they do chat with each other. And we collected this data two years ago, and there’s still text messages coming through. But we again, just this idea of a safe space. We wanted to make sure people felt safe and that if they needed some additional support, the group could continue, and that person could get their support. So those are two really, really important things for us.

### Keri-Lyn Durant

Yeah, I really love that you added that April, because you’ve reminded me that use of the breakout space for those people who really felt, yeah, that they wanted to be somewhere where they could own their story and perhaps not have it, as you say, leaking into the other spaces, etc. There are also, I wanted to just comment, because I got a real sense of what you were talking about there, about that community building, right? And I think people are very quick to assume that in person stuff is going to lead to sort of community-based connectivity. We had a similar situation where people wanted to stay connected, and they have created an online community where they can do so, and we talk about having a reunion in cyberspace, but because we were also siloed in different provinces, you know, two of our participants who lived in the province of British Columbia, have now since gone to death cafes together, or have had library events where they share their digital stories and they go as a team that met in this particular, you know, digital storytelling workshop. So that’s really cool.

I love the power of people to really decide how they want to continue those relationships. Because really, and I don’t, I can’t speak for you, April, but you know, spending those six weeks or seven weeks with people in those intimate, intimate spaces talking about profoundly intimate experiences that they wish to you know capture in digital stories. There’s a certain amount of relationship building and a certain amount of falling in love with one another. There’s a certain amount of saying, “You showed up for me again this week, you listened. You listened to when I couldn’t decide, a piece of music. You helped me pick a photograph of my late husband. I really was having trouble, was it this one to tell this particular moment in the story? Or that one?” After six weeks, I don’t know that we wanted to let go of those relationships, but being on the research team, that’s not appropriate. But when the participant looks you in the eye and says, this felt like love, this felt like friendship, we’d love it if you would check in with us once in a while.

One thing I just want to tack on to that idea too is – and I am really interested to hear from you April as well – is we’re so focused on taking care of the research participants and making sure that we afford them this safe space. We really had to group together as a research team and with the digital storytelling specialist to make sure that we were taking care of ourselves in the middle of it, too. And I would love to hear more, if you’re okay Janna, with me, hijacking your interview. I would love to hear more about how your team really kind of reflected, decompressed, you know, met so that you could take care of one another while you’re taking care of your people?

## **April Bell**

Well, one of the things we did immediately following the workshop is we would take like 30-45 minutes as soon as we finished the session to just say, like, what happened and how we felt about it, and you know what we were going to do. There was always a task, like, what is the thing you're going to do in the next 24 hours, just for yourself? You know, and then to, like, check in to make sure people really did it. So you hear a lot of things. Sometimes those things are really heavy things that you hear. So we always took time immediately following, just to decompress about like, what we heard, how we were feeling about what we heard. If something, if anything, happened that we thought maybe we handled well or we should handle differently. And then really, like, what is this thing you're going to do to take care of yourself in this next 24 hours? And then I would make it a point to, like, either text them or email them like, "Hey, did you do that thing? If not, well, what did you do? And if you didn't do it, like, you still have time. The 24 hours isn't up yet." And I made it a point to model it myself, to take the time to do the thing myself, so that my research assistants could see that I'm also taking it quite seriously to do the thing, to do the caretaking for myself.

## **Centering autonomy and addressing power dynamics in online spaces (19:32-33:09)**

### **Janna Martin**

Thank you both. I'm curious if you want to speak any more about how an online space affects power dynamics. You know, as COVID was happening and you were moving your digital storytelling online, did you notice anything about how power dynamics shift in an online space and like how to be responsive to that? It could be positively or perhaps negatively.

### **Keri-Lyn Durant**

I don't know that I necessarily can speak to whether it was a positive or negative. I know some of the things that I really had to take into account in an online space. And one of those things was, if I am using a software where I have access to the participants digital story. So we use a software called We Video. I can be in the story with the participant. What I had to be emphatically inflexible with myself was that I could not allow technological obstacles to get in the way of, take the power away from creative choices, right? So I'll give you a concrete example of how do I understand this. So I worked with a research participant who will later this year or in the foreseeable future, have medical assistance in dying for herself as a choice. Her situation is such that physiologically, she can't use a computer very well. So what I did was I geographically lived close enough to her that I said to my primary investigator, "How would you feel if I actually went down and worked with her face to face?" And this was, course, after COVID, so it was a possibility. What that meant was that I could be in the same space with her. I could be hands on, on the computer with the software, but I had her literally beside me. So I really felt like I was very much the scribe, to use an old fashioned word, right? I was the person who was very much punching it in, making it, you know, setting up the technology, etc. Was I there to say, you know, I prefer this picture over that, absolutely, but it was her. How was I going to replicate that in an online [space] where I had people coming in from another province who didn't know how to take pictures off their iPhone and put them up on the desktop so that we could drop them in?

And as painstaking for that participant as it was, we went step by baby step by baby step so that at the end of it, she could look at me and say, I did it. I did it. I figured it out. Thank you. I don't know about you, April, but the overwhelming gratitude from the participants. "Thank you. Thank you." Everything, things that I get so used to in my research spaces as almost no, they're not rote. You know, I'm a squishy human. So they're certainly not rote. But those things that I take for granted are the things that are active in my life. Here I've got this lovely human who says to me, "Oh my gosh, Keri-Lyn, that took an hour and a half and you were there the whole and you didn't get frustrated and you didn't roll your eyes and you didn't, you just were there the whole time." That's like, gold, right? So yeah, it took the hour and a half in that little breakout room to upload every single photo, but at the end of it, did she walk away from the workshop feeling like she had accomplished something? And I didn't go, oh, okay, let's you know we've got 10 minutes to do this, so let me do this for you. So was there a power dynamic? Of course, there's always a power dynamic. I did my utmost as the squishy human that I try to be good squishy human, to really take into account that the bottom line was autonomy for everything. Did I turn my computer on myself? Yes, you did, right? So if autonomy was the bottom line, then how was I going to get out of the way of myself to let those things happen, or even to and kindle those things right?

### **April Bell**

Similarly, I would say that definitely the power dynamic is there and a reminder to myself that this is not my story to tell. Because sometimes people will tell you a story that you're like, "Oh my god, that is the best thing ever," but then they decide that's not the story they want to tell, and you gotta be okay with that. If I'm going to stick to my principles and my ethics of centering the participant, then I got to be okay with that. And so then my job really is to facilitate them bringing that story to life.

I've also had people who were just for, for whatever reason, couldn't get over the hump of writing the script. So I have gotten on Zoom with them, have them tell me the story, and I write it while we're talking, and then, you know, they go through it, and "Did I get something wrong? Is that a word you would use? Oh, that's not the word you use. Let's change it." So we would do it in real time again, like meeting people where they are recognizing that they're the expert of their story, and then providing assistance so in terms of how it looks and how it sounds.

So yeah, I think there are a lot of places where power could be used to exert a force to make a story go a certain way. But one of the things that I remind myself of is this is not my story. My job is to help them make the story that they want to make, and I train my research assistants to do the same thing. To recognize that people are the experts of their thing. They may not have the technical skills, but they have the story, and that's the most important thing. So our job is to bring that story forward.

### **Keri-Lyn Durant**

Yeah, I think that's so true. And I think I'll go back to something you said, April about you know, they're the only person who can tell that story. I think also what we really emphasize in our research studies is that there's no need for any dissemination of that story, because the product belongs to them. They get to decide what happens to it. And so we've had participants create a beautiful story and say, "Yep, done. And that's now a file on my computer, and I feel good about that." Other people who are out flogging their story any chance they get. So I think that's an interesting thing to take into account, too.

### **April Bell**

Yeah, I'll say that we ask folks, you know, when we start the project, we say that we're going to be using this for research and that we're going to analyze these stories. And then we say at the end, when your story is done, you've seen it, you know what's in it, we're going to ask you how we can use it. And so again, I take that very seriously. And in thinking back about the power dynamics, one of the things that I do throughout is again asking them, "Who's going to see the story? Who are you going to share this with?" Because we want to make sure that there aren't details in there that don't need to be in there that are going to impact how they interact with these other people, right? And not to have them like, self-edit, but just to say, "Like, okay, so what do you think the impact of you including this and the story is going to be and is that okay?" And if they say, yeah, we move on. But again, part of my responsibility as an ethical facilitator is to help them think about the impact of some of the things that might be included in the story. And often those details don't need to be there for the story to make its point. So again, helping people think through that. And I think that's a fine line too, because you don't want to unduly influence somebody, but you also want them to be thinking about the potential consequences of including that positive or negative consequences of including a particular tidbit in the story.

### **Keri-Lyn Durant**

I think that's so important, and I'm so glad you raised it April, because we have a podcast associated with our research study called *Disrupting Death: Conversations about medical assistance and dying*. We did three sort of, we called it the trifecta of digital storytelling, and we interviewed every digital storyteller, every digital story creator, and then we had them on our podcast. They live on our website. And so to go back to that Janna, you know, ages ago we talked about that issue of flexibility. I think there has to be reflexivity. There has to be that kind of coming back to things again and again and saying, "Yes, you gave us permission to speak at the conference six months ago, a year ago. How are you feeling now about the fact that I'm, you know, taking your story and I'm going to speak to policy makers and healthcare professionals. How are you feeling today?"

### **Janna Martin**

So just as we near the end of this conversation, I was wondering if you have anything more to say about what other kind of facilitation practices do you think are important for that online space when addressing equity and accessibility with digital storytelling.

### **Keri-Lyn Durant**

I'm going to talk about something that I definitely it came up at in this last study we did, and I really think about it a lot, and it's this issue of lived experience. As a person who has not accompanied someone who chose medical assistance in dying, I am a trained death doula. I've worked in these spaces as a researcher. I did my doctorate in dying, death and loss education. That's all lovely, but I have never accompanied somebody who chose MAID. And the issue of lived experience really, really came to light for me, and it's something that I kind of marinate and continue to marinate on, thinking about the value of having someone on the team with lived experience. Because, as it turned out, we had a team of, well really, when it came down to it, about six people, including the primary investigator, and not one of us had lived experience with MAID. So having said that, I don't know where I stand necessarily about whether [if] that's an essential component, but it's definitely something that has given me major pause

for thought, and I really would like to kind of sit with that for a while and think about the role of lived experience and what that would look like.

### **April Bell**

I 100% agree with that. I think it helps build a rapport and the like the safety net for folks. If they feel like folks in a space who are facilitating the space have the lived experience. That has been my experience so far. And I think that's really true. I still go back to, you know, before, I didn't say this earlier, but before we did the workshop, we did a prescreen interview with everyone who signed up, right? And when we did that interview, people kind of got a sense of us and like, what we were trying to do in this workshop. And our goal was really to document the stories of Black women who've had abortions. That was it. It wasn't to say a certain type of [story] that what we're looking for. And so we were very clear about that. But we still wanted to screen people, because we got a few folks filling out our interest form that, you know, things were not right on there, so it was good that we were checking in. We also want to make sure everybody was Black and did identify as a Black person who'd had an abortion. We also wanted folks who might have a difference of opinion, but could be in a space with people who didn't share their same opinion, because we did want people to feel safe coming into the space right? So that was really important to us.

### **The transformative impact of digital storytelling (33:10-35:03)**

### **April Bell**

Most people left this workshop saying that they felt empowered, that they felt seen, that they felt heard, that they built solidarity amongst other people, that they feel like there's a certain sisterhood now. One person said, I think every Black woman who's had an abortion should have an have the opportunity to be in a workshop like this, because you leave here feeling empowered and owning your story. But like, one of the people left the workshop saying that she had carried the shame of her abortion for 50 years. That you know, her mom never spoke to her about it. Her mom always told her she was disappointed in it, and she was leaving it in this workshop. And I said to myself, "Man, if I never write this paper, that is enough." And it's true, that is enough, but I also need to keep my job, so I need to write this paper. So yeah, again, rambling, but the takeaway message here is that we worked really hard to cultivate a space where people felt safe and felt they could be vulnerable.

### **Janna Martin**

That's a really powerful story. And I like how you brought in some of the words of what your participants said as a result of the digital storytelling. That's really, really powerful. Well. Thank you so much to both of you. I've really enjoyed this conversation and your perspectives and how you describe your experience with digital storytelling. I think our listeners are going to really enjoy hearing from you.